**Unexceptional Moms Podcast**

**Episode 36: Bringing Together Parents of Kids with Disabilities and Disables Adults**

Ellen 0:01

Welcome. I have two guests with me: Carlyle and Kevin. So, I'm going to let you guys introduce yourselves. First Carlyle, you get to go first.

Carlyle 0:11

I'm from Idaho, I'm married, have a teenage daughter. I am autistic and I'm physically disabled.

Kevin 0:21

I'm Kevin, my wife and I have three children ranging from 12 down to 6. I am non-disabled. One of our children is multiple disabled, and for the past four or five years or so I've been thinking about disability as an academic, which is my day job.

Ellen 0:39

And actually, we're together and because Carlyle and I got to speak to one of your classes, and I think it went really well. It was lovely.

Kevin 0:46

It was great. It was exactly what I hoped for, giving my students the opportunity to hear a wider range of input and especially having Carlyle here, getting the chance to take a class with an autistic individual rather than just having a class where a non-autistic faculty talks among other things, autism.

Ellen 1:07

And I hope that for younger people, that this encourages them to think differently, because we've talked about this, I didn't change the way that I looked at disability until I had my own kids.

Kevin 1:20

And unfortunately, that's what it took me to.

Ellen 1:21

Yeah. And that's what happens. So there's something that I call, “The Great Divide.” And I refer to this as the parents of disabled children and then actually disabled individuals. And I feel like there's these two teams, right. And you have disabled individuals saying, “Hey, listen to us. This is what we're saying. We are the experts on disability.” And on the other side, it's us the parents saying, “No, you don't get to speak for my child. I know my child best,” which it is true, right? We know our kids. But there's this great divide and I feel like there has to be a way to work together. But I do think it starts with parents listening to actually disabled individuals. And Carlyle, you do get to help parents, more specifically when they have kids with autism. So how do those conversations go?

Carlyle 2:17

Well, it's changed a lot over the years. For the first few years, it basically consisted me constantly reminding people that their kids were getting older, and they would end up facing the same world and the same challenges that I do. But then some would start listening to me and now I meet new parents largely by word of mouth, so some parent tells another parent and so I get an introduction and those conversations work out much better.

Ellen 2:54

Do you feel like the parents approach to autism is very different to what you suggest.

Carlyle 3:03

It really is. Most of the time, it seems, parents are focused on changing their kids so that they fit into the world better. Or maybe just don't stick out quite so much, which on a certain level, I kind of understand. But the problem with trying to fit a square peg into a round hole isn't that it takes so much pounding, it's that it destroys the peg.

Ellen 3:39

That's a really good analogy actually.

Ellen 3:42

I know for my kids, the best thing that I did -- specially for Nina right because she has cerebral palsy -- I feel like the best thing that I could have ever done is really connected to people in her community. So she has two mentors who also have cerebral palsy and we're friends, so I feel like in our conversations, not even with my daughter, but we would be talking and we would be having conversations and I would say something about this ability. And we got to the point where they could be like, “Um, can we talk about this for a second?” And it was usually, honestly, them pointing out, “Your view on disability, it's kind of really bad. Like, there is no wholesome approach or even recognizing that disability is just different.” So I feel like first as a parent, I thought that a little bit because I felt like, “Look, I am the expert on my kid,” which I still think I am. And it also challenged me a lot personally, “Am I doing this wrong? They're saying I'm doing this wrong. I'm not doing this wrong.” But the more I started listening, the more I started thinking, “Hmm, maybe they're right.” And I feel like from learning, I've changed the way I parent, which in turn has been a super positive thing with at least with Nina. Right? So it's the allowing those voices of the real experts and not the “professional” experts to actually speak into… not even my parenting, because they've never said this is what you need to do with parenting. It's more, “This is what you need to understand about disability. This is what you need to understand about our challenges. This is what you need to understand about accessibility.” Those things that really reframed how I saw disability.

Ellen 5:32

I hope that makes sense.

Carlyle 5:34

Oh yeah.

Kevin 5:35

Andrew Solomon has a really great book called, “Far From the Tree,” in which he talks about a number of different, he calls, vertical identities, identities that parents don't have with their children. So Solomon is gay, and this sort of started him thinking, how does a gay child relate to his straight parents that had very problematic views about homosexuality. And for lots of us -- probably most of us that have disabled children, right? this is a vertical identity. We ourselves don't have the same relationship to disability that our children do. And actually, in Carlyle's case it's the opposite way. Right? Which is really interesting. But as a parent, when you first recognize that your child has this identity, it's almost always because of a medical context or a school context. And then, you know, with depending on what the disability is, there's medical issues that do need to be addressed. There's therapy issues that do need to be addressed. There's educational challenges that do need to be addressed. But all the early input that frames how you think about this is given by these professional fields that if we look at them more carefully, are really really problematic in their assumptions about disability. That’s then made worse if parents don't directly know disabled adults. All they get is that the framing of disability from grim, you know, medical professionals, you know, this is where the focusing on “cure” and all this kind of stuff comes from. And so there's a real, I think a good causal explanation for where the “Great Divide” comes from. It's that most of us don't have direct access to people with our sons, you know, or daughters or, you know, children's conditions even before they're born. Yeah,

Ellen7:34

You're right. And I always say, when the doctor who delivered the diagnosis -- and I knew when I was pregnant, that my daughter most likely was going to have Down syndrome -- but I remember when he came in, he asked my husband to sit down because he had bad news for us, and that's how he framed it from the beginning. And even before he could say anything, I told him, “You're going to say that she has Down syndrome you think she does.” And again, his first thing, “Yes, I am so sorry to give you this news.” So it was bad from the beginning. And then when my midwife came to see me, she cried, right? So all these people that are the professionals that I'm supposed to rely on, it was so negative, it's like this tragedy just happened, which is, “your child is disabled.” So I think as a parent, when you're not expecting it, you go, “Oh, this is bad. I mean, they're acting like this is bad. So this must be really bad.” And in the medical model, unfortunately, most of the time, they do deal with families in crisis. So that's also what they know about this ability, right? They know everything that can go wrong, the illness, whatever their field of study, sees, they don't *have* a child with Down syndrome at home or any disability to say, “they're just a child,” right? Like my daughter. She plays Barbies. She does makeup. Like they didn't tell me, “when your daughter is a teenager, she will like to do her makeup and play with Barbies.” Like, that would have been a normal thing for a child to do. It's more, “This is everything your child may never do. These are all the medical complications your child may have.” And it's overwhelming and compounding, and even for the autism diagnosis, which is different as a parent or as an adult, but I feel like it's reframed over the, “These are the areas where the child is lacking. This is the problem,” unquote. And it's that frame of disability that's so prevalent. And people say, “I'm sorry,” all the time.

Carlyle 9:45

And this situation, and the divide between parents and disabled adults is reinforced by the language around it. We call children who are disabled “special needs children.” We call their parents “special needs parents.” And as Kevin pointed out earlier, I am the disabled parent of a non-disabled child. So what would you call me?

Ellen 10:10

A disabled parent…

Kevin 10:13

You’re “normal needs parents.” It doesn't quite frame it the same way.

Ellen 10:21

Yeah, that is true. I mean, besides the divide, and we don't need to talk about this, but you know, it's even the language that parents prefer to use, versus the language that the actually disabled people have been saying for a long time, “Please listen and respect to the language that we would like you to use.” And I always think, in this great divide, I'm a parent and I have kids, but my kids are gonna grow up, and then they're not going to be on my team. They're going to be connecting with their community. Right? And will I still hold on to my own views or will I be respecting and honoring what my kids have to say. I mean for you, Carlyle, do I respect and honor what you have to say? Hopefully I do since we're friends, but not everybody does. And you get that a lot, that people say, “You don't get to speak for disabled children.”

Carlyle 11:17

Yeah, and especially that I don't get to speak for autistic children. And the language thing is very interesting, because we find several different communities around specific disabilities have strong opinions one way or the other. For example, the deaf community, the blind community, and the autistic community -- autistic adults. Not all of us, but a very large number of us prefer identity-first as opposed to person-first. And this is something that really comes down to a matter of respect of how the person would like to be addressed.

Kevin 12:23

One of the reasons why I think the respect is hard. And again, this is speaking as a parent of a disabled child, is because when you get that diagnosis, right you get it from a doctor or a school that has suggested you get an IEP or disability evaluation to see if you qualify, or for some of us, you know, very early on kids need to be in physical therapy. Our son has been in physical therapy of one sort or another since he was about six weeks old. And this began way before we realized that he's disabled, right? He just needed to have physical therapy because the muscles on one side of his neck had torticollis, so he had a rigid neck and so he could hardly look straight ahead and much less to the right. Well, it turns out now that was related to this underlying disability which has low muscle tone and low muscle control, but because these early experiences, all are shaped not by encountering autistic adults like Carlyle, but medical professionals, educational professionals, therapy professionals, and these are the fields that are most likely told that person-first languages is required, rather than identity-first language. And so it's actually sometimes parents of disabled children that are most resistant to the identity-first framing.

Ellen 13:51

And I will say when I speak to parent groups, and I do sometimes use people-first language and sometimes I use identity-first language, and I do it on purpose. And at the end sometimes I say, “How many of you noticed that I use identity-first saying disabled kids or disabled individuals,” and people raise their hand and I ask, “How many of you were bothered by it?” And most of those people are bothered and I guarantee you, probably people who listen to this, they might, be thinking, “They are not using people first language.” But for us, Kevin, for you and for me, we're very connected with the actual community, the disabled community as allies, because we know we're not a part of it. But we do listen to what they have to say. And I don't have a problem with identity-first.

Kevin 14:44

And then my scholarly work because of the awareness, like Carlyle mentioned, that most disabled adults -- certainly most autistic adults --prefer identity-first language, that's what I use when I wrote, “Disability and Inclusive Communities,” right? This is sort of a more general audience book. And so, a lot of it is often framed in terms of person-first language even though I talked about the linguistic divide. Except when I talk about autism, and then I talk about autistic individuals. But one of the reasons why is I didn't want to alienate right, there's a certain readership that had heard so much about the importance of person-first language, even while trying to break down that idea that if we don't use person-first language, then suddenly we don't value their personhood. And, Carlyle, one of the ways that I tried to value your personhood is to respect your preferences, respect what you want, and respect what I can learn from you. Right? And so I'm not in some way, limiting your personhood by saying you're an autistic adult, right? This is actually a sign of my profound respect for your personhood and what you have to give to me by using the language that you prefer.

Ellen 16:13

I liked what you said, when you were presenting Carlyle, because you reassured the students, “I really don't care what you call me or what you say. But once you know my preference, respect it,” I mean, to anybody. For me, it's the same thing. If somebody refers to my kids, as they have special needs, that's fine actually, it doesn't bother me. I use the word disabled, because that's what I have learned their community prefers. But personally, it doesn't bother me, but then again, I'm not disabled. So for me, again, I can only come at this from a parent perspective, right? But besides the language I do know that when you talk about issues of autism, a lot of people say, “You don't get to speak for my kid, also you are too ‘high functioning’ and my kid is not. So what you have to say basically, I don’t have to respect it. And it doesn't apply to my kid.”

Carlyle 17:18

Yeah, that that happens a lot to those of us who are outspoken autistics, and the main problem with that is that they're assuming that there is not a functioning mind behind the base of their child. So really, they're insulting their own kid when they decide that. That isn't to say that we're all the same as other autistic people. But in reality, most non-speaking autistic people who are given access to alternate communication methods eventually do learn to communicate. And they will eventually come around to say, “I understood everything that you said.” And parents really need to go about this, expecting that to happen, and to understand that there is a person that they're talking about. And my whole message and that of other autistic advocates is that we as people deserve to be respected and to be treated with dignity. And when you think about it that way, and you look at the things that autistic people object to, like having children's meltdowns videoed and put on YouTube, without the child necessarily having any input into that. That's terribly damaging to the kid and that's arguably using the kid for the parents benefit. And it's most certainly not preserving that child's dignity.

Ellen 19:15

Yeah, I would agree with that. And wouldn't you say that some of the challenges that you faced being an autistic individual are probably the same challenges, or maybe not the same but similar, to even someone who was nonverbal?

Carlyle 19:32

Right. In fact, that's one of the reasons why I started early on just basically seeing your kids are getting older. For many of them, they're going to age out of services and then what. Parents get older, tend to die before their children, then what? I understand this is kind of a sticky issue for parents because, you know, it's a pretty serious fear that your child's not gonna be able to take care of themselves, but this is the reality of it. And autistic adults, as advocates, we’re advocating for all of us to be listened to. And this is us who can speak, using our ability and what privilege we do have, to try to bring up those who aren't. And insisting that only the parents can speak for their children, creates a situation where what voice their children would have is gone, because the parent ends up speaking over the child.

Ellen 20:53

Yes, I'm thinking for example, sensory issues, right? Like you have some sensory issues and it's pretty common for individuals with autism. I feel like I have sensory issues but I know my sensory issues are most definitely not the sensory issues that you experience. So, if I was the parent of an autistic child and they have sensory issues, chances are, you understand what that means much better than I do because you experienced that as someone on the spectrum.

Carlyle 21:28

It is pretty interesting to see there's research starting to come out showing that there are some common factors in our sensory issues, for example, I've said for years that I have difficulty with visual noise. So, lots of things happening in my field of vision. There's actually been research to show that autistic children are more sensitive to motion, so able to detect smaller emotions and at a greater distance than non-autistic children.

Ellen 22:00

So you could have someone who's nonverbal, and Carlyle, and you could both be experiencing the same distress. The differences may be you can verbalize it and maybe someone who's nonverbal is not saying it, but you do have that experience.

Kevin 22:18

Our son's autism diagnosis is very likely connected to an underlying genetic deletion that he has. He's missing part of one of his chromosomes. And our son's autism experience is very different than Carlyle's experience. Right. So I could say, “But wait a second Carlyle. You don't have Jamison's underlying condition. You don't get to tell me what his experiences is like for that.” But if you think about it, while respecting that our son's autism experience is different than Carlyle's autism experience, Carlyle's very, very, very likely to understand our son's autism experience better than I can. I don't have either the autism diagnosis or the underlying genetic condition. And so while respecting the diversity of those experiences, there's still a sense in which, even though I know more about the underlying genetic issue that he has than probably you do -- and very often more than his doctors do -- there's still a sense in which even if you can't help me understand exactly what it's like, for him, you're a lot closer than I am. And so even though it's a very different experience, this is there's so much for me to learn from.

Carlyle 23:37

This is an area where my physical disability actually makes a great parallel. So I have a lot of nerve damage, and that means that my left arm is paralyzed. I don't have any real problems with my legs so I can walk. I have a friend who is paralyzed from the waist down and when we were first getting to know each other we talked a little bit about the paralysis and she made the comment that I was the first person who was able to walk that was able to describe to her the experience of being paralyzed. And so even though she and I are functionally very different, I know about the other issues of having a paralyzed limb, like the circulation problems and generally what paralysis feels like. And those issues, so even though I'm able to walk and she isn't, I still have a much deeper understanding of her paralysis than even her parents do.

Ellen 24:45

And I was talking about this when we were having lunch, but my daughter who has cerebral palsy will come home and she'll say, “This happened,” somebody said something or did something at school and I can sympathize with her and be upset with her and I’ll say, “Yes, I get it.” And she’ll say, “No, you don't. You recognize that it was frustrating, you recognize that's an issue, but you don't get it because you're not actually disabled.” And that's fair. So then she'll go and she'll call, you know, my friends who are disabled, and they also have cerebral palsy. And she usually starts with, “Has this ever happened to you?” And usually we get a yes. So then they have this community where they're talking about what that experience feels like, you know, how you can handle those situations and honestly, sometimes I listen to the conversations and I didn't think, “Hmm, I would have never thought about that.” Part of it is because I've never experienced it. I mean, only from the outside, right? I experienced it as a as if I was watching a movie you could say, and I'm very emotionally invested in this movie because it's my kid, but I'm not actually experiencing what she goes through because I am not disabled. And I think she's right. There are things that I will never understand. I can have sympathy, I can have empathy. But I don't know what I don't know. And I think that's fair to say. I mean, honestly, it's really hard as a parent to accept that because we like to say we're the experts on our kids. And I think to some degree we are. Yet, we're not an expert under disability because we don't have a disability. Now, I feel like we can learn from you Carlyle, and I have. I'm still the person who gets to go fight the school for my kid, and I still take them to the doctor, right? I'm still doing the things that only *I* can do as a parent that you can't do for my kid, Carlyle, because they're not your kids. So I think as parents, we can be confident to say, “Hey, I still get to be the parent, right? I still get to call the shots. But that doesn't mean that I shouldn't be learning from the people who have my children's disabilities so that I can become a better parent, so that I can do my parenting job better.”

Kevin 27:13

Many of us as parents, by the time we've become a parent, we've been shaped by 20-25, 30-35 years of these cultural assumptions and just about how bad disability is. And so even though we're the experts, right, in many ways, we're biased experts who have inherited all the problematic assumptions that our culture at large sort of instills in us. And so we can recognize and like, you know, push back, but we often don't realize just how deep some of that kind of stuff runs. I mean, even I look back to, you know, some of what I thought, six, seven years ago, and I'm just pained by it, right? I wish I would have known then what I know now. I have to be willing to admit, maybe there's things I need to know now, so I can't be done learning. But especially as Carlyle said, for many autistic individuals, it comes with sort of hyper memory. Right, this memory that doesn't let things be forgotten. And I remember you telling me that and thinking, “Wow, what are those things that when I was still in this learning process, when I had these problematic assumptions about what disability was and what it meant, what are the things that I said that if my son's memory functions that way, when he's 25, 35, 40, right, he’s going to remember, ‘Dad, this is what you thought.’”

Carlyle 28:47

I have had quite a few moms ask me when their autistic teenager will stop bringing up things that they said when their child was four or five years old. And I tell them, “When you die because it's in there.” It is really interesting if you consider the other way around because the power dynamic changes. So, as I said earlier, I'm a disabled parent of a non-disabled child. And arguably my child is an expert on my disability. I would say to the point that I could send her to do something and I could ask her whether I would be able to do it and how and be confident in her response. But when you when you change this dynamic, you start to see how disabled people can be treated with dignity and respect and be viewed as people. I told the story earlier in the class and I think it's worth telling here. Several years ago, my daughter wanted to buy a game. And this was when she was kind of new to having an allowance. And so she asked her mom if she could buy the game and Kristin said, “Go talk to you, dad.” And so she did. And I told her, I didn't mind her buying the game, but just looking at it, it seemed like it would be something that I couldn't play because it required a significant amount of manual dexterity. And so she ordered the game and it came. And after she had had it for about a day, she brought it to me and she said, I think I figured out how you can play this game. And so she put one hand behind her back and she demonstrated all of the tasks involved the game. And when she was done, she said, “Do you think you can do that?” And the difference here is that even though she definitely is an expert, she knew full well that I was able to do what she was asking me whether I could do or not. This was just a girl asking her dad to play with her.

Carlyle 31:22

I wish we could figure out some way to put that into the relationship of parents with their disabled child, or for that matter, parents with their disabled peers.

Ellen 31:38

“Do you think you can do that?” I mean, I think the fact that she asked you that she didn't just say, “You can do that.” It was that respect of “you are the expert.”

Carlyle 31:51

So yeah, even though she knew, she was still able to offer that, and that would go a long way to building that sort of relationship and showing the child an example that will help build confidence and to help them understand that they can they can grow up and be their own person.

Ellen 32:23

Yeah, so let's talk a little bit about communication norms because I feel like we hinted at them, so, do you want to take it from there Kevin?

Kevin 32:34

Yeah. So Carlyle and I have had a number of conversations about why certain kinds of social settings are difficult for him as autistic. And this is sometimes focused specifically on the church, but I think it's sort of a general point. And, well, Carlyle, you've got a particular way that you describe what it's like to be autistic. Give us that description because I think it's really insightful.

Carlyle 33:03

Yeah, I started just saying that to be autistic is to live in a constant state of culture shock. And that's because cultural norms are communicated nonverbally, nobody sits you down and says, “This is the way you do it.” And you are certainly expected to pick up your own culture. But because autistic people have such a hard time with those nonverbal signals, we tend to not be able to pick it up very well unless we make a conscious effort to study it. And then we may still be quite a bit off because of further reliance on nonverbal signals. So there's this constant anxiety, of doing things wrong and being hyper vigilant, trying to figure out what's the correct thing to do in a situation.

Kevin 33:51

And since the majority of culture is non autistic, the default norms in our public spaces and our interpersonal interactions are the neuro typical norms. And, you know, this can play out in all sorts of ways, the ways that body language can indicate sarcasm, right? And I'm a very sarcastic person, oftentimes, and if somebody has a hard time picking up on the nonverbal cues, or how sarcasm is function in a particular way. Or another example that Carlyle and I have talked about before is the way that we interpret when somebody asks a question. So sometimes, questions aren't really questions, their criticisms, right? Because they come across as nicer that way, or they're really loaded questions, or they're steering questions. And oftentimes when Carlyle hears a neuro typical person ask a question, he takes it as a legitimate question. And if it's given not as a question, then we've got this disconnect. Or when Carlyle asks a question, he means as a question, but it's interpreted as not a question. And so right there's this cultural disconnect, on the way that sarcasm or sort of like friendly jabs at each other or questions work. And so given that the majority of folks are not autistic or neurotypical, Carlyle is at just at a statistical disadvantage because he has to interact with more non autistic individuals that I have to interact on a daily basis with autistic individuals. But now if we put the further burden of who has to figure out the cultural disconnect here, if we put that on Carlyle, now we've sort of doubly disadvantaged him, because he is happening as the person who's learning the second culture, right the dominant culture from a different culture, he's disadvantaged there. And if we also say, “And you're the person that has to learn how to translate between cultures,” we've doubly disadvantaged you.

Carlyle 36:22

And the translation is extremely difficult because when it comes to sarcasm, properly translating it requires being able to detect and interpret the body language associated with it. Deciding whether a question is really a question is largely the same thing. And I've reached the point in communication where it seems most likely that things will turn out for the best if I just take the words as they come. But it still means, there are many cases where it doesn't.

Ellen 37:05

We’ve been in enough interactions together online, Carlyle, that I think that a lot of times people have expectations for you. And you are not meeting those expectations. So you're not meeting those expectations, so then you become the bad guy. Like, we have seen this play out.

Kevin 37:27

Numerous times.

Ellen 37:28

Numerous times. And I think a lot of times the people who think that you're not playing nice and you're a bad guy, are parents who have kids with disabilities and who have autistic kids. And I think, “That's gonna be your kid when he grows up. And how are you going to feel that somebody is calling your kid the bad guy?” Because I feel like the expectation is for you to not be autistic. Stop being so autistic Carlyle!

Kevin 38:00

Play by our dominant culture.

Carlyle 38:03

And a lot of that comes from the idea that autism is something that needs to be cured. Another large chunk of it comes from people looking at other people and based on appearances and the expectations they might throw into that. For example, I've been told that I should be able to do something because I have two good hands. That's not true. I have two hands. And one of them is not obviously non-functional, but it's still not functional. So whatever it is, if it requires two hands I simply can't do. If I'm expected to clap my hands this is not going to happen. If I'm expected to detect sarcasm, I could get lucky. But it's largely a coin toss and I just stick to the ways that I have been doing, and as I get to know a person better, I could get better and better at detecting their sarcasm. I take everything that is said to me I run it through several filters. First off, does it make sense as it is? If so then I just work with it that way. If not that, is it some sort of idiom? And if it's not, then is there some context I can think of in which this would be a joke. And if I can't think of anything there, I'm going to turn around and ask you what you mean. Or some other questions so that I can figure it out. And sometimes people find these questions offensive, but that's the best that I can do.

Kevin 39:43

But think of all the time, energy, mental labor that goes into having to run down that checklist while the conversation is still going on. So we have the communicative norms about sarcasm and some of this, but I also think about the ways in which just the pacing of our conversations go sometimes. So back at the church we used to attend in Idaho there was an elderly gentleman who had Parkinson's and he had always stuttered his entire life but as his Parkinson's got more and more severe, the stuttering got way way way worse, and so having conversations with this individual just took longer, for him to get his part out. Now with Carlyle and sort of the mental checklist, “How do I interpret it?” It's not his outputs that take longer and more work, but it's all the inner stuff that we can't see as he's going through this checklist. And I could tell that when this friend, the elderly gentleman with Parkinson's would get really bad stuttering, he didn't like it, but you could also just on the faces of people around him see them tune out. The extra time wasn't worth him being part of the conversation.

Ellen 41:11

Yeah, but that happens to everybody. So my daughter with Down syndrome, nobody stops enough to listen to what she has to say because she's hard to understand. She does have the processing issue. And a lot of times people go, “Yeah,” so she's not even a part of the conversation. And she has learned that there are certain topics that she can use and rely on to insert herself into conversation. The thing is that sometimes it really doesn't flow in the conversation. It feels like it's so left field what she's talking about that -- I know that some of her classmates -- they just go like, “Oh, there she goes asking about my dog again.” But that's because that's what she knows. It gets her inserted back into the conversation, gets a response from people. And I really believe that if people stopped to, you know, listen to what she has to say, be patient with her, work it out until you actually figure out what she's saying, and then you get to know her, then you can have other conversations that are not just, “What's your pet's name?”

Kevin 42:22

That's part of your daughter's script to reinserted herself in the conversation, but often -- and I have never met your daughter and I've never met your daughter's friends -- but a lot of times that script is going to be then seen as sort of an infantilizing gesture and so even if it's the tool that she's trying to get herself back into the conversation, it often is going to come across to these other folks that aren't understanding what's going on or taking the time as further reasons to sort of exclude her.

Ellen 42:55

Yeah, that’s exactly how it works.

Carlyle 42:57

Yeah, I've had a few of these little tricks. In fact, even before I was diagnosed, one that I think is particularly funny is my wife would say something, and I would hear it, but not have fully processed what she said. And I would say, “Huh?” and that would usually buy me enough time to figure out what she said. And I would start responding to it as she was repeating herself. And she would say, “You heard what I said.” But that was just me trying to buy myself processing time.

Ellen 43:34

Which, I wonder, as we're having this conversation right now, how often this happens for a lot of

individuals with disabilities, children, adults. We are so used to a fast pace, right, like just our culture's and our way of life is so quick and especially now with social media and attention. Everything has to be quick and witty, and entertaining, and exciting even I feel in conversations. When I go to the lunch room and I see how the girls are talking and how fast it is, and just the pace of neurotypical conversation, it really doesn't allow room for anybody who may have communication differences whatsoever.

Kevin 44:27

And actually, I think this point generalizes not just autism or communication, but to disability more broadly, right. One of my favorite stories to tell about this is back when we lived in Idaho, we were having Halloween, and we knew we had four or five families and these were families that knew us really well. They knew our kids, they knew Jamison, our son, and we'd get together and we'd have soup and then we hit the neighborhood. And again, these were families that loved us, families that valued us, but because of motor control, and balance, and various kinds of issues, Jamison is just slower to walk. And then he often wants to not just get candy from a house. In fact, he really didn't care that much about the candy, he wanted to go into the house. And so leaving houses took longer and so within, you know, seven houses we look up and the other group is, you know, in house 17, 18. And these kids who are so motivated by candy, they want to hit as many houses before the lights go off. And I remember my good friend, Stephen. Stephen, and one of his kids, they cared more about walking with us than they cared about getting the candy. And so for them, the way that they most showed that they valued us, most showed that they really didn't want to further stigmatize, further isolate us, was just to walk slow, and to talk with us, and to get less candy. But that for me was so moving. Here's somebody else that would rather Jamison and I not walk alone for Halloween. They care more about us than the candy.

Ellen 46:21

There's more value in the people than the candy. And I wonder how often it is the motivation and I think that's why that piece of disability is so hurtful, so often there is no value. And that's what happens you end up being -- I mean, my family, because my family experiences that we get left behind. But for my kid, and I don't know Carlyle if you’ve experienced it, but it just feels personal, because it's you.

Carlyle 46:51

It definitely is personal. And for me I was a little different because I'm older but you know, I don’t get invited to a lot of things and I have started asking some people why that is. And some of the responses that I've gotten include, “Oh, I wasn't sure if you could do that,” or “I wasn't sure if you'd be able to enjoy that with your disability.” And I would really like the opportunity to make that decision. I would like to be invited to things, and it feels good to be invited even to something that I am pretty confident that I wouldn't be able to do just because it feels like a person wants to connect with me and they're leaving that decision up to me. So I really wish we had more people that were willing to put the focus on their friends and walk slower, talk slower, send out the invitation.

Kevin 47:54

And to keep sending out the invitation. It's not enough to get it once. You need to get it a second time, and the third time, and there certain social invitations that we have as a family -- and it's not just the individual but as a family -- I've had to turn down because well, it's been a particularly rough week and by Friday night, Jamison just doesn't have the energy or it's going to be in a place that for whatever reason we think it's probably best not for us to come. But then if you do that enough times, right, what happens? You stop getting the invitation. And again, this is a thing that isn't just about disability. I know I've got friends who have anxiety or depression or other sorts of things, right. And if you're going through depression, you might not want to go to whatever it is. But the more you say no, the more infrequently the invitations come until eventually it looks like these people that you thought were your friends just aren't investing, even in the invitation, right?

Ellen 49:03

So I think this is why, because we talked about the divide of parents, I feel like this is why the connections between the parents of disabled kids and actually disabled individuals can work so well together. Because I feel like, although we come at it from different perspectives, that level of understanding is there that you can't find with another friend. So let's say Carlyle invited me to his house and let's say that he lived on the second floor in a building and we have a wheelchair. I could say, “Nope, sorry. We can’t come because there are stairs.” He might be more willing, not willing, but able to recognize, yep, that's an issue. And I'm guessing he'd be the first one to say, “Of course. Don't worry, we'll go somewhere else so that you can be included.” Where some other people, they just go, “Oh yeah, sorry, that's not gonna happen.” And that was a terrible example because you would never do that, because you are more aware.

Carlyle 50:11

I wouldn't learn the second floor because I struggled with stairs too. I don't use a wheelchair, but sometimes it's pretty painful to walk and climbing stairs can be especially painful, I would never do that.

Ellen 50:27

But I have found that the people who understand my family best are my friends who are disabled, and of course parents of other disabled children as well. So like my best friend, her daughter also, she has two daughters with disabilities – Erin, who I do the podcast with -- so we do have that connection, you know, in the in the families, but aside from those friendships, it is my friends who are disabled who get my life. And actually, you talked about the peeling layers that disabled people are expected to disclose so much about themselves, I find myself being happy that I get to disclose so much about myself that maybe for someone who's not disabled, it's not appropriate to write, to talk about certain things, and it's not appropriate to address certain situations, or talk about things in a way that doesn't make you be super grateful, the expectation that you should be grateful about all the things all the time, even if they're not done with the right intention… there are certain conversations that I feel like I can have with you, Carlyle, that I probably couldn't have with even some family members because they're not disabled and they just don't get it -- even though I'm not disabled. And to me, that's the piece where we can start building some bridges as the parents and actually autistic or disabled individuals. What's the connecting point? Our kids. But then aside from the kids, what is the connecting point? Where is the friendship? And we talk, we've said this. If you're a parent who has kids with disabilities and you don't have any disabled friends, that's the problem, especially if you expect your kid to go to school and to have their friends include them if we're not modeling inclusion. You know, how can we expect children to do it, if we're not even doing it ourselves?

Carlyle 52:36

If there is one, hard and fast rule of parenting, it's that, “Do as I say, not as I do,” does not work. So if you expect your non-disabled children to connect with your disabled children or their disabled peers, or if you expect the non-disabled peers to connect with your disabled child, you're going to have to model that and you're going to have to be friends with your disabled peers. Something that I have long said to moms in my area is that you can't expect the next generation to treat your children any better than you treat your own disabled peers.

Kevin 53:29

And that's not often received very well.

Carlyle 53:34

I have had so many parents in my area, come back to me and say that connecting with autistic adults has changed the way they relate to their autistic children for the better. And that's actually how I've made the friends that I have, in the area where I live, because I found if you can help a mom better connect with her child, you will have made a friend. I just wish that more could actually see that.

Kevin 54:23

It'd be nice if it didn't take being the parent of a child to have that need. And again, this is where my own biography is problematic. It'd be nice if I would have started thinking about these things prior to being thrown into them, in part because then I wouldn't hear about them from the medical professionals, the therapists, the educational folks that all have this negative understanding of what disability is. So Carlyle if you and I become friends before I became a parent, that would have been wonderful, but it also would have helped me be a better parent of a disabled child a lot quicker. But it also would have helped me become a better parent, just full stop, a lot quicker.

Carlyle 55:09

And it is true. It generally takes being the parent of.. I mean is it is a look through the list of people that I might actually go and hang out with, there are only two exceptions to the mom of a kid like me and one of those has an autistic brother and the other one is a speech therapist who works with autistic kids. So it seems I can't get away from that.

Kevin 55:41

There's a third, there's a dad of an autistic kid. Right? I mean, I think it is interesting the way in which a lot of this stuff plays out culturally, it is also related to not just sex or gender, but also race, and I'm white, so like I don't have the same first personal understanding that other folks who are themselves racial minorities would have. But there's a lot of gendering with respect to disability too, in part because the parents that are most often providing the primary care, the primary point of contact are themselves women. And I remember the first time I went into an IEP meeting on behalf of another family, and this is a when we lived in Idaho. Jamison's best friend had Down syndrome and so I went in to help that family having some of the same educational struggles, and we came out of the meeting the mother who I had gone with -- in part because I went because the father himself had debilitating migraines so he couldn't -- so I went as a friend, but we walked out and mother said, “This meeting went so much differently than all the others.” And I'm thinking, well, there's two reasons why. One, you're not alone. But you're also not seen just as female or as mother – the gender. So I turned to her and I just said, “That's because there was another penis in the room.” And that's kind of crass, but so much of these things that we've been talking about are about power dynamics in social settings. And let's just be honest, women in most social contexts in the US today don't have the same kind of power and so it also plays out in lots of these ways. So if you go to most “special needs ministries” or “special needs parent groups,” or all these phrases that are kind of making many of us around the table cringe, are almost all dominated by women.

Ellen 58:01

Which is really, unfortunately, unfortunate because there's so many dads who have kids with disabilities who feel like they are on the fringes because they didn't get to be included. And now we see more involvement from dads, times are changing, and maybe some who stay at home. My husband was a stay-at-home dad for two years and I was the one working. So those dynamics, it's true ,yet in the professional setting, you have the dad walks in, and there's a little bit more respect and it's approached very differently. Yet the expectation, or the knowledge, really, in certain situations, it's with the moms. As moms, we have our own network. I'm sure your wife has a network of connections that you don't even have. Because that happened with my husband, I would say, “Hey, we need to figure this out,” and he would make a call and they would say, no, and I would say, “Well, they say no, I don't think so.” So I would go on my Facebook group, my Minnesota moms and ask the question and they’d say, “Well, they say no, but you can do this, this and this. And this.” I had those connections. He didn’t. Because it's primarily divided. Oh, man, we could keep talking about that.

Kevin 59:15

I mean, this is actually how we first learned that our son's school was violating state and federal law, because my wife went with the wife of this family that I was just talking about to a Treasure Valley Down Syndrome group, where they had an outside speaker. So this was a Down syndrome group, it wasn't open only two moms, but I mean, just the way that these things sort of play out in our culture it was almost entirely moms. And so Allison and our friend come back from this meeting, and they're just both weeping, because they're like, “Wait, we thought our school was doing this great stuff.” But here because of the social connections that you're mentioned, we just went to this thing and they're not. So had it not been for those connections, we wouldn't have realized that our sons were having their state and federal rights violated, we wouldn't have become involved in trying to secure those protections. And we wouldn't be doing some of the advocacy work that we're doing now.

Ellen 1:00:14

Yeah, I think it's good to point out, and I know Carly kind of pointed this out on something I posted on Facebook, that I said, “If I don't fight for my kid, who will?” Which is true, like, like I go to the IEP meetings, but you said…

Carlyle 1:00:27

Disabled people will.

Ellen 1:00:28

Yes. And you have been. You’re doing really significant advocacy work, especially with police force, and with lots of things. It's not just for you. You're doing it for all these young individuals with autism. And I think as parents as we come to recognize that the fierce disability advocates that are changing the world for our kids are actually disabled adults. At some point, that was the parents, because if you had a child with disability, they would go to an institution. Now we have a generation of fierce, amazing, powerful disability advocates. And they're the ones doing the fights trying to get legislation, looking at accessibility issues, at education, they are the ones really tackling that because they were that kid. Now they're the adult, and they know that they need to change things for the kids. So I think as parents if we really get to see our role as allies, right, like I hear parents saying, “I love being a part of the disability community.” I'm like, No, we're not. Our kids are a part of the disability community. We are on the outside, we're allies. And when we take our rightful place as allies, and allow the disabled people to do their work, and what we do is support, open doors, and we've talked about this sometimes you do need someone who's not disabled to open the door because unfortunately that's the world that we live in, so when we can leverage our privilege as able bodied, neurotypical people to open those doors to recognize it's the Carlyles who are breaking down barriers and making sure that things are being done rights and talking to whoever needs to be talked to from a federal perspective and maybe state legislature, whatever it entails. It's no longer the parents work. We can't say that.

Carlyle 1:02:31

This is an area where it would be really helpful if parents and disabled people could come together. When I do the law enforcement training, I always co-present with the mother of an autistic child, who is a Boise police officer. So we have both of those areas covered, but I am able to go in and have these discussions with law enforcement because I don't particularly struggle with law enforcement. I'm not intimidated by law enforcement professionals. And there are several reasons for that, where a lot of people who are disabled, and especially people who are autistic, really struggle with interacting with law enforcement. Autistic people are very likely to have bad interactions with law enforcement because of the autism. But this is a thing that I am able to do, and I'm able to give them first person experience but then the thing that I really need and want the most is something that is very difficult for me to fight for, that someone like you or Kevin would have a much easier time with. In fact, we have already seen that I can go into a group that is focused on this particular topic and I can present ideas and meet with resistance, and then Kevin can take the very same idea

Kevin

That I learned from you.

Carlyle

And he can write it in his book and somebody in that same group will turn around and compliment him for this great idea. And it's the same idea. It's just the messenger that's different. But we can all work together to make this work is maybe Kevin doesn't need the law enforcement work that I do. But maybe he needs something from someone who does benefit from that. And so if we all work together, we can cover all of these pieces way more efficiently.

Kevin 1:04:35

But that would be hard to do if those of us who are parents of disabled children don't see disabled adults as our best resource.

Ellen 1:04:48

Yeah, absolutely. Well, thank you both very much for being here.

Kevin 1:04:54

Thank you for having us.