00;00;10;11 - 00;00;38;24

Cortland Nesley

I found it far more freeing to sort of very loudly and proudly go, Nope, I'm autistic every time, sort of masking unintentionally because I'm still working through dismantling that. But every day I feel more confident in owning that and speaking to it and and being able to describe that in ways that I hope can can give other autistic people similar freedom.

00;00;41;15 - 00;01;08;04

Courtney Ringstaff

Welcome to Adjusting the Sales, 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. Hi, everyone. We are so glad you've joined us. Melina is the assistant director of communications and marketing at the Center for Excellence in Disabilities and the project director of the West Virginia Family two Family Health Information Center.

00;01;09;18 - 00;01;36;21

Courtney Ringstaff

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. I can come together, exchange information, educate one another, and find support and connections 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.

00;01;41;11 - 00;02;08;05

Cortland Nesley

My name is, quite honestly, I use him pronouns. I work at the ECB. I am the manager of the Chronic Brain Injury Program. I am here for autism because I am autistic. I am a autistic self advocate. I speak a lot about neurodiversity, which we will talk about today. And I'm also a public health student, and I'm very interested in sort of public health research, particularly in the context of autism, and trying to build a more robust understanding of autism in a more holistic way.

00;02;08;18 - 00;02;36;28

Cortland Nesley

I'm very excited about all that and excited to talk about sort of my journey and my experience as an autistic adult in the world. With you all and your listeners. I think there's a lot of ways that I can sort of start this this story. There's so many different vantage points. Like, you know, I could talk about my experience as a as an autistic kid for, for example, a lot of which that story has to do with my support system particular my parents in particular, my mom, who is an astounding, truly astounding advocate for me growing up, fought tooth and nail for so much of the sports that I had had.

00;02;37;05 - 00;03;00;18

Cortland Nesley

And I think, frankly, she can probably speak to that than I in some ways. I think for I want to sort of talk about today and start with today in particular is sort of my transition from more of, you know, childhood and then into high school into sort of my experiences in college as I was finding out who I was as as a human being in the world and as an adult, as, you know, neurotypical or neurodivergent people do, you know, at that at that time.

00;03;00;26 - 00;03;19;24

Cortland Nesley

But I think I want to center the conversation on that in particular, because I don't think we have, you know, a lot of narratives centered around that in the sort of as, I guess I think a lot of narratives around autism comes from a very child centric perspective. I think a lot of it's just because that's where the research is, that's where the money is, too.

00;03;19;25 - 00;03;42;29

Cortland Nesley

So much so that we we we associate autism with child in this way. I mean, logic might dictate the children are going to grow up, you know. And so I think it's really important for us to understand, like, what does that transition look like, you know, and what are ways that I'll say what I found helpful, right? As I kind of discovered, you know, what does it mean to be an autistic person in the world at large?

00;03;43;22 - 00;03;57;15

Cortland Nesley

In particular, when I when I when I started college and did that because I was going through high school, I had a very actually I had a very successful high school experience in large part because of my strong support system and advocates. I had a lot of you know, I have a pretty robust IEP that we fought tooth and nail to enforce.

00;03;57;18 - 00;04;22;24

Cortland Nesley

And people that want to had a professional, you know, a lot of different things. But as I transitioned into the next phase, you know, I did have some struggles. You know, I was doing well academically. I even had friends and peers, but there was something that I felt was really missing emotionally for me. I felt, you know, sad, often very isolated, you know, honesty.

00;04;23;01 - 00;04;46;18

Cortland Nesley

I wasn't quite sure how to find my people or my support systems as I navigated the college experience. And I think so much of what that was, was because I had never taken stock of internally, was like, well, what does it mean to be an autistic person in the world? Right. I was in sort of told, you know, because, you know, I got diagnosed around like nine years old on nine, ten.

00;04;47;04 - 00;05;02;14

Cortland Nesley

And I was told, like, you're autistic, that's what this is. And I was like, you know, as a nine year old, you're not, like, super critical of of what that might mean or entail. You're kind of like, great, I'm going to go with that. But as I grew up, I started to wonder like, hey, I feel very isolated from the people around me.

00;05;02;14 - 00;05;26;14

Cortland Nesley

I feel very different than the people around me. And what is the depth of that beyond sort of a series of of, you know, symptoms or, you know, pathologize checklist of like autism? Is this behavior, that behavior, that behavior. And it's a sort of reductive framework. And so for me, I think what I was wrestling with is I didn't know who I was in a lot of ways.

00;05;26;20 - 00;05;45;28

Cortland Nesley

And I think that's really hard because even when you have a strong support system, you know who's telling you, you know, and trying to instill in you confidence, trying to instill with you that like you're enough, you're existing and navigating in a world that's very deficit forward when it comes to autism narratives, especially when I was growing up, right when I was growing up in like the mid 2000s.

00;05;46;07 - 00;06;08;28

Cortland Nesley

Man We were in a real heyday of, of autism intervention marketing using real fear based approaches. And even though I was probably too young to like conceptualize or even really engage with a lot of that media, that media, it permeates throughout the culture, right? It frames how we think about autism and how we think about disability, you know, because we're operating under what's called a pathology paradigm, right?

00;06;09;09 - 00;06;31;24

Cortland Nesley

That pathology understanding of of autism, it frames disability as a problem that exists in and of itself. Right. That just the fact that your brain diverges from a sort of, you know, typical normal brain and I'll use normal in scare quotes because an old brain doesn't really exist. Right. But that that in itself constitutes a problem. Right. There's no further context that's needed.

00;06;31;24 - 00;06;49;08

Cortland Nesley

You don't need to dig deeper like the autism is the problem, you know. So for example, in 2007, the New York University Child Study Center, there was a there's a big campaign that they had called a ransom note campaign where they would have these billboards of where they would personify autism as writing this ransom note that they like.

00;06;49;08 - 00;07;09;25

Cortland Nesley

We have your child, right? Held hostage. Not great. I get that. It's embedded in a lot of ablest ideas about what autism is. We'll see. In 2009, you know, Autism Speaks puts out I Am Autism Video, which is fairly notorious. And I encourage people to take a look at it where a lot of it is framed around this similar thing of like personifies autism.

00;07;09;25 - 00;07;30;00

Cortland Nesley

Is this force that's going to go ruin your marriage, it's going to steal your child away from you or from themselves, really? And I and I bring this up just to sort of, I think, paint a picture of like this was the discourse of autism when I was growing up. Like, this is where that discourse was at. And I think when you're growing up, you start to start reckoning with that.

00;07;30;00 - 00;07;54;15

Cortland Nesley

Your relationship to self-worth, that your relationship to how you think about yourself is going to be informed and impacted by that discourse, whether you're directly involved with it or not. I mean, think about how even, you know, pervades language that we use, right? So for me, still, I see, quite frankly, like, you know, I was told growing up I was a person with autism, for example.

00;07;54;15 - 00;08;16;28

Cortland Nesley

Right. And the implication there to some degree is that like there's Portland over here and there, there's autism over there. And it's like interacting kind of paints autism. That language is a sort of an invasive force. Right. And for my money, you know, that that's not congruent. That's accurate to my experience of being an autistic person. And I think people who use that language qualify.

00;08;16;28 - 00;08;32;24

Cortland Nesley

People can call themselves what they want. I think I think it is up to the individual what language they use when it comes to being disabled, when it comes to being autistic or person's autism that they prefer, but the implication in many ways was that like autism is a separate thing from you that you have to manage and mitigate.

00;08;32;24 - 00;08;58;13

Cortland Nesley

Right. But my experience of internally is autism colors everything, right? It colored every sensation, every thought, every touch, every feeling I was having. And so when you have discourse that suggests that autism is a separate thing that you have to deal with. Right. That that the problem but it's then translated through an experience of autism is who I am whether I had the language to explain that or not.

00;08;58;28 - 00;09;14;23

Cortland Nesley

It's going to lead to a situation where you're like, I'm the problem, you know? And that might be semantic, but I think the semantics really matter and it really matter to me when I would really self punish myself for going, you know, why am I not having a lot of social success right at this, this next level? Right.

00;09;14;26 - 00;09;39;19

Cortland Nesley

Why do I feel like everyone else is getting something socially that I'm not getting? And then I go, Well, I guess it's me. I guess I'm the problem. And for me, finding different ways to think about myself was the thing that really started to crack open. Hey, wait a minute. Maybe. Maybe I don't have to self punish in that kind of way, right where I kind of go down that road.

00;09;39;19 - 00;09;55;18

Cortland Nesley

I just want to give another example here of I think about this a lot. And, you know, in the lead up to this podcast, I've been thinking about this like what are the different things that like led to me really harboring, I guess sort of call it internalized evil, right? The idea of like, hey, I don't like the disabled parts of myself.

00;09;55;18 - 00;10;13;19

Cortland Nesley

I didn't think about growing up. There is a sort of proliferation, especially of like the autistic narratives you would see on TV were these like, you know, these savants that were like, it's the same story every time and is very lazy around. They're a genius at math, but they're bad at social things. And that was like every autistic story from like 2000 to now and growing up.

00;10;13;19 - 00;10;27;18

Cortland Nesley

You see that over and over again. And when you see that same narrative over and over again, you you start to believe it. Even if you have good support systems, even if you have the you know, again, parents did a great job in my case, but like you start to go, hey, I guess my worth is tied to like making myself useful.

00;10;27;24 - 00;10;51;25

Cortland Nesley

I guess it's tied to, like, I got to be really good at this one thing to supplement. Otherwise, you know, that's what separates the the quote unquote good kind of autistic person from the quote unquote bad type of autistic person. And I think I had a lot of fears that, like, I get to be the good kind of autistic person I need to be, you know, and and there's kind of language in those mid 2000 that separated those two things because I was diagnosed as Asperger's, for example.

00;10;51;25 - 00;11;11;20

Cortland Nesley

Right. You know, which is, you know, at this point an antiquated something anymore, autism or rather Asperger's. But, you know, that diagnosis first got taken away was 2013, I think roughly seven, 13 or 14. That was around my freshman year in college. And I remember feeling very hurt that that got taken away. I was like, hey, that's the thing.

00;11;11;20 - 00;11;31;27

Cortland Nesley

I am I my Asperger's, right? But as I kind of grew, I kind of started to realize, hey, wait a minute, when people called me Asperger's and they're like, Hey, Cortland, you're, you know, you're a person, you know, who has Asperger's. I think what they were really saying was kind of a coded language thing in many ways. They're saying like, you're autistic, but you're not that kind of autistic.

00;11;31;27 - 00;11;50;19

Cortland Nesley

Right. And again, from a mental health perspective, from a self-worth perspective, if your entire framework is hinging on like you're this thing, but you're not that kind of thing, right? You're you're you're almost a bad thing, but you're not the bad things. I think that can do a lot of harm. And ultimately what it leads to is it leads to a lot of masking.

00;11;50;19 - 00;12;11;17

Cortland Nesley

And for those who listeners may not know what masking is, so masking is when an autistic person or it doesn't have to be autistic. I'll use autism here, though, sort of performs neurotypical behaviors in an attempt to sort of mask your autistic sensibility so that you can you can navigate in the world as an autistic person because those behaviors are deemed more acceptable.

00;12;11;17 - 00;12;32;25

Cortland Nesley

Right. And sometimes it's really important to mask race. Sometimes it's a matter of of safety. Right. It is worth noting that a lot of data and research suggests that somewhere between a third and a half of people who are killed by law enforcement are disabled. Well, masking in these instances, it's a matter of safety, right? A lot of times it's because of bias that those people are shot.

00;12;33;19 - 00;12;56;03

Cortland Nesley

But oftentimes, you know, we might think of masking as a a conscious effort. Right. It's something that you actively do or put on or perform. But what I found as I started investigating, hey, what does it mean to be autistic was I was masking subconsciously, right? I was performing the idea and idea of neurotic fatality because I thought I would be rewarded for doing so.

00;12;56;08 - 00;13;24;08

Cortland Nesley

And I thought it would it would alleviate my isolation, that it would alleviate my loneliness, that it would alleviate these feelings of pain that I had. But in the long run, it's just not sustainable, right, Matt? Because what you're doing in your masking is you're denying your authentic self an entry point into the world, right? And when I was masking and I still I'm still going through a journey of figuring out what parts of myself I'm still masking in public spaces because again, subconscious so often at the time.

00;13;26;02 - 00;14;00;08

Cortland Nesley

But that's, that's directly cascading out of the internalized ableism. Right. If you're like, hey, I don't want to be that thing. I've been told by the media, by autism intervention marketing, that being autistic is bad. I don't want to be that. So I'm going to mask and then you keep masking. For one thing, it's exhausting, like truly tiring, you know, I talk a lot with a lot of other autistic folks who talk about just how, you know, we assume autistic fatigue and autistic burnout is simply a matter of like functioning deficits, which it might be.

00;14;00;08 - 00;14;21;11

Cortland Nesley

I mean, I think it's a complicated thing, but I would venture to get that. A lot of it also is just like this. People are masking all the time, and that's a performing of self all the time is exhausting. And it just also it creates a negative self feedback loop, right? If you're masking that, you know, feeds the idea that it justifies my internalized label ism, right?

00;14;21;22 - 00;14;43;14

Cortland Nesley

Like if I masking and I'm rewarded for doing so, then it's like, Oh, I was right, being autistic is bad, right? That cycle, hard cycle to break. And so I think in many ways the key question I had to face for myself was like, how do you break that cycle? How do you break the cycle of internalized embolism and masking?

00;14;44;19 - 00;15;07;29

Cortland Nesley

It's hard because I think conventional artistic intervention doesn't provide a lot of answers to that. And in fact, I think one of the reasons why I'm a big critic of a lot of compliance based interventions, which tend to permeate the space, is because, you know, operant conditioning isn't particularly concerned with, you know, breaking that cycle. In fact, it reinforces that cycle.

00;15;08;10 - 00;15;28;16

Cortland Nesley

It's telling you like, hey, here's the behaviors that are acceptable, here's the behaviors that are unacceptable, and we will we will condition you to sort of remotely, you know, perform those things, not consciously, mind you necessarily even. Right. Because the goal of operant conditioning, it's not providing someone with a tangible tool that they can use. Right. It is.

00;15;28;29 - 00;15;55;00

Cortland Nesley

We are going to modify your behavior, but modifying behavior is not the same thing. Is changing an internal experience. Right. It just encourages more masking in my mind. And so I think the the challenge in this instance is pretty pervasive because I think our our typical answers for fixing autistic people. And I will use that in scare quotes.

00;15;55;26 - 00;16;18;25

Cortland Nesley

There's not a lot of research around like what are the long term harms of that, right? Or what are the long term impacting? I shouldn't assume it's harm, but I mean, I'll use I see as, you know, that kind of things a harm for me for sure. And, you know, and that's not even just a matter of, you know, we can talk about, you know, just sort of rebranding away from adverse lives, right?

00;16;18;26 - 00;16;40;06

Cortland Nesley

Where, you know, ABA is not these days punishing autistic behaviors as much as they are rewarding neurotypical ones. But it's the same problem fundamentally because the issue still is that you're teaching that autistic child that, you know, autistic behavior is bad behavior, you shouldn't do it. And that's just going to, again, breed the internalized ableism and it's going to encourage more masking.

00;16;40;24 - 00;17;00;23

Cortland Nesley

And I think often it's because I think as as a whole, as a culture, we're really bad at discerning between what is an unsafe behavior versus what is an uncomfortable behavior. Because don't get me wrong I some behavior modest that's like if you're if someone's stimming by banging their head against the wall. Yeah you might want to like deal with that.

00;17;00;23 - 00;17;26;19

Cortland Nesley

That's a real problem. That's a safety concern. If someone's issue is that they're flapping their arms a lot or stimming, maybe you don't have to deal with that. You know, who's harming and what it's centering in many ways is it's centering, centering, neurotypical comfortability more than it is actually healing the harm that's being done to that child in the long term effects as that child becomes an adult, you know, what are the impacts of of that intervention?

00;17;26;29 - 00;17;48;25

Cortland Nesley

And I think it's really, really important. For me, it was really important. I'll use I statements here really to make it personal. Like one of the big first aha moments I had was like one of the moments where I'm adjusting my behavior to appease sometimes an imaginary, sometimes real idea of neurotypical comfortability. And I should be able to find that term neurotypical.

00;17;48;25 - 00;18;09;21

Cortland Nesley

Those, those whose brains tend to match status of what we consider typical are normal. And there are divergent, you know, various ways in which the brain might diverge from that norm, like being autistic, you know, a, you have ADHD, you know, for example, there framework, etc..

00;18;09;21 - 00;18;24;09

Courtney Ringstaff

Could you describe what what ableism is when in in the realm of like the focus of what you are talking about and also what is appropriate behavior?

00;18;24;18 - 00;18;53;24

Cortland Nesley

Yes, for sure. I'm going to be talking a lot today about because something I experience a lot was in the cold in an internalized sense of ableism. So ableism is when different people are structures make assumptions is where being disabled, whether physically or cognitively, etc., is inherently worse than not. Being disabled right is making massive assumptions about a disabled experience that categorize it as something that's less than right.

00;18;54;09 - 00;19;24;03

Cortland Nesley

And so an internalized fatalism is when somebody who is disabled begins to take those things, is like inherently true about themselves in the world, right? So an internalized ageism is when I began to assume that autistic parts of myself were bad because I was absorbing the cultural signs around me that told me that that was the case right.

00;19;24;03 - 00;19;46;13

Cortland Nesley

I also later I'll talk a little bit about behavior modification interventions because they're so pervasive in the autistic space and they tend to dominate that space. Whether that's appropriate for them to or not operate conditioning. So that's just a matter of like a a conditioning where you take a behavior and then you attach a consequence. That behavior, whether positive or negatively in an attempt to modify that behavior.

00;19;46;26 - 00;20;19;25

Cortland Nesley

So maybe sometimes the consequences are natural, but oftentimes they're not. Maybe they're they're arbitrary. So, for example, yes, if somebody wants to stop an autistic person's stimming behaviors, they might either give them a reward for not doing that behavior, or they might punish overtly that person for doing that behavior. Right. In either instance, there is a sort of an artist special consequence that has been placed into that relationship with stimming that's going to impact that child.

00;20;19;25 - 00;20;43;05

Cortland Nesley

And one of the reasons sorry, this is a slight, slight tangent, then I'll get back on track. And I think one of the big criticisms of some behavior modification as a as a base for autistic intervention is that like that's not particularly consensual relationship, right? When you're going, hey, we're going to, you know, create these sort of artificial consequence structures for your behaviors that aren't cascading naturally.

00;20;43;05 - 00;21;05;07

Cortland Nesley

You know, the child's not super involved all the time in the that that that relationship is happening. And in my mind, that's not a tool. Right. I think I think from an intervention perspective, providing tools for people to use is more useful than attempting to modify behaviors in ways that I think have consequences, which I'll, I'll, I'll talk about as we go forward here.

00;21;06;29 - 00;21;30;07

Cortland Nesley

So that's kind of the problem laid before us, right? There is this negative feedback loop where I was feeling bad about myself because of the access to scripts that were given to me. And so I was kind of by the time I was like midway through college, like sophomore, junior year, somewhere like around this area. I was feeling real, you know, and I was doing okay again, you know, I was doing okay academically.

00;21;30;07 - 00;21;50;08

Cortland Nesley

I was I was even doing okay socially, but I just felt like a desperate need to like understand myself better because I feel like I couldn't speak to who I was to other people. And as a result, they didn't know really who I was. Right? Like I felt like most of my relationships that I dealt in college started very surface level.

00;21;50;08 - 00;22;14;09

Cortland Nesley

It was very like, you know, we were more colleagues. And then like I was developing, I think, really robust peer groups in many ways. And I think what I kind of deduced at that age was like, you know, they were telling me all this time that like autistic people struggle socially. So maybe I should investigate that right? Maybe I should take a look at like, how do other autistic people feel about this?

00;22;14;09 - 00;22;33;13

Cortland Nesley

Is this a common experience? And it's so funny because I initially went in going, you know, like, I would like some some help, please. But what I actually found was just a completely different way of thinking about who I was from. And I was an autistic person. So one of the first pieces I encountered was a piece by Jim Sinclair.

00;22;33;13 - 00;22;54;04

Cortland Nesley

It's called Don't Mourn for US. I think it was from back in like 93 pieces older than I am, but changed my life. Like instantly I read it and I was like, I reread it like almost immediately after and went, Oh my God. That piece was a lot about how it was actually addressed to two parents. They are someone who was autistic.

00;22;54;24 - 00;23;21;22

Cortland Nesley

And Jim kind of laid out the idea of like, Hey, it's okay to like it's really important for parents to go like, oh, my God, this autistic experience is is different than we thought it would be. But he makes this really, I think, a yes to distinction between like no, what you're mourning your mourning an idea you're mourning the idea of a child he thought you were going to have do not.

00;23;21;22 - 00;23;46;24

Cortland Nesley

And it's critical that you don't mourn the child that's in front of you. That child's there. They're not gone. They're right there in front of you. And and the image they were framing, this is like Autism's not just like Shel that overtakes a person, right? Like it is the person. It's not invasive, it's pervasive. And all of a sudden, autism wasn't like an enemy, right?

00;23;46;24 - 00;24;09;24

Cortland Nesley

In my mind. I'm like, Oh, wait a minute. That's just like who I am. And that's a heck of a starting place. And that might seem somewhat innocuous in some ways, but it was it was such a game changer. There's a quote I want to pull from that article. They say it is not possible to separate the autism from the person and if it were possible, the person you had left would not be the same person you started with.

00;24;10;29 - 00;24;39;18

Cortland Nesley

And I think that begins. I didn't have the language at the time. I think what he did is it be can me on a sort of journey of like radical self-love and acceptance right where I needed to begin to understand that when I was punishing myself for autistic behaviors, it wasn't just like, Hey, I'm addressing this behavior. It was like I was skewering my entire being in many ways.

00;24;40;22 - 00;25;11;25

Cortland Nesley

And this this thing flipped that on its head. And all of a sudden I start just tearing into more, more writers who were adding even more nuance to what it meant to be autistic writers like Lydia Brown, Nick Walker, Julia Bascom, Melanie Ergo, Amy Singh, queens like and, and I was just devouring these because an autistic thing is are you know, I get very hyper focused sometimes and this became my hyper focus in many ways for for the good like back half of my college career.

00;25;11;26 - 00;25;44;14

Cortland Nesley

So much so that eventually I was like, I should probably just work in the field of disabilities. You know, I think what was really key is that it was painting a picture of autism that was more textured and nuanced and layered where it became like a mirror. It's like if all the problems were happening in my mind or my body and it became, Hey, there is a complicated relationship between the way your brain works, the culture that's around you, the environments you place yourself in, and the fact that you're access needs may not be being met.

00;25;44;26 - 00;26;19;19

Cortland Nesley

You might have to advocate for them more. You might have to ask for them more in the fact that that's not like them adjusting, doing some big adjustment for a broken body that that's like they're not accounting for people like you in and and that kind of is what brings us to like the neurodiversity paradigm is what neurodiversity and a lot of these writers are sort of speaking to that is the idea that there is an infinite array of neurocognitive experiences in this world, like truly infinite in that we ought to validate all of those is like a natural part of human diversity.

00;26;19;19 - 00;26;36;05

Cortland Nesley

Instead of trying to pathologize them, categorize them, put them in a box and then rank them, and that ranking them is really, really critical. And because that's what happens, it's not just a categorizing. Sometimes categorizing can be freeing. I find a lot of use that I can talk to other people who have been categorized as autistic and we can share experiences, for example.

00;26;36;15 - 00;26;54;20

Cortland Nesley

But it is when we begin to rank those categorizations against each other, right? When we begin to go, Hey, this kind of person is better than this kind of person. Happens all the time, you know, even within two. Previously we talked a little bit about like Asperger's, right? And how my mind became a stand in for a functioning label.

00;26;55;03 - 00;27;21;26

Cortland Nesley

Well, all of a sudden after I read some more nerd diversity stuff, I start to think about that relationship differently. What if instead of like, Hey, my brain is better than another autistic person's brain because I can go out into the job market or, you know, exist in space. What if it's more, hey, I can pass as neurotypical because my access needs tend to be met more naturally by the systems around me than other kinds of autistic people.

00;27;22;22 - 00;27;49;16

Cortland Nesley

And that almost sounds semantic, but it's really, really critical because instead of going, My brain's better than your brain, it becomes, Oh, my privilege is actually stemming from my ability to to seem neurotypical, right? And all of a sudden the illness isn't placed on my body or someone else's body or my mind. In somebody else's mind, it paints a more holistic picture.

00;27;49;16 - 00;28;14;13

Cortland Nesley

Right? It forces me to zoom back and go, what are all the different factors that are leading to me being able to access the space that maybe another autistic person isn't right? And that makes me and my advocacy more specific to right. All of a sudden I'm starting to think about and question as I'm reading this different assumptions I might have had about what does it mean to be autistic, even even beyond sort of my personal experiences.

00;28;14;13 - 00;28;41;05

Cortland Nesley

So for example, if we talk about those who are non speaking right, and oftentimes that the path for non-speaking autistic folk is the goal is get get them orally speaking, right? That is like priority number one. But why? Right. Like maybe, maybe neurodiversity in my access to question, why do we value vocal speech more than we might see speech right.

00;28;41;05 - 00;29;07;09

Cortland Nesley

Because there are tons of advocates who use ATC that are brilliant, right. That we're not associating intelligence with speech. Also, intelligence shouldn't be tied to words either, for that matter. You know, just to say. But like that makes me, as an autistic person, start to question the world around me in a more critical way. That hopefully leads to a more liberatory framework for autistic people of all kinds.

00;29;07;09 - 00;29;38;16

Cortland Nesley

Right? Maybe it makes me look at like, hey, in which way is our speech language pathologist? Maybe a gatekeepers to ace? Your position is gatekeepers to see them, not them individually, but structurally, you know, in what way is why are we hesitant to teach autistic people ASL right? For as another example, right? Even though no evidence suggests that ASL doesn't hinder speech development like at all, the evidence suggests it doesn't, but nonetheless, we're pretty hesitant about it, even though it can help a lot of people.

00;29;38;16 - 00;30;06;06

Cortland Nesley

And so our personal journey that really started to take to shift things, and then I started really craving, I need to be in space with other autistic people, right? So I start reaching out to other, you know, like autistic organizations, the Autistic Self Advocacy Network, for example, incredible resource like really fundamentally changed my relationship to being autistic. This one wasn't for me, but a lot of other people I've talked to a found was success with the Autism Women and Non-binary Network.

00;30;06;16 - 00;30;29;22

Cortland Nesley

For example. And then and this is good advice I would give to autistic adults or maybe even, you know, parents as their autistic person gets older because, you know, there's not like a plethora, I would argue, of spaces for autistic people to have these sort of conversations and forums. I just made them right. I so I run I run something called neuro tails, which is a place for Neurodivergent writers to come.

00;30;29;22 - 00;30;49;11

Cortland Nesley

And it's like a writer's group. And a lot of that was just like, if you build it, they will come to some degree, right? I was like, I bet other people are feeling exactly what I'm feeling. I bet you there are a ton of autistic people across this city because I was, you know, well, I was in Boston and I in your hotels, but I was feeling isolated while I was in Boston.

00;30;49;18 - 00;31;06;22

Cortland Nesley

But like, I bet there are other people all across this country, across my town, just in my backyard, who are feeling just as isolated, just as confused about what it means to be autistic and wants to be able to talk about that with other autistic people. And and so eventually it took me some years to do it, but like, I was like, I'm just going to build it.

00;31;06;22 - 00;31;27;26

Cortland Nesley

And I think there's a lot of value to that where I'm like, If you don't think you can't build the thing, you can build the thing. It doesn't have to be fancy. It doesn't have to be a big, robust network. It might just be putting fliers up or, you know, sending out a post to a Facebook group, going, I want to talk about this thing.

00;31;27;26 - 00;31;44;20

Cortland Nesley

Do other people feel this way? And in my case, I was very fortunate. It turns out a ton of people wanted that kind of space. And we still meet every Sunday for the past four years, but that comes directly. I would not have been able to do that if I had not previously done the work to sort of just not dismantle.

00;31;44;20 - 00;32;08;22

Cortland Nesley

I'm not saying it's like gone, but with to start to really poke and prod my own internalized herbalism, my own masking because those are the things that gave me enough confidence to go, Hey, I'm a proud autistic person who exists in the world. I don't have to shy away from that. That doesn't have to end with a qualifier that, you know, if people want their privacy with their autistic diagnosis, that's like valid in their choice.

00;32;09;02 - 00;32;34;26

Cortland Nesley

For me, I found it far more freeing to sort of very loudly and proudly go, Nope, I'm autistic. And and there will be times on a masking. There'll be times that are masking unintentionally, because I'm still working through dismantling that. But every day I feel more confident in owning that and speaking to it and and being able to describe that in ways that I hope can can give other autistic people similar freedom.

00;32;34;26 - 00;32;55;11

Cortland Nesley

Right. I want other people to be able to hear, hey, wait a minute. I feel like there are times when I exist in spaces where other people's comfortability is prioritized over my access needs. Maybe I should say something about it. Maybe I should. Maybe I should be able to advocate for myself, right? Because that's kind of what I want to do.

00;32;55;22 - 00;33;14;03

Cortland Nesley

I won't be able to provide that kind of thing. And I was kind of I think my journey in many ways from like, hey, I'm doing okay, but I'm feeling pretty rough right now and I don't know what it means to be autistic to the sort of path I'm on now, which is more I'm feeling very confident of who I am as an autistic person.

00;33;14;03 - 00;33;33;20

Cortland Nesley

I think I have a better grasp, if not understanding it, at the very least, understanding that like the relationship between being autistic and a world around me that's not built for autistic people is complicated and nuanced. And that that's not my fault, right? Or at the very least, like it doesn't all fall on my shoulders. And that's not to say I don't do things or like Portland.

00;33;33;20 - 00;33;57;15

Cortland Nesley

That was your fault. You should probably fix that. But it's so much easier to go like, Hey, calling it your fault. Sometimes you should fix that rather than like, I'm broken, right? If you're starting from a place of I'm broken or even from a place of like autism is inherently bad and it's breaking you. I, I would argue you're going to inevitably get some long term mental health negative outcomes.

00;33;57;22 - 00;34;25;09

Cortland Nesley

At least I did. I can't see I don't have data with me, but like mainly because they're not researching that go hey, if a researcher listening, go do that, go research that. But like for families that are listening, what I might encourage is like take some time, if you can, to like maybe read some books by autistic authors, see if you can develop a language that you can have conversations as your autistic child starts to become an autistic adult around you, do you ever feel like you're masking?

00;34;25;09 - 00;34;41;28

Cortland Nesley

Do you ever feel like you have that internalized fatalism? And then how do you, as a family unit, be able to negotiate that and work through it right emotionally and have those language in those tools to do so? Because I think don't get me wrong, some of the clinical stuff is absolutely very important and it's what's foregrounded often.

00;34;42;12 - 00;34;46;03

Cortland Nesley

But I think some of these pieces are really critical for long term success.

00;34;47;22 - 00;35;17;11

Courtney Ringstaff

I think I'm glad and you touched on it a little bit just now at the end, but yesterday I feel like it was one of that we had a conversation about sometimes parents are so busy with, yeah, you know what's right in front of them that they don't have the opportunity to think about what's down the road or even necessarily to check in on like how are you feeling and having those conversations.

00;35;17;20 - 00;35;51;14

Courtney Ringstaff

I think it will really help a lot of families to hear the pieces that you're talking about related to mental health and how to change the stance of I have autism, there's something broken in in my brain and that's why things are this way versus I have autism and I access things differently than other people. So I think that it's like you said, it's just, you know, those words are so strong and a shift.

00;35;52;07 - 00;36;18;20

Cortland Nesley

Sure. So, for example, my mom, who I said incredible advocate, like in ways that I still blow me away, is the fights that she had to fight and were willing to fight. But when I was first starting to to sort of discover a neurodiversity paradigm and go, hey, wait a minute, you know, maybe there's something to owning and embracing an autistic experience and the unique specificities that come with it.

00;36;19;06 - 00;36;34;21

Cortland Nesley

You know, there was some like something that got lost in translation, a little bit of like it took her back a little bit. And I think part of what took it back is when she was fighting for my access needs all throughout school. You know, I think there's a real sense of like, what is the next challenge that's in front of you?

00;36;34;23 - 00;36;56;13

Cortland Nesley

Something very pragmatic about that kind of fight. And I imagine a lot of parents have a similar situation. They're thrown into a system that, again, is not built for for your child. And so you got to really, you know, pragmatically go from a challenge to challenge challenge, challenge. But I think because of that, it's sometimes really hard to see, you know, what is what is the results?

00;36;56;21 - 00;37;12;14

Cortland Nesley

You know, if you're not changing the way we're thinking about autism, how does that manifest in the autistic individual five, ten, 15 years down the road? And I say that with like all all the sympathy and empathy in the world, because I think it's not designed to be able to think about that kind of thing on a day to day basis.

00;37;12;21 - 00;37;30;27

Cortland Nesley

They're going through their own through real advocating fights. Right. But being a mom had to have a lot of conversations around, you know, in her mind, the goal was to like, baby, I don't know. She put it in this blunt words. I want to put more general. She's not here today. I love your mom. If you're listening to this, you did great but like to to overcome the autism, right.

00;37;30;27 - 00;37;56;11

Cortland Nesley

Or that like you can do anything an autistic person can do. And I totally understand that. I imagine there's a lot of parents like feelings are ultimate goal. But for me I found that framework to be so narrowing right or so restricting in some ways that the goal and that's embedded in the entire history of of literature. You go back to Lois and Abby, his entire goal was like make them indistinguishable from her peers was the quote I believe.

00;37;56;23 - 00;38;18;29

Cortland Nesley

And my stance and goal was like I was able to perform that in some ways, but it killed me inside, right? I was able to perform a neurotypical ity and pass as neurotypical still can in many ways. Sometimes it's useful to do so, like I said. But. But that that's where the loneliness stemmed from. The loneliness didn't stem from actual like proximity to people.

00;38;18;29 - 00;38;45;25

Cortland Nesley

I had people around me. I had people I call friends. I still do call friends. Some of them are great like like but if you feel isolated from yourself, you feel isolated from who you are intrinsically, internally, authentically, that loneliness is going to stay right there, no matter how many peers, no matter how much of a picture of a neurotypical person is implanted onto you, you're not going to deal with those.

00;38;45;29 - 00;39;03;19

Cortland Nesley

You're still going to have those problems emotionally. And so for me, you know, in some ways it was like supplemental, right? Like I had all these tools that that my mom was able to fight for and give me. And I still and still keep them. But they had to be supplemented and they had to be coupled with my own journey, right.

00;39;03;22 - 00;39;28;09

Cortland Nesley

As an autistic person. And and these tools I had gathered around, Hey, what are these times when I have to prioritize my needs over others comfortability, when there are times where I have to draw my lines in the sand right about what am I comfortable masking? When am I not comfortable masking? And I would just encourage parents like be prepared for those kind of conversations, right?

00;39;28;09 - 00;39;55;27

Cortland Nesley

Like if you can and again, I know the day to day can be really hard in a lot of these circumstances. So like, you know, move at the speed of trust, move slow, move gently, but down the road, maybe thinking about, you know, how how do we foster an environment in a situation where autistic people feel comfortable enough to show that authenticity, to be able to be who you are and fly in the face of of, you know, of that able ism.

00;39;56;10 - 00;40;12;12

Cortland Nesley

And to be clear, in my circumstance, my mom is very good at being able to be like, no, be who you are and go get them. I actually know this is useful for parents. I think cause I have this conversation my mom of time where, where, you know, all expressed like, hey, I'm feeling this thing that's internalized ABC Evil is in me.

00;40;12;16 - 00;40;35;20

Cortland Nesley

And she goes like, but I taught you not to do that. And I'm like, Yeah, but there's a whole culture around me that you don't have control over, right? So. So when you do want to, like, put some like ease parents minds in some ways that like there are going to be things that might impact your kids or, you know, grown child's they as an adult like self esteem relationship to autism relationship to like what does it mean to be artistic person.

00;40;35;23 - 00;41;00;09

Cortland Nesley

They're like completely beyond your control, right? Again, we still exist in a pathology paradigm, right? We are still deficit forward when it comes to discourse around autism. We're getting better. But like it's still it's still there, right? We're still in terms of media representation, still so narrow. And every time I see an autistic person on my screen, for the most part, they're like, that's just a series of like DSM symptoms that you slammed into onto the page.

00;41;00;09 - 00;41;22;11

Cortland Nesley

That's all that character is, and it makes me very mad and frustrated. That's going to impact how autistic people feel about themselves. And so the goal in some ways is not to if may happen. And if it does, how do we be prepared to have conversations to be able to dismantle those things? How do we have the tools as family units available to us to?

00;41;22;11 - 00;41;44;03

Cortland Nesley

Really look at that internalized ableism and go, how to how do we deconstruct this? How do we dismantle this? How do we how do we emotionally prepare ourselves for for a world that's not built for you, for you, that's hard. Like, I'm not going to sit here and say, That's easy, but I'll try to provide a list of readings and organizations and maybe they can help you.

00;41;45;24 - 00;42;06;02

Courtney Ringstaff

As a parent to a child who was just diagnosed, you know, like a year ago. I find that like I'm even having to navigate some of that, even though it's not even me who has autism, but just because like I find myself struggling in situations where people have expectations of him because he passes.

00;42;06;09 - 00;42;07;21

Cortland Nesley

Yes, 100%.

00;42;08;04 - 00;42;27;29

Courtney Ringstaff

But because he can't communicate and he doesn't like he can't tell them things like they're they're expecting him to behave away or they're expecting him to say a certain thing. I find myself internally being like, shut, tell them he has autism. Like in that like to to basically justify why he can't answer that question or why he's acting the way he's acting.

00;42;27;29 - 00;42;38;18

Courtney Ringstaff

And I have before and then sometimes I feel guilty about doing it because I'm like, they don't really need to know that information, but it makes me feel better that they're not like, Oh, she's a bad mom. Yeah. Or, you know.

00;42;38;26 - 00;42;58;23

Cortland Nesley

And I might say to you, Courtney, too, is that like, that's a hard situation to be in as a parent when to disclose? We're not too. And the problem is we don't have a lot of systems in place to have conversation about access needs generally because like, I think what is really important for people, everybody's got access needs, not just autistic people, not just people who are disabled.

00;42;58;29 - 00;43;19;10

Cortland Nesley

Everybody has access needs and they're fluid all the time. And how much easier, I'll give an example. So back before I worked conceived, I was an accessibility consultant in the theater because I went to theater school and when my first kind of goes out, it was pretty unsuccessful. And the reason is I was working with an autistic actor who had a lot of sensory problems from with sound.

00;43;19;10 - 00;43;36;23

Cortland Nesley

Right? They would get overwhelmed and oftentimes they would need a place to, Judy, you know, like de-stress and go, okay, I need to get away from all that noise. And so I was like, well, this is all I'll do. I will create a space in that rehearsal room that is for them where they're get, you know, if they get overwhelmed, they can just go to it.

00;43;37;11 - 00;44;01;03

Cortland Nesley

Easy peasy day of the rehearsal comes. I can see this person's getting overwhelmed by sound and I'm like, Here it comes. They're going to go to the space and they don't go to the space. And it was a good lesson for Cortland because what I realized is what I didn't do is I did not create a culture in that rehearsal room of being able to address access needs and people feeling empowered to give themselves what they need.

00;44;01;21 - 00;44;24;05

Cortland Nesley

And so in the future, do you know, how much easier is it for that autistic person to go, Hey, I'm struggling to communicate this thing, or in your instance, or like, Hey, I need to go use that space to, you know, be away from sound. If you create a culture that's like, Hey, I'm really tired today. I didn't get a lot of sleep that might impact my functioning today.

00;44;24;15 - 00;44;43;17

Cortland Nesley

It's really hot in this room. I need to go to the water fountain more often than I usually do. Having those kind of access need check ins, right? And if people are already having that conversation, if we have a normalized mechanisms to talk about access needs, how much easier is it for you to go, Hey, my kid is autistic.

00;44;43;18 - 00;45;08;05

Cortland Nesley

He might struggle to communicate X, Y and Z, right? But we don't have that right now. It's important for us to start building that up, right? Like how do we normalize these kind of conversations? And the second part of it, too, is just like and this resonates so much with Courtney, we're like, again, is this frustrate adding divide when it comes to passing where it's I feel like everybody who doesn't pass as neurotypical, like everything that makes them great gets completely overlooked and it's just all deficit forward.

00;45;08;05 - 00;45;27;29

Cortland Nesley

And then for a lot of people who do passes neurotypical, like every struggle, they had these questions and like all their access need problems are like, now you're fine. It's a real double bind, you know, and it's almost like if we create systems that are a little bit more fluid and accommodating, instead of trying to box people in to like, well, it's this, it's this binary of dependance and independence, right?

00;45;27;29 - 00;45;45;06

Cortland Nesley

Either you're independent and you don't need any buddies help at all or you're dependent and you're a burden you're going to burden the system. And neither of those things are often wholly true. Right? We're interdependent each other. Everybody is interdependent on each other. Not one of us in this room right here, our virtual room runs Zoom is independent fully.

00;45;45;06 - 00;46;08;21

Cortland Nesley

That's nonsense, right? We all need each other to operate in the world. And maybe some people's needs are more effort intensive. Maybe some other people's needs aren't met by typical structures because it's not built them. But that is different than sort of a centralizing it to like this person doesn't have any needs, this person has all the needs and that's the end of that conversation.

00;46;08;21 - 00;46;28;15

Cortland Nesley

And I think it makes it so there's a long way to answer your question, Courtney, but I get excited. But like to your point, when you have that struggle around, like, you know, do I tell them he's autistic or do I not tell them he's autistic? I think part of it is like we don't have, I think, a lot of cultural tools to engage in the nuance of acting that you're getting at, because there's a lot of nuance involved in communication.

00;46;28;29 - 00;46;47;09

Cortland Nesley

I don't even say communication struggles. It's oftentimes just disparate types of communication too. Like I would imagine your child, I could be wrong. I don't like communicates. Maybe it's just not always in in a typical way. I mean, this is even shifting away from like, you know, things like Theory of the Mind where in for I'll try to find my terms here.

00;46;47;09 - 00;47;08;28

Cortland Nesley

So theory of mind for for listeners is kind of develops out of a study done by Baron-Cohen suggests that if cystic children struggle to understand the interiority of a person they're interacting with. Right. And that's kind of where we get a lot of the ideas around like autism as defined by social deficit. Right. Or autism as defined by mind blindness that they use the term.

00;47;09;20 - 00;47;30;15

Cortland Nesley

But there's been a lot of research since then that sort of suggest that's a very reductive framework. Right. And that's a very narrow way to look at autism these days. There's been a lot of talk about something called the double empathy problem, which is a little different. The double empathy problem suggests that it is not a situation where autistic people are mind blind and can't communicate or can't understand the interiority of the person in front of them.

00;47;30;27 - 00;47;52;11

Cortland Nesley

It's that it's two people missing each other, right? It's that autistic people don't quite understand the interiority of the neurotypical person in front of them. And the neurotypical person probably doesn't understand the interiority. That autistic person in front of them. And I think that shifts really important, right, because it creates the problem. The problem doesn't become this person is broken, let's fix them.

00;47;52;19 - 00;48;10;04

Cortland Nesley

The problem goes something's getting lost in translation. How do we build that bridge? And I just think that's far more useful from an autism intervention perspective. It's just so much easier. Like how do we provide tools as to to bridge these gaps of communication as opposed to going, what's the deficit? How do we fix the deficit?

00;48;11;16 - 00;48;35;29

Courtney Ringstaff

One thing that I was thinking about when you were talking is kind of building this culture of acceptance and just figuring out how to make it a part of the world. And it made me think of some of the things like when you first introduced yourself, you said, my name is courtly, nasally. Courtland Nasally. My pronouns are he him?

00;48;36;07 - 00;48;58;29

Courtney Ringstaff

Yeah. And so when I was at a conference last week at OECD, which is our National Disability Conference, when the presenter had their first slide, I took a picture of it because I was like, I love this. It was like, here's the name of, you know, the presentation. And then their very first slide was on accessibility and it said a slow applause.

00;48;59;15 - 00;49;28;04

Courtney Ringstaff

Use the space how you need to move case sit on the floor, ensure there is room for people using wheelchairs to enter. Exit Move around. One person speaks at a time and I thought to myself like, we all need to do that. Like we just need to add that in there. Because even in lectures, like in my classes, students can get up and they can walk around and they can pace in the back of the room if that's what they need to be able to concentrate.

00;49;28;04 - 00;49;44;08

Courtney Ringstaff

And, you know, it's like these small things that start to become part of the norm, I think are ways that we can help do that. So I'm always looking for kind of things like that. So a few ideas.

00;49;44;20 - 00;50;02;21

Cortland Nesley

One I loved, that's very heartening to me that that conference did that. That makes me happy. It's great. I mean, like, it's so important. It's a layup in ways. It's a gimme, right? Like, and it's like we, we have this conversations, backgrounds in theater all the time because there's so much talk about like how much is like proper theater etiquette is just like a sort of behavior policing.

00;50;02;21 - 00;50;24;02

Cortland Nesley

And similarly, like, I think this goes back to the paradigm of like, hey, is that an unsafe behavior or does that just make you kind of uncomfortable? Right. And if somebody is like, hey, someone's walking around, that makes you uncomfortable, I might encourage them to reflect on why, why? Why does that make you uncomfortable? More than I would tell that person to sit down and be quiet or to, you know, like, you know.

00;50;25;02 - 00;50;42;24

Cortland Nesley

And part of it is also we have a very, I think, narrow idea of what like good student behavior. And I used students. But again, I think it applies beyond adolescence of like paying attention means like sitting still and putting folding your hands in your lap and like looking up at the person or it's eye contact. I that's a big one is autism.

00;50;43;05 - 00;50;57;10

Cortland Nesley

That eye contact is like how you show respect or that you're listening. And I'm like, that doesn't show I'm listening at all. Like, not one little bit. I can be listening to someone and not giving them eye contact. We do it all the time. This is why I love Zoom. I can just look at me if I want to.

00;50;57;19 - 00;51;23;07

Cortland Nesley

But you're right, Marlene. I think I think what that gets at is like it's two things. One, I think really be cognizant of questioning the pillars we hold dear, right? Like what are what are the cultural pillars of professionalism and respect that we think are essential ideas that we think are like critical and really and some of them might be right, but and some of them might not be some of them might go, hey, actually, is this thing doing us any good?

00;51;23;19 - 00;51;41;28

Cortland Nesley

And then how do we normalize it? Right? Even something as simple as naming it at the top of the lecture, like that's it's huge, right? Giving permission, right. That like it's not enough to be like, hey, we're not going to add. And, you know, an adverse consequence to a stem is how do you actually go you're safe to stem, right?

00;51;42;08 - 00;52;02;25

Cortland Nesley

It's okay. Because that person identity through cultural osmosis, they have learned is not safe to stem in a lot of places. Right. And so I think it's not enough to to not cause harm. I think we have to actively heal the harm. Right. You got to actively go. It's okay to be autistic in this space. It's okay to do X, Y and Z in this space.

00;52;02;25 - 00;52;23;18

Cortland Nesley

There's also something that's like universal design here, right, that we're brushing up against in many ways. You know, it's funny, I always have mixed feelings, but every once in a while as an autistic person, you'll come across a sort of some variant of like, everybody's kind of autistic, aren't they? Right. And I always have kind of mixed feelings about it, because on the one hand, I think it's often wielded in a sort of dismissive way, particular because I pass as neurotypical.

00;52;24;28 - 00;52;40;27

Cortland Nesley

But I think there's a lot of truth in it too. And the truth in it is like, you know, nobody did a brain scan on me. I went, there's where the autism is. Not to say that the research doesn't suggest there's some, you know, genetic component or something happening in the brain. But like practically speaking, No. One, there's no biomarker, right?

00;52;41;10 - 00;53;00;02

Cortland Nesley

Like what happened is, you know, a series of, you know, cultural sentinels, like a teacher or even my like my parents. Right. Went, Hey, something's going on there from a behavior perspective. Let's take a look at it. You know, and that's I'm not saying that's not useful, but what I'm saying is that that's a very subjective science in many ways.

00;53;00;02 - 00;53;17;13

Cortland Nesley

Right. And that is to say, it's not a binary of like, you know, one, you're autistic, zero, you're not autistic, you know, and that's not me. Like trying to pathologize Melina and going like, if you need to feel the need to stand up in and, you know, stretch your legs is the presentation. Guess what? You're a little bit autistic.

00;53;17;13 - 00;53;36;29

Cortland Nesley

But what it does mean is that I think it's really important for us to understand that these categories are not arbitrarily drawn boundaries. Right. They're thoughtfully drawn boundaries, but they're also they're artificially drawn boundaries. Right. They're not the end all, be all. Moses didn't come out in high with the DSM and go like, all right, this is the truth of the matter, right?

00;53;36;29 - 00;54;05;19

Cortland Nesley

These things are fluid and in conversation all the time. And I say that only to mean that I think it's really important that, again, we how do we create frameworks where it's not just simply as simplistic and reductive as like, all right, this is what we do with autistic people. It's more about exploding the idea of like, what are the cultural things around us that make the lives of autistic people harder?

00;54;05;28 - 00;54;18;10

Cortland Nesley

And oftentimes it makes a lot of people who aren't autistic harder to write like that sort of cultural policing is more pervasive than just, you know, autistic people.

00;54;18;10 - 00;54;40;27

Courtney Ringstaff

So I do have two questions that might lead us to closing. And the first one is, you know, you mentioned that some of the literature and studies that you read over might have helped lead you to working in disability services. But do you find it ironic at all that you work in a TBI program and you're also an adult with autism like you didn't find yourself working in autism?

00;54;40;28 - 00;54;41;26

Courtney Ringstaff

That is correct.

00;54;41;26 - 00;55;05;26

Cortland Nesley

Mostly because I well, I mean, the thing is correct with this a one is just like I came from a theater background. So part of it was just like, I need to get my start in disability somewhere here. Who's got a you know, I was starting from pretty entry level places like somebody take me in this TBI that took me we're actually really fortunate about I think learning the TBI perspective is really expanded.

00;55;05;26 - 00;55;27;12

Cortland Nesley

My notions and imaginations about disability do and I would really I this is a little more like high end or high level like I don't think this is like immediate but like for autistic people that might be listening, I really do encourage that like looking beyond our own noses, right? And that like other disabled communities have a lot of really interesting things to say that I think add to a more holistic view.

00;55;27;17 - 00;55;56;18

Cortland Nesley

Like I learned just as much from this thing called like mad studies, for example, that talks a lot about like mental health in ways that I find very evocative that like radically changed my ideas about autism or like critical disability theory more generally like that stuff. So that's one part of it. The other is I think I am almost too emotionally close to autism where like I feel like when I want to do my autism advocacy work, I really enjoy it on my own terms and in my own ways.

00;55;56;23 - 00;56;24;25

Cortland Nesley

Like there are I have firmer lines in the sand about autism feelings, right? I am less willing to sort of, I think, negotiate certain things around, like because there are certain, I think, autism interventions or autism things that I'm just less okay with from an ethics perspective and from my own feelings about it. Perspectives that where when I am ready to go do my artistic work, I kind of want to grasp that in a way that is more conducive to my personal relationship to it.

00;56;25;03 - 00;56;53;09

Cortland Nesley

I think, you know, because I came in and see me as like an administrative assistant role and I just feel like on the day to day I would have to negotiate like a lot of feelings about a lot of things, ways that might inhibit being an administrative assistant, if that makes a certain sense. And so me I think, ended up being a really good home for me to both expand my notions about one, just like also getting a better understanding of like disability services generally and understanding like how these structures and systems work.

00;56;53;16 - 00;57;18;16

Cortland Nesley

Also meaning a lot of great people and you know, working with them like you too. But, but I think there is part of it where I'm very self aware that like my relationship to autism advocacy and autism is so specific to, to my feelings about it, like I think I'm when I'm ready to do that kind of work on, on a more professional level, I think it's got to be a little bit more on my own terms that that makes a certain sense.

00;57;19;16 - 00;57;25;22

Courtney Ringstaff

And that was my next question was what are your goals for like advocacy work in autism?

00;57;26;01 - 00;57;43;28

Cortland Nesley

Sure. So I'm studying public health right now, you know, learning more about epidemiology and public policy and stuff like that. I'm particularly interested in like filling in gaps of research because I think there's a ton of them in autism research where we talked a lot about, for example, like the lives of autistic adults is like very little looked at from a research perspective.

00;57;43;28 - 00;58;06;17

Cortland Nesley

I think the long term effects of of behavior modification are particularly looked at. I think it's evidence based is also pretty shaky. I'm Particularly interested in the way is that how is like the market interests of the autism services market impact, how autism intervention is constructed? I think that there's some discourse on that, but not for those are interested in that sort of discourse.

00;58;06;18 - 00;58;29;23

Cortland Nesley

By the way, it will be in the show notes, but it's a really good book called Autism Inc Autism Industrial Complex, another book that like threw me for a loop and my understanding of of autism. But like, I'm really interested in going what's missing right now, not, you know, in terms of a knowledge base, in terms of understanding autism and a sort of broader perspective like that.

00;58;29;23 - 00;58;57;08

Cortland Nesley

So that's kind of eventually where I want to land. I am interested in research. So that's my goal eventually. And I think I'm also just interested in building autistic communities a little more. I have my neuro tells, but also like I'm very interested in community based research and public health seems to be going this route generally, which I think is nice where like, you know, thinking about research that how, how do we make sure that the voices of those who are impacted by by intervention are like deeply involved and rooted in the construction of its knowledge base?

00;58;58;10 - 00;59;26;02

Cortland Nesley

That's a particular passion of mine. So I'm I am also interested in making sure and advocating for that that autism research is in conversation with autism communities, especially because autism communities are better organized now than they've ever been. You know that the advent of the Internet like I mean, the autism community was really, really boomed near a similar time where the Internet started to bloom and places like wrong Planet dot net, for example, like, you know, tons of autistic communities kind of sprang out of that.

00;59;26;06 - 00;59;40;03

Cortland Nesley

It's easier now than ever, I think, in some ways to like include autistic voices in discourse. And making sure that happens is something I want to make sure happens.

00;59;40;03 - 00;59;55;21

Courtney Ringstaff

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