

The Conversation Continues: When it Comes to Autism, Can We Reconcile the Medical and Social Models of Disability?

Full Article and Interview Transcript

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On Behalf of the Organizers, Presenters and Panelists of the Northeast Regional Spring LEND Conference of May 8, 2023

On June 15, I (JF) had the pleasure of re-convening nearly all of the panelists* and speakers from the NE Regional Spring LEND Conference of May 8: [When it Comes to Autism, Can We Reconcile the Medical and Social Models of Disability?](#) The conference focused on the idea of exploring and reconciling the polarized ideas circulating in popular media that celebrating one's neurodiversity as an autistic person somehow diminishes or invalidates the emotional pain of caregivers of individuals living with what has come to be known as "[profound autism](#)" and vice-versa. We agreed that, given the important ideas and meaningful discussions generated by the conference, it would be of value to try to recreate them as a reflective interview in written form for our greater LEND, UCEDD, and AUCD community. We are hardly the first to call for reconciliation and healing around this topic^{1,2}, but I could not be prouder of how these speakers and panelists – a developmental-behavioral pediatrician, people with lived experience, and parents of individuals with autism – came together to so thoughtfully discuss and wrestle with these important issues. As you will read below, we came to the conclusion that, at least for this particular topic, the distinction between the medical and social models – much like for the distinction between "high functioning" and "low functioning" autism -- is a false dichotomy; and what we may really be dealing with is the legacy of historical trauma from structural ableism embedded in our healthcare and educational systems. In speaker Carol Weitzman's words, "We need to acknowledge that we don't know everything about this disorder...and we need to learn to live with ambiguity." I also need to thank our self-advocate panelist Chase for introducing us to the metaphor of the "social battery", a quite elegant way to understand the periodic need of people on the spectrum to disengage from social activity and recharge.

I am a firm believer that the secret to a good interview is to assemble the right people, ask the right question, and get out of the way. I hope that you will agree that this goal was achieved. Thanks for your attention, and I hope that you will all continue this important conversation. With that, please allow me to re-introduce the speakers and panelists and let you dive into this transcript. For the presenters' and panelists' full bios, click [here](#).

Gyasi Burks-Abbott (GBA), LEND Self-Advocate Faculty, author, public speaker, and board member of several autism and disability organizations

Susan Baylis Jewel (SBJ), CCHW, Manager of Family Support at the Autism Project, parent of Julia and Emily, 27 and 24, on the ASD spectrum.

Chase Mulvaney (CM), LEND Graduate, self-advocate, first generation college student, graduate and disability/inclusion counselor at Salve Regina University, incoming Program Manager for AUCD Community Inclusion Program

Miny Ortiz (MO), CCHW, Bilingual Family Support Specialist at The Autism Project and The Children's Neurodevelopment Center, at Hasbro Children's Hospital, mother of five children with developmental disabilities and learning disabilities

Carol Weitzman (CW), MD, Developmental-Behavioral Pediatrician, Co-Director of the Autism Spectrum Center at Boston Children's Hospital

*Thomas Ledbetter, autistic self-advocate and advocacy fellow in the LEND program at the University of Rochester Medical Center, was not present for the interview transcribed below, but his spirit and contribution to this conversation were very much with us and acknowledged with gratitude.

The interview has been edited for brevity, clarity, and grammar.

JF: When I proposed the topic of this panel -- this was at the AUCD meeting in November 2022...[during] a meeting of all the regional LEND Directors -- I got some raised eyebrows, [because] at the time this was proposed, at least in the press, this was a controversial topic, this was inflammatory...And I'm wondering, did you have the same sense of that when I invited you to participate?

CM: Honestly, no, and the reason for that -- I'm not going to know the exact statistic off the top of my head -- we know that more people in the population have [ASD]; and me being in higher ed, some of our best students at our institution, the ones with the most success, tend to be differently abled. So to be able to talk about, how do we reconcile these models so people could have better outcomes, I thought this was a good time to do it. [JF: What made it a good time, Chase?] Moving into my education background, into my political science background a little more, we're seeing a lot of people moving around the country for social mobility reasons and for safety reasons; and one of the means of social mobility is where you pick to go to college, and as we know, some colleges are better at accommodating people than others...When we look at where people choose to go, one student [who was] differently abled and of color told me, "I chose the East Coast, I chose [Salve Regina University] with intentionality." And so to be able to say, "how do we set folks up to have good high-functioning lives," especially in this context, is one of the reasons why I was excited for this panel.

MO: I'm always happy to have a seat at the table, always, always, because the journey that we are on can be very different for everybody, and one thing that I have learned, because I have three adult children with autism, and they all look different [symptomatically], and they were all diagnosed at different times, they come to the table with a different perspective. Ben, who was the first one diagnosed at 8 years old with atypical Asperger's...At the time that his siblings were diagnosed in their 20's, he said something very poignant: "Ah, you went from one child

with autism to three, but only one received the appropriate supports.” I thought that was so powerful, right? And I can see the difference in their perception about the medical versus the social model depending on the supports that they received. My two adult children who did not get the support that they needed, because their autism was missed, they have a lot of resentment. They did go through a lot of mislabeling. They did go through a lot of punitive repercussions for their perceived behavior, so for them, that social model, they’re waving it [as their flag], because of how they suffered. We had one clinician say to my daughter, when we were having a difficult time communicating – (it was just a big mess) – she said to my daughter, right in front of her, that because she had been born at 25 weeks, “Well, of course we know that her brain is fried, so what do you expect?” And we know that’s not the right thing to say, right? There’s a saying in Mexico, that everybody tells [a different] story about the party depending on how much fun they had, so I think that has an impact. There’s sometimes not a lot of uniformity in how a person gets the diagnosis or what is considered autism vs. just being entitled (laughs), [or] ADHD, [or] anxious, right? So I think that variation affects how self-advocates will perceive the medical vs. social model.

I can say for Ben, who has received all kinds of supports, because his autism was clearer – it was just easier to pick up – he has no resentment, he is open to supports, because he hasn’t suffered by not being understood (at least to my understanding)...But I think having a voice at the table is really helpful, and just like in anything, you can’t generalize, it’s not either-or, we need everything to move forward. I just said in a class the other day, as the parent, unfortunately, autism is not something where love is enough to get them through.

GBA: When you first suggested the panel, I almost thought of it as like a peace summit, that we have these two entities that are in conflict, and we have to come to an agreement; and I thought this was a great avenue to do that, because, like with any peace summit, there’s usually far more that the two sides have in common, and they just need to focus on their commonality, their common interests, and overcome their differences...And it made sense, because I really think there’s no need for conflict between the medical model and the social model – they can live together quite harmoniously.

CW: I’ll jump in – and Gyasi, I totally agree with you, I love [what you said] – Jason, I will say when you first raised the topic and people raised eyebrows, I totally understand that, but I’ll speak for just a moment as a clinician...With *DSM-5*, there’s one big sort-of bowl of soup that’s called Autism Spectrum Disorder, and within that there are many different types of people who carry that diagnosis, and within the world of autistic people and families, there is not always a lot of agreement...And sometimes it does feel as a clinician, you feel like if you say one thing, someone’s going to be upset with you, you say something else, someone else is going to be upset with you...It’s hard to know how as a clinician or a researcher to proceed. The words we choose matter – I’m with you, Gyasi: there are more commonalities -- [and] there should be some place where lots of people with lots of identities are included; but people are very passionate about this and have strong feelings, and it hasn’t always been easy to have these conversations with respect and open-mindedness. I understand why we talk about two

models, but there's a lot we [still] don't know about this thing we're calling autism, and [we need to] keep ourselves humble.

GBA: Can I piggy-back on that a little bit? Because the way I see it, the medical model looks at the reality of the body and the mind, and the social model adds to it [by addressing] how does that body and mind interact with society. So in essence, the medical model would say, "This person can't walk, so they can't go into a building that [requires the use of] stairs" – pretty cut and dried – but the social model would say, "Actually, no, you can put a ramp on that building so that they can [fully access it]." It's the difference between impairment and disability – how that body and mind interact, *functions*, in its socio-cultural environment.

CW: If I may, I think those of us who live within what you would call the medical model think very much about those [socio-cultural/access] issues. The medical model [is] sold short...Most clinicians think about functioning in the world and implications far beyond the very narrow perspective [that is attributed to the medical model].

SBJ: I agree with you, Carol. I think that the medical model and social model go hand in hand, but what we hear is inflammatory language. We hear that in the medical model, the person is the problem, and we hear from the social model that society at large is the problem, because [people or institutions] are intolerant, they don't provide accommodations; and nothing in life is totally right or totally left...So for me, I didn't think, at least I hoped that [the panel] wouldn't be this controversial thing, because to me both [models] make sense, they should be hand in hand. In the medical model: "This is the diagnosis, this is what it means, this is what it is"; in the social model: "These are the accommodations that we should be making...and people should be nice to each other" -- I don't know why that needs to be said, but it does (laughs)! I think it's the inflammatory language that gets everybody going.

CM: To speak on your point, Carol and Susan, I definitely think that clinicians, in doing this work, are always thinking about the impact on the individual, wanting to achieve the best lifestyle for the individual. I think, though, that we're entering a time that we're thinking about this differently – it's definitely taken some evolution of our thinking – about what the medical model sort of lacks, and we're starting to build that in now, is the open door for growth. This condition will not present itself at the same time in the same way, but it will present itself differently throughout a person's lifetime – moving in either a high-functioning direction or a low-functioning direction. That's a slider that needs to be built into the medical model.

SBJ: I think by nature of the diagnosis itself, Chase, it being a *neurodevelopmental* disorder, because we talk with families all the time: As our kids develop, their autism looks different, their sensory needs look different, their communication needs look different – just like any person, right? As we develop, we look different...We talk a lot about [this], because parents want to be reassured that it's not a behavior disorder, but it's going to look different as our [children] develop.

CM: Definitely...I think sometimes, when [ASD] is presented, though...We like to be predictive: “This *will* look like this,” when in fact I think we need to say, “This *might* look like this. There’s things we can do, Early Intervention and things, to help smooth the process.”

SBJ: Agreed. I’ve had really great clinicians on my kids’ team, and my take-away is, “Nobody ever rose to low expectations”, right?

JF: Gyasi, that was a very poignant part of your segment: the battle between the medical and social model; and having read your autobiography, having talked about it with you, the whole being misunderstood aspect really rung out poignantly. I was hoping you might say a few words about that.

GBA: I guess, yes, being misunderstood, and I think with the way that the conversation is going now, I take Carol’s point that the medical model is not bad – it’s not [solely] biological determinism – it’s appropriate in its own context. I think, interdisciplinarily, we deal a lot with public policy, disability rights and passing certain pieces of legislation. It doesn’t matter what the disability is or wherefore the disability, this person still has rights. I almost make an analogy to [a person getting] shot. They wind up in the emergency room. Deal with the bullet wound, then we can maybe figure out the psychological [fallout] and sociological [contributors].

CW: I’m going to be honest with this group and tell you I don’t like the idea that we have this dichotomy of medical model, social model. I think it’s artificial, and I don’t think it works. [Heads nod in agreement around the Zoom]. I love your points, Gyasi, but I think certain things are being conflated when we’re talking about the medical model – and I don’t know, Miny, if this was what you were referring to a little bit...

I don’t know how much people are familiar with this SAFE project that I’ve been working on, but we’re developing this consensus statement about creating supportive and accessible environments in healthcare for people with neurodevelopmental disabilities; we’re very close to finishing the consensus statement that we’ve written, which was crafted by people across disciplines, family members, self-advocates...I feel like what I’m hearing here is how medical healthcare systems embrace and provide access to people with neurodevelopmental disabilities – or not. Meaning a lot of times we expect people to check their neurodevelopmental disability at the door and be able to function within a medical system without accommodations, without respecting the diversity that people bring to healthcare encounters – inpatient or outpatient. That is not a “medical model”. That is a healthcare system that has not been responsive, that has a lot of structural ableism in it, that does not promote the notion that people interface with the healthcare environment differently across levels of severity...I don’t love this artificial distinction. I get the concepts [of medical vs. social model], and I would just love to have a unifying thought.

But Jason, to get back to your original question of why do people feel like this is controversial, it seems like because of the breadth of the spectrum of people who identify as autistic, there are people who are very severely disabled and people who identify as neurodivergent, and how do

you reconcile that? As the clinician, I feel like some of that controversy stems from the autistic community, and I'd love to hear from everybody here about that thought too. [JF: Carol, you and I talked about your journey with developing your talk for this conference, and this segment does justice to your deep thinking. I just want to express my gratitude for that.] You don't want to offend people, that's really it. You want to dip your toe in controversial waters, and you want to encourage healthy conversation, but not offend people and make them feel like you're saying things all wrong. That's why it was hard to do.

GBA: I definitely hear what you're saying Carol. I think a lot of what you're describing is based in what one might think of as historical trauma. My interface with the psychological community when I was younger is not what someone in their teens and 20's would experience now, because things have changed, and I think that's positive. The medical model is not as medical as it once was; it does take into account diversity – both cultural and neurological. And there are even programs like Operation: House Call in Massachusetts that train future healthcare professionals in neurodiversity. (We also have Linking Hands at Boston Children's Hospital). So I would say things have changed, and the distinctions [between the medical and social models] are not so great now, but historically they might have been, and I think people are responding to a certain extent to the historical trauma.

I don't think the medical model applies solely to the profound autism crowd and the social model applies solely to high functioning [ASD]. For instance [if we were to say], "People with profound autism, they can't speak, they're intellectually disabled...50 years ago, we'd have just thrown them into an institution and forgotten about them." *No*. Social model: They have every right to be part of society. It's our job to make accommodations for them, whatever those may be. And of course, [the] medical model: People who are high functioning need medicine, to be treated for certain things.

CM: Gyasi, I really like your point; I really love how you're taking it from a rights-based approach. (With my philosophy background, I tend to come at things from that perspective as well). Carol, to your point as well, I would agree that the medical systems that we've historically had to interface with do have that structural ableism, and my question is, the analysis we need to do is, where do we need to remove that structural ableism from the medical model? We've come to a point that both [medical and social] models need to improve, and I think what we're moving toward is synthesis and an arithmetic mean of...how we build society moving forward. It's more than just a medical issue.

CW: Amen! Such great words you guys have said – brilliant! I can't wait for this consensus statement to be done so I can share it with you guys; I think you will appreciate it. Gyasi, I do think your issue of medical trauma is really an important one. The implications [of a healthcare system not embracing neurodiversity] are profound. When you look at the rates of morbidity and mortality among people with autism, they're higher, and it's because of these issues of trauma, adverse care, foregone care, all of these things. [Health]care is a basic human civil right.

MO: One thing that Sue and I have discussed many times with all of our colleagues at The Autism Project is, “For parents, which side is harder”; and the conclusion is neither and both. Because as the parent of Julia and Emily, Sue doesn’t have to say, “Look, my kids need this kind of support,” because it’s more obvious the support that they need. Now my kids, they can speak, they graduated from college, but the supports that they need, we have to throw them under the bus to get, we have to highlight [their difficulties], because they are so impacting as to not be able to function...One of them has better skills at masking, so they are able to get through a job, the other ones don’t. The other one is plagued by OCD; those things keep tripping you up. One thing that I can attest to, because of the work that I’ve done with The Autism Project, because of the work that they have done with me, is that the more each individual understands, “Oh, that’s what autism is! Oh, that’s why they need that support,” the more they bring that to their place of work, whether it’s the bank, whether it’s the hospital...my own husband, he’s a physician, he’s an endocrinologist, he deals with diabetes – but now his radar for autism is up. So as soon as he sees a person that needs additional supports, not just for their diabetes, that radar goes up: How do I present the information so that this person can understand [it]? How do I explain treatment, so it makes sense? How do I schedule, how do I support? Because his way of thought has changed. He tells me that [I] taught him that. I learned that at The Autism Project, and I taught it to him. We bring it forward, and it gets embedded, but if we don’t understand what autism is – even if you make all these systemic changes, it comes down to that individual.

When we understood that people in wheelchairs are people too, things changed. When we understood that people who are blind are people too, things changed. Not a lot of people understand the real meaning of what autism is and how it impacts everybody differently...I wish [for] the day that I don’t have to throw my kids under the bus to get the supports that they need. That would be awesome.

SBJ (nodding in agreement with MO): It’s a huge problem, Miny. One end of the spectrum isn’t any easier than the other end of the spectrum. It just looks different. The challenges that Miny has with her children are different than the challenges I have with my kiddos. Language is always changing, and we’re always so careful, Miny, of how we talk to people, and we have a group of leaders here, adults who have been with us since they were little, who come to our trainings and really help us get the [terminology] right, and one thing we’re really getting away from is “high functioning/low functioning” – because there are some Level 1 “high functioning” [air quotes] people who are really impacted by their autism, but because they have language and don’t have impaired cognition, they’re somehow high functioning. It’s so misleading to families as well. How many calls do we get: “The doctor said their child has a ‘little bit of autism’”? I said to Miny, that’s like saying a little bit pregnant. [My two daughters] are ASD, Level 3 – they’re both different even though they’re on the same end of the spectrum. Miny’s kids, on that other end [of the spectrum]: Different, different, different.

I say, for my team, but it really fits here I think, the poet Maya Angelou said, “When I knew better, I did better,” and I say that to myself all the time, with the more we’re learning, “Man! I

got that wrong! Can I get a do-over?" The parent guilt, right Miny? **MO:** Yeah, big time.] So when we know better, we do better, and it's going to be an evolution, I think.

MO: You see the comparison between the medical model and the social model? Why fight? We're all on the same team. We know better on both sides. How do we come together to provide that support, understanding, and navigation for every person on the spectrum?

CM: I agree wholeheartedly, and I think a lot of this is, to use an analogy, what happens when we have a bad road. When we have a bad road, only some people can travel it. When we have a smooth road, it's easier for everybody regardless of how they move around. Especially for education around autism, one reason why it's so important is that even for people who are high functioning, they feel a distinct sense of otherness from their peers. That has an effect on mental health, and it's also very draining. Imagine being on the spectrum and not really understanding why your social battery burns out as quick as it does – or how to even start to figure out some of those self-care things -- and also imagine being on the profound end [of the spectrum], and not knowing how to be connected with community, how to find your own form of self-expression. I think all of this boils down to that rights-based approach and agency.

JF: Chase, that's such a perfect segue. I'm just going to jump to my last question. What I love about this group [is that] one question covered all the topics! [The group laughs]. I had this stack of imaginary [cue] cards, and [pantomiming checking off a list of topics] oh, we covered that, we covered that...So my last question: I've seen this extraordinary, idealized conversation in a bubble that we're having in Zoom right now, and I've seen this really contentious town hall meeting that...erupted into some pretty unpleasant, pretty angry conversations; and I'm wondering: Do we have ideas about how to find the middle ground? Is there a way that we can have this civil conversation that doesn't require this tightly controlled Zoom bubble?

MO: In my opinion, it's a tough conversation, so maybe we make a little bit bigger bubble, and then you make that bubble bigger, because tensions are high and everything is very divisive right now. Trying to have a smooth conversation about something controversial is very challenging, right? As Sue will attest, I'm a big proponent of the ripple effect – you start little and extend from there – because the voices might be drowned out from so much anger; and it's not only [with] autism, it's in every area of life. How do we build bridges, that's the question.

As a parent of kids on that Asperger's range of autism, I can honestly say – and it's not that they have a bad life – but if not for the amount of money that we have invested for their progress, they would not be where they are. My husband's a physician; we have invested most of our money in our kids. But think about this: What if we didn't have that ability? Where would my kids be? Would I be celebrating? Probably not. I celebrate [them and their accomplishments] now, because they're my children, I love them to pieces, this is who they are. But to be a volunteer – yes, I want autism for my child? Probably not, because it makes life harder, and without resources, support, [and] information, love is not enough. And that is scary. And the

biggest worry is what happens when I'm not here? That petrifies us all: Where will they end up?

CW: I would say this is not a distinction between the medical and social models, unless you're assuming that the medical model only talks about profound autism, and that's just not true. These terms don't resonate. Here's what I was thinking (I have three things):

#1) We need to acknowledge...I cannot think of any other issue that crosses the span of what we talk about when we talk about autism, and we need to recognize that we don't know [everything about] this diagnosis – it's a big mess – and someday, I'd love it to be in my lifetime, that we look back and go, "Oh! That's crazy: *that's* what we used to call 'autism'", when it's really 50 different things that happen to have this somewhat shared behavioral phenotype. Do we really think that this definition in *DSM-5* captures the breadth of what we're seeing? I just think we as a society – not just medical professionals -- need to understand that we're at a very early point in our understanding of this.

#2) We have to learn how to live with ambiguity, that there are people who celebrate autism and there are people who think autism is a severe disorder. You can have two competing ideas that can both have truth...But I know why people fight about that, I get it: They feel like if I do one or the other, it cancels or invalidates the other. We have to be able to [come together] and say that [we] can have these two truths that are valid and reasonable.

#3) We need to do better, more careful outcome studies that look at different people with different kinds of profiles and figure out who needs what [services]. I never use that high functioning/low functioning terminology anymore, because I think it does disservice to everyone. [Miny nods in agreement]. So having really well-defined outcomes about what people really need. I think we're shooting in the dark a lot of the time...

GBA: See, that's where I think we can learn from the medical model. One thing that strikes me is that dichotomy between high functioning/low functioning – that's a very autism-specific thing. Like with cancer, and with a lot of physical [health] conditions, everybody's not going to be affected in the same way, and we can understand that without saying "high functioning/low functioning." Like we would never say that the person with skin cancer, which is more treatable, has "high functioning cancer" and the person with lung cancer has "low functioning [cancer]." We're able to understand that cancer is cancer, and it will affect people in different ways. We can separate the person's success in life, and the esteem we hold for them, from their physical condition. I always go back to two things: FDR having Polio, and perhaps that affected what he did as President, with the Great Depression, but no one would ever lament that Polio is gone from the Western Hemisphere; and I also go to Stephen Hawking – no one would ever suggest that he had "high functioning" ALS. That's maybe the lesson from the medical model, that we're able to separate [the person from the condition] and appreciate the nuance. And there's the identity piece too: When my mom got cancer, she was advised to find other people who had cancer and create a community.

CM: Thinking about the identity piece, [neurodivergence] can be a portion of one's identity, not their entire being. No one would ever wish this upon anybody, and there is this money piece – and that's one of the reasons why I'm so passionate about this topic...By investing in society, and making these services more accessible and more affordable, [neurodivergence] can be more a part of someone's identity and not *define* their identity. [One might] be able to say, "I wouldn't wish this on anybody, but look at what this person is able to do even under this constraint." [Miny nods in agreement].

SBJ: You know, Chase, it's interesting in the way you were saying [neurodivergence] is part of who you are, and us folks who are not on the spectrum, we walk around on eggshells all the time, because we were raised with "Julie and Emily *have* autism", because it was always the person-first language; and now there's a whole chat about the identity-first language – "I am autistic" – so when we're presenting, we go back and forth and explain it and everything...It's interesting: Not everybody is going to view it the same way, you know?

CM: Indeed. Quick aside: I recently told my best friend, from when I was 3 [that I have nonverbal learning disability], and when I had that conversation, I said, "I'm still Chase, *but* so you can gain a little bit more understanding about me, I'm also [neurodivergent]. It doesn't stop me from being Chase fundamentally at all, but this is another aspect of what being and operating as Chase is on a daily basis." And he was like, "Man, I had no idea!"

MO: And that's where that idea of "the spectrum" comes from, right? Some cannot perceive [one's ASD], and with others, it's obvious; and for a lot of people [overt features of ASD] is all they see. Or they may not see the [autistic person's] other potential, and that can be difficult. So hopefully, that's where that social piece comes in: The more we all understand, the more we can be kind to everybody and not assume that because somebody has a difference or difficulty in a certain area that they know everything about that person or that they're not capable. Taking that example of Stephen Hawking: But for his ability to communicate with that machine, everybody would have assumed that his cognitive abilities would have gone the way of his muscles, right? So for a lot of our kids who have trouble communicating, people assume that just because they can't talk that they can't think, and that may not be correct. We just may not have found a way to access their communication. [**SBJ:** Or even to test for it. When you're giving a non-speaking person a Stanford-Binet test, of course they're going to get a 54. How do you test somebody's cognition when they're not able to speak?] And that's where the controversy may lie, because so much of the perception of the value of the person is tied to how other people see them as better or worse, because they have autism, whether they can speak or not. [Susan nods in agreement]. And I still remember people saying [whispers], "He has autism", and if they're whispering, then it must be bad, right? We have to learn to celebrate it, because it's not something bad, but it doesn't mean that it's something easy either.

CM: I'd also like to acknowledge that I'm very fortunate to be able to be in a spot where I had parents and people in my life who educated themselves, and to be where I am on what we call the spectrum – I just want to acknowledge that.

JF: We have four minutes, and I want everyone to be able to have a last word. My last word is that I felt [at the May conference] and continue to feel enormously privileged to be part of this conversation. I had the best seat in the house. My last question from before was a selfish one, because I would love to see this [dialogue] extend into society and maybe heal some of the rifts that the media created. So I want to thank you for helping me think through that today.

CW: One of the greatest contributions that the autistic community will make to the medical world, the world at large, is the following: I think when we think about the issues we discussed today – trauma with the healthcare system, accommodating people, meeting people where they're at – when we do these things, everyone benefits. It's not just autism. Everyone who needs things done in a more individualized way, outside of the narrow band, benefits. We're going to have a lot less adverse and foregone care for people with neurodevelopmental disabilities. But [I have] a question, and I hope you'll all speak to it when it's your turn: How do you feel about this term, "invisible disabilities" [a term that came up during the May 8th conference] -- because I'm thinking about it for this consensus statement, but not everyone has them...?

MO: I live with [my children's invisible disabilities], and it's hard. Invisible disabilities that are so impactful...Now that you see them, now you can support them: the time management, understanding communication -- anything like Dyslexia, ADHD, that you don't know has such a huge impact on functioning. I believe truly that there are so many invisible disabilities out there, that if we don't take them into account, the person suffers.

SBJ: I'm glad that we had this conversation, and what Gyasi said, I think we have a lot more in common than [not], and the problem is divisive language that's out there...People fight about things for sport! I would never pretend to know what it felt like to have autism, but I have to be the voice for Julie and Emily. I think we're moving in the right direction, but it comes down to understanding autism, and there's still a lot of people out there who don't understand autism.

GBA: This has been a great conversation, and I could say a whole bunch of other stuff, but in the interest of time I'll just say that I'm pretty optimistic, and Jason, to your question about how do we make this bigger, I think this is the start. The article you write can be the start. We can model what it means to have a nuanced conversation, because as beneficial as social media is – especially to someone like me who's not that social – it can also be very divisive. The media loves controversy. They love the shiny object...If my mom was here, she'd tell you all about it, because that was part of her expertise as a film scholar. But we're going to try to cut through the noise by having a more nuanced conversation. We can model that.

CM: I think this ultimately boils down to a human dignity conversation. What this conversation is going to do – what the autism community is going to do, eventually – is get us to look at these medical issues, to look at disability, both visible and invisible, through a more accommodating lens; and that's going to help society to move to a more accommodating,

accessible place...It's going to enhance equal opportunity, and it's ultimately going to better human rights; but there's going to [need to] be a lot of work to do that better.

These conversations are tough, but they need to be had, and doing the work that we do helps to secure services and provide education for people who have never met a person on the spectrum in their life -- and all they know is sometimes very limited and wrong (and sometimes not).

JF: Thanks so much everybody.

Citations

1. Morehead, D. (2023 Jun. 6). The Neurodiversity Movement: Confusing Illness with Stigma? *Psychiatric Times: Affirming Psychiatry, Episode 11*. [[The Neurodiversity Movement: Confusing Illness with Stigma? \(psychiatrytimes.com\)](https://www.psychiatrytimes.com)]

2. Naseef, R. (2022 Nov. 13). Let's NOT Divide the Autism Spectrum: My view from the trenches on "Profound Autism". *Neurodiversity Press*. [[Let's NOT Divide the Autism Spectrum: My view from the trenches on "Profound Autism" - Neurodiversity Press](https://www.neurodiversitypress.com)].

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