

# Morénike

**Andrew Komarow** 13:40:21

Welcome to "Adulthood on the Spectrum," I am Andrew, an autistic Certified Financial Planner. I co-run "Adulthood on the Spectrum" with Eileen Lamb. Hey Eileen!

**Eileen Lamb** 13:40:30

Hey everyone. I'm Eileen Lamb and in this podcast, we want to highlight real voices of autistic adults. Not just inspirational stories, but real people talking about their boring life. Basically, we want to give a voice to people like us. And today, our guest is Morénike and I think we're gonna have you say your full name, so we don't make any mistakes. Hi Morénike.

**Morénike Giwa Onaiwu** 13:40:54

Hi. So, it's "Morénike Giwa Onaiwu." But that's quite long, so I usually sign everything as "MGO."

**Andrew Komarow** 13:41:00

So, Morénike is an educator, writer, public speaker, parent, global advocate, proactive resourceful professional, disabled woman of color and multicultural neurodiverse sero-different family. Morénike, who is American born to immigrant parents, possesses undergraduate and graduate degrees in international relations and education.

She is passionate about human rights, justice and inclusion. Morénike has written for or been featured in numerous blogs, abstracts, magazines, books, other platforms, often drawing from her personal experience as a late diagnosed autistic adult woman, a person of color, an autistic parent of autistic and non-autistic children, and a survivor of intimate partner violence. Welcome.

**Morénike Giwa Onaiwu** 13:41:04

Thanks so much! That bio was a lot; I need to shorten it.  
(All laugh.)

**Andrew Komarow** 13:41:42

Um...we did actually shorten it a little bit for you. So I go through the same struggle when I have to share one. So... (All laugh.)

**Eileen Lamb** 13:42:04

Hey Morénike, thanks for joining us tonight. We always start by asking our guests how they like to identify, and I'm talking about pronouns, and also your identity as an autistic person or person with autism.

**Morénike Giwa Onaiwu** 13:42:19

Sure! So for pronouns, all my life I've been using "she, her, hers," so I'm kind of attached to them and don't want to change, but I also use they, them, their. So, people can use them interchangeably - use one or the other. It doesn't really matter as I identify as a non-binary woman, so both work. In terms of the other part, I for the most part use "autistic person" or "autistic" or I might use "on the spectrum." I almost never, I'm trying to think... Do I ever, for myself, use person first? It's an additional syllable, you know, you know. "With-au-tis-m." "Au-tis-tic." ("With autism" and "autistic" are stated slowly and phonetically to emphasize the amount of syllables in each.)

**Andrew Komarow** 13:43:01

So actually, one example, there was a...there's a company that's "Driving with Autism." And I think that's appropriate, though, because "driving while autistic," sounds too much like a DUI. Right? So. (All laugh.)

**Morénike Giwa Onaiwu** 13:43:19

Wow, yeah. So it's interesting, because, like, I don't think I like the way (some) words sound. So, I used to not like "ic" things like, you know, "epileptic," "diabetic," uugh. Just, it's like, the sound of it I didn't like, but just the idea of like, with, you know, like, you know, what a lot of people say. You know, the whole, like, it's not something that, you know, we - the way that a lot of us (think), you know, we're fairly concrete, and we're not carrying it (autism) around with us, you know. That just sounds and feels, you know, odd. And so it's... it's something that's kind of interwoven. So yeah. It's just...but I can understand about the driving thing. That's, like, totally different, because like, when you stated "driving while autistic," it made me think the same - DUI or "driving while intoxicated" or "driving under the influence." Yeah...not so good; let's not go there. (Laughter.)

**Andrew Komarow** 13:44:07

So, tell us about your autism diagnosis...but also, what was it like, being an autistic parent at a support group, led by, quote, autism moms?

**Morénike Giwa Onaiwu** 13:44:24

Okay, which one should I say first? I could do the second one because it's shorter...

**Andrew Komarow** 13:44:30

Just do the second one. I kind of always ask the first one, but I, I want to...I want (you) to answer the second one more, so maybe you can relay them both?

**Morénike Giwa Onaiwu** 13:44:39

I'll try. And so apologies, anybody who's listening, if you've heard this before, but it's just...what happened. Like so... so, I remember my children's diagnoses preceded my own. And so, I think I'll try to answer them both if I can make sense. And so, you know, you know, my, you know, the whole... my daughter was diagnosed, you know, and then my son was being evaluated. He wasn't yet fully diagnosed - yet. And you know, I just remember just really kind of countering everything they said.

Like, "No, she's doing this because of this reason. This happens because of this. And this is why you'd do this, and this means this." I - and they were like, looking at me all weird. I was like, "I mean, don't you do that? Or do you do that?" And they were like (no), and I just was like, "That's just her (my daughter) trying to do this (whatever thing). That's not autism." And they're like, "Um...that's autism." And like, I was like, "I always do that," or "I do this," or "When I do this, it means this," or whatever.

And so eventually, they were like, "Okay, have you ever been evaluated?" And I was like, "No, why?" And I'm stimming at the time that they're saying this. and they're like, "Because if I diagnosed adults...well, you ping my 'aut-dar.'" And I was like, "You think I need to be, like, evaluated???" I was really, like, confused, and they were like, "You're *just* like, your kids...*who are on the spectrum.*" And I was like, "Okay." Well, you know, whatever. I just went too, for the heck of it, you know what I mean? Just because, you know, whatever. And so, it was just really interesting.

Because, like, I, at first, I was like, "No." But the more I read, essentially, before I got the formal diagnosis, when I read more closely, you know, the actual, you know, information about autism and not what people talked about, I essentially self diagnosed. I was like, wow, you know, it's kind of like when I was looking into it for my daughter, but now you know, it's for myself.

So, before going - and I went to two different people, because there's not as many people who diagnose or evaluate adults as there are, you know, children, and so I was on two waiting lists. And so it just so happened that they both called me, you know, within a very short period of time, so I was like, let me just go to both, just for the heck of it, for a second opinion, because, you know, people are always looking at Google and like, self diagnosing with stuff that they absolutely do not have. So I was just like, whatever for the heck of it. And so yeah, I got the diagnosis.

And it's funny, because I hear a lot about people, you know, talking about self diagnosis, or complaining about it, and I'm thinking how there's a lot of research that indicates that most parents who suspect their child might have an autism diagnosis are typically correct. I'd venture to say probably the same (is true) with adults (who self-diagnose or suspect they might be autistic) as well, except they're (not taken) serious(ly).

But moving back to the support group thing. I remember feeling, like, so super excited, because I was like, I'm going to be like, you know, around people who *understand*. They're not going to be, you know, wanting to know, "Why doesn't your child talk?"

Or "Why does your child do this?" or "Why do you have to carry this around?" You know, being all weird. They're going to be understanding!

So I won't have to, like, look at it as shame like you are often in a lot of mommy (and me) groups when your child won't, you know, "Toe the line," so to speak. I was like, "These are going to be people who *understand* autism, and people who love their kids - just like I love mine, and it's going to be *awesome!*" You know...my *people*...and I'm just, like, super excited. It's...so...because I'd just felt so alienated from people that I've known and loved for many years, who just didn't have any type of compassion or

understanding, you know. Who'd tell me my child is "spoiled," or my child "needs to be spanked" or whatever, you know. Or whatever ridiculous things, you know, and comments that people make. Or people not wanting you to go places with them because you know, you can get kicked out because of the child's reaction or whatever.

And so...I remember thinking, when I'm in there...I had been looking forward to it. And I'm like, there, and I'm just super excited. And like, you know, I just feel like, this is going to be a sisterhood! I'm totally feeling these people; we're gonna bond!

And they start talking about how, like, in these emotive tones; you might as well have gotten out the (tiny) violin...they're talking about how it was like *September 11th* for them; like the Twin Towers being attacked, at (their children's autism) diagnosis.

And everyone's nodding (in agreement), and people are like, starting to weep, and I'm looking around at everyone, and now it's basically a "bitch session." I know... language. I know it (the podcast) is an adult /over 18 thing. I almost never have to use any profanity, but my kids are not around.

But everybody's talking about how *horrible* autism is; how much it *ruins* their life; they can't go to yoga; they can't go get coffee; they can't do this; they can't do that, blah, blah, blah, blah. Basically, autism ruins their lives. (*Sarcastic tone.*)

And I'm just sitting here, like...dying inside. (*Tearful/emotional.*)

And I'm thinking...you think *having a child like ME...having a child like MY children*, that are my freaking *world*, that I *love*... (*emotional*)

Is like a *TERRORIST attack*??? *One that KILLED people?*

You *really* think this? You're equating *this* to *this*? And *all* of you agree? (*emotional*)

I was just like, trembling; you can't even imagine. I just...it couldn't have been worse. Because I had been anticipating it - so happy and so excited to be here with people who are going to understand me. But...they didn't.

They weren't here to understand.

They were here to *battle* and to *hate* something that's an integral part, whether we like it or not, of who their children are, and who my children are. And it was horrible; it was absolutely horrifying. I was in a room full of people, and yet I've never felt so *alone*.

**Eileen Lamb** 13:50:07

The reason we really wanted to have you on this podcast, Morénike, and it's because you have, I guess, well balanced views on what's going on in the autism, autistic community.

And we don't agree on a lot of things. *(All laugh.)*

But...we are still able to have these conversations in a respectful way, without insulting each other. And I think that's how we're going to change things. By having these conversations, you know, in a polite way.

**Morénike Giwa Onaiwu** 13:50:46

I hope so! I *want* to be optimistic. *(Laughter)*.

**Eileen Lamb** 13:50:48

And anyway, I want to hear from you. What, what do you think about this infighting within our community? What do you think we can do? To come together?

**Morénike Giwa Onaiwu** 13:50:53

You know...my instinctive reaction, what I wanted to say immediately, is "I hate it," because I do hate it (the infighting). So, I know that they say, you know, "the absence of discord" is not "real" conversation. And "for anything to happen, there has to be, you know, turmoil," and you don't want "stagnant water," and all those other little cliches and things about how things happen, you know. That people are not always going to agree to constructive dialogue.

I think that that's true. I think that there's never going to be, you know, unity in all points of view, but I don't recall who it is - that saying about "In essential things, unity; in non-essential things, diversity or something; and in all things, charity." I can't remember, it's something like that. I will see if I can find the quote.

But I basically feel like it's one thing to have different views, there's a whole 'nother thing to just demonize one another. (To demonize) An entire subgroup or an entire group of people. Or to completely discount a perspective or point of view, because of who it came from, or because of the way it was stated.

I feel like it, you know, it's very toxic. It's very painful and hurtful. I see it in the way that I see a lot of the political discussions, you know, this, you know, political party and this political party, in that it's become so divisive. And I don't think it was ever really, you know, like, you know, "Kumbaya, my Lord," -esque...you know, all "together" (to begin with). But I think that it's become, you know, polarized in a way that's very harmful to everyone.

And...and I understand that there's a *lot* of emotion on both sides, and pain and wanting to be heard. And I think there's also a lot of misunderstanding of one another's positions, too, because I think there are things that both sides say about the other that's like complete crap. And if they would just simply listen, talk, or read, instead of assuming things, they would figure out that there's "common ground."

And then, there's areas where there is *not* (common ground between the different "sides"). And I don't know who said this, but there's a saying about basically, when...when a person's point of view or

opinion infringes upon one's civil rights, or human rights, or one's right to exist, then it's no longer just an opinion, and, you know, it's become weaponized. And that is something I *do* agree with. You know, that everyone has boundaries, you know, or non-negotiables.

But still, at the end of the day, these are all *people*. Fellow human beings. And...and many times, you know, a lot of the time, these are people who care and want, you know, the best for, you know, you know, individuals who are on the spectrum, even if they don't agree with methods. And so, I feel like all this shouting at each, while justified - because on both sides...I've seen *both* sides start drama, start fights; I've seen both sides be hella bullying, you know what I mean - whether they intended to or not. And I just think that eventually, we need to like, "put the guns down," and like, talk and negotiate a "ceasefire." Before everything around us burns.

**Eileen Lamb** 13:54:08

Yeah, well, that's why I'm so thankful you're here today, because, you know, we've tried to invite people from quote "the other side." (*Morénike laughs.*) And it's just like, people don't want to have these discussions, you know? And the thing is, if we don't have them, nothing changes. Right?

**Morénike Giwa Onaiwu** 13:54:27

That frustrates me. Because, like, I think I understand like, people needing to, you know, self-care, people needing to protect themselves. And so, as a person, you know, who, you know, as a survivor of intimate partner violence, I understand that in some cases, you need to keep a healthy distance between yourself and certain, you know, situations, because it's just not, you know, emotionally wise for you to engage in such discussions. In some cases, I absolutely...I *absolutely* support and agree (with various people's choices not to have these difficult discussions).

But at *some* point, somebody *has* to do *something*. Somebody *has* to say *something*. *Everyone* can't be like, "Oh, no, that's too triggering." "Oh, that's *too* much." "Oh, I don't want to do that," "That's too much work," or "It's gonna take too long to get through to them," or "They...they already judged me anyway," or whatever, whatever, whatever.

You know, like, I don't think that...or, I really hope that it's not at the point that we're "Fox News" to each other, you know what I mean? (Laughter.) Like, you know, just a "foregone conclusion" that it's ("a lost cause" or hopeless to try). You know? I don't know. I mean, at times it feels that way. I think we *certainly* have battled. But I really feel like most people on both sides really care. Really deeply. And that's why they're fighting. That's why this hurts so much.

That's why they can come in with their "heart on their sleeve," and, and maybe their "foot in their mouth." But they're not given "grace and space," you know, as my friend (Sandy K.) used to say. No. People don't assume good intentions. They laser in on certain points or certain perspectives and invalidate everything that the other person is saying without taking the time to think about their experiences, their perspective or their knowledge.

**Andrew Komarow** 13:56:15

Do you think there's enough representation of color in the autistic community?

**Morénike Giwa Onaiwu** 13:56:22

Hell to the no. (*All laugh.*)

**Andrew Komarow** 13:56:24

What can we do better? Okay, there was a bit of, like, a rhetorical question; it was kind of like setting you up for that. (*More laughter.*) Like, I mean, I kind of knew the answer, all right? But I really, really, it's the second part of the question that that, you know...

**Morénike Giwa Onaiwu** 13:56:37

So, it's so interesting. Like, I told you all about how I was put on a waiting list, you know, before I got my formal diagnosis. And so, in the meantime, you know, I was reading and devouring everything...you know, those up till three in the morning things - just like I did for my kids, you know; only I was doing it for myself now - reading. Reading *everything* that you can get your hands on about everything; every single type of idea; or forum; or, or, you know, account that someone has; or articles; or round tables.

And I remember coming across a few different (informal) assessments about autism, and I came across a few of them with my kids, too. And it was just hilarious to me: "Only people with blue eyes are autistic," or "The only people who are autistic are people whose hair is like this." And I'm thinking *okay*, like *no* people of color are autistic then? (*Laughter.*) It was just ridiculous. Sometimes the criteria is seen through such a narrow lens, without even having an understanding of the fact that that's not everybody's reality.

I remember some of the people that I...that I consider friends or colleagues in the autistic community are people that I (first) met simply because I was so excited to see another face that was brown, even if it wasn't as dark as mine, at autism events. I was so excited to finally see, in this sea of thousands of people, on all these panels - (non-autistic) parents and professionals *only* on almost *all* of them - that (occasionally), oh my gosh! *There's a person of color* (here)! Like, I almost wanted to run to them, and like, grab them and hug them. And you know that's not me (*laughter*).

Because it's like, there was *so much invisibility*.

Like, I live in the fourth largest city in America. And when I would go to autism related events, you know, sensory friendly things, or whatever, you know, with the children, people would immediately know to come and bring me my kids when it was time...when it was over. Like, that's how little diversity there were (was) at these things. Not only the fact that I have (both an autistic) son and a daughter, so the gender part (lacked diversity) - she was almost always the *only* girl a lot of the time - but also the race.

There's always so many examples, you can literally - I've done this before - Google "autism" or "child with autism" or whatever. Do like an image search - I haven't done it in a few years, so maybe it's improved - but, like the amount of white faces, it's just like, you see, is...like, *everywhere*.

And then we ask people when they think about autism, they think Temple Grandin, white. They think Rain Man, white. They think "Atypical." "Parenthood." Need I go on?

Like, we (autistic people of color) "don't exist" unless...until when people need to raise money. When they need to raise money, they're throwing *all* the brown faces in there. (*Sarcasm*) Or we exist when you want to use them (us), for example, to help when people need something. Then (we exist); we're like your "sob story."

You know, it's almost kind of like the election years.

Aside from the fact that it's just wrong, that it's not representative, and it doesn't help any of us have a full understanding, it (poor representation of autism among people of color) also really, truly, literally hurts lives.

You know, in terms of the late diagnosis, you know, so many, you know, and we could control for income, and educational attainment, and insurance type, and geographic location and all of these other factor. We can cover *all* those things, because (otherwise) everyone will try to say (sarcasm), "Well, there's all these other social determinants," or "People of color are more likely to be on Medicaid," or "They're more likely to..."

So (in evaluating data), we can control for all of that, right? We can do *all* that with data. And yet you *still* have a huge lag in the...in the, you know, time of diagnosis, and the acquisition of services and treatment, and all of these things. You have it...you have it in the private sector, you know, amongst the clinicians; you have it in research work. You have it in school districts; it's just there. There's a huge race problem.

So, I guess the first thing I'd say... that...I guess to answer your question, what we need to do about it is *recognize it*. Because we have *not*. We all say that we have...we have not, because we, this wouldn't *still* be happening. We haven't recognized *anything*. We just know that's what you're *supposed to say*. (*Sarcasm*) Just like if someone says, "Are you racist?" You're *supposed to say* no. Or you know, how you're supposed to answer ("Fine,") for "How are you?" (*Andrew laughs.*) You know, regardless of what the true answer is, you're supposed to basically just give *that* answer, not actually the truth, right? There's no other alternative.

Of course we (society) know it's a problem. But we're doing *nothing* about it. And we continue to have situations, you know, where there's almost *no* representation. I'll use (as an example), the Lancet (report on autism), you know, that was recently released. I've emailed, you know, Dr. Lord and the other people. And I know that they made a big effort to try to be a lot more inclusive than people had in previous years in terms of Global North and Global South, and gender, and perspective. But at the end of the day, *there were zero autistic people of color* on an internationally commissioned report that, you know, spanned over three or four years, with 30-something people (authors). *Zero!* There were, I think...there was, one, or maybe two black of people (neither are autistic). There were a few people who were Latine/Latinx. I mean, it's just like...this is messed up; why didn't you do your research?



You know, often people talk a lot about how, you know, you know, there's a lot of meta analyses, that look at the fact that a lot of research, especially recent research - as it certainly wasn't like this in the beginning - when, you know, when autism, was, you know newer. But a lot of research in the past decade, maybe I'd say even the past two decades, or decade and a half, have really, *really* excluded people who are non-speaking, or people who have intellectual disabilities, like my oldest son who's non-autistic. You know, it's...basically, people want to enroll who they want to enroll and who it's *easier* for them to enroll. And so we're looking at the same community over and over, and not looking at the *totality* of the community.

I would ask people to do the same (meta analyses) with race (about the enrollment disparities). Pull these, because I read research...I am a big nerd. Pull and look at the results, if they...*if* they report race, because a lot of times they don't. Because they don't want to!

Either 1) because they have very little diversity, or 2) because they just assume *everyone's* white, so why would you say *anything* about (the study participants') race? Of course it's white. (*Sarcasm.*)

Look at the data; look at the groups. Look at study after study after study after study, and you find we (underrepresented groups in autism i.e. people of color, nonspeaking individuals, and/or people with intellectual disabilities) are non-existent.

And so when we have presentations (of autism) that don't match someone else, then it isn't noticed. And we are, you know, called paranoid or whatever. My youngest son has pediatric heart disease because of medical racism. No one...people don't have an understanding of how these things look in communities of color, and it's putting our lives at risk, not just in terms of what we receive, you know, in terms of diagnosis, or understanding, but how we're, how we, you know, how people relate to us if and when you're in a situation.

You know, like the Matthew Rushin situation. You know, Neli Latson. They see (us as) Black first. They see autism...maybe 10th - and they don't even see that right away.

You get treated like a Black person, but unfortunately, a Black person who doesn't know to act like when Mama had "the talk." You know, (the talk teaches you that you must), be still. Say "Yes, sir. No, sir." "Yes, ma'am. No, ma'am." Don't move, because they might think you're a threat or something. Don't repeat what they said to process (the situation); do it in your mind, you know. Do what they say to do; you do what you need to do to stay alive in this situation. Be robotic, follow the rules. You can't do that (expect others to factor in your disability) when you're...you know, neurodivergent and scared and of color. And that could cost you your life, *literally*. It's a huge problem. And I'm sick of it.

I'm sick of people having conferences and you have *not a single you know, autistic person of color* anywhere except. maybe some panelist that *maybe* got a \$200 gift card *if* they were lucky...*if they got anything*. Or how we are not on research teams - look at your research teams! Or you look at... the...

anything. *Anything* that is autism related. Look at staff; look at the people who are in charge and who make decisions there. There are so few people (who look) like me. They don't exist. It's sick.

**Eileen Lamb** 14:04:35

Can you share with us a mistake that you made in your earlier advocacy days and what you learned from it? I know we talked earlier offline, how companies or people make mistakes and it's good when they learn from...from them. So is there a mistake you made, and did you learn anything from it? And additionally, what did you get right from the start?

**Morénike Giwa Onaiwu** 14:04:59

I guess one thing that I think I got right from the start was even before, like, I knew anything about autism. I was completely...I was really ignorant, right? It just wasn't a part of my life, but I had been fortunately involved in like, social justice advocacy and you know, refugee resettlement, you know. My...my family's multicultural; we have, you know, we're, you know, both a biological and adoptive family; there's just a lot of things. I've always...I've always been... And then, I guess also being autistic, you know, we kind of...it's not that autistic people can't have biases, but you know, it's just, we kind of are...we don't follow social norms and the rules, so I've always cared about, like, you know, and respected differences.

I also understood that things can coexist in, you know, in, you know, in different capacities, and that it is not scary or horrible or bad just because it's different. And so I've always applied that philosophy to the advocacy that I do, you know, with autism. I did...I actually came into, like, I, the people who nurtured and trained me as an advocate, as a "baby" advocate, are people who had been a part of the HIV activism (movement), like ACT UP, you know, luminaries, and people who were really involved in treatment advocacy. And so *these* are the people who...like, were, you know, like, coaching and guiding me (as an advocate). I was looking up to these people...they were like *gods* to me.

*And these people...use person-first language (not identity first language).*

You know, it (using person-first language) is *not* (automatically an example of) trying to separate themselves from the, you know. It (the use of person-first or identity-first language) is all about the *meaning* (for the choice of language as opposed to the words themselves).

These people emphasized, "I am *a person living* with HIV" (person-first language). Because people once saw it (HIV) as a death sentence, *that* (their choice to use person-first language) was a *radical* move (that definitely does not support that person-first language = self-hatred).

And I know that people (today) don't understand that back when person-first language came out what its intent was (to empower disabled people). And I think things *do* evolve. And again, identity-first feels, to me, like a better fit. *But...is it (really about) the language someone's using, or what is the reason behind (their choice of words)?*

These people (HIV advocates and other disabled people who use person-first language) wanted to be involved. "Nothing about us without us." We should respect it (people's choices).

You see, these are people who were, you know, chaining themselves to buildings and “bum rushing” doors, because they *wanted* to be part of research; they wanted to be part of decision making and policy. They wanted to...they wanted to impact things that have to do with their lives. They didn't want to be just talked about in a stigmatizing type of manner. The “[Denver Principles](#),” you know, it's like the Magna Carta, you know, of the HIV world, in terms of the way that you should not use stigmatizing communication. So, the autism community is so far behind.

The idea of how they (HIV research networks and HIV service organizations) have community collaborators who actually are seen in a mutually respectful way, and not just tokenized; really involving people; expending resources to educate people; talking about people in a way that explains what's going on, but doesn't belittle them. We (those of us involved in autism) haven't gotten there, as a community.

So, that's something I think I've done right: to implement some of these things, you know, these kinds of transdisciplinary, you know, views and values, those values into my work.

But a mistake that I made, my goodness...*was* I *naive* when I came into this! (Laughter.) Because I came in first with my mommy “hat” on, right? I came in as a mom. And so and that's...that's, *I'm a mom first, last, and always*, before I'm anything else. My kids come first; everything else comes second. And so I came into this with the mom hat, and later, you know, put on the, you know, the self advocate hat. And I still wear both hats. And I feel like I ignorantly assumed, in the beginning, that people, you know, would have understanding for, or caring for, both sides.

Like, I felt that, you know, parents would not have problems with...or be so cruel to (autistic adults) someone who could be the way *their* child is, when they grow up in 20-30 years. And I thought people on the other side, (autistic) adults, would understand that parents are scared; parents are lost; parents are going through a lot; and they're not getting much sleep (jokingly) because they have autistic children, you know. (Laughter.) And that they (autism parents) are gonna bumble around some, but *they mean well*. I thought that...that goodwill would be “a given” on both sides. So (I was) ignorant enough to try to, like, do things, you know, activities or, you know, and you know, like, you know, events and involvement or even like, virtual communication, where I was, you know, pulling in people that, you know, I worked with from different...different sectors. You know, this parent group, or this self advocate group. And it was like *oil and water* (how the groups clashed); oh, my goodness! The sparks just *flew*. I realized very quickly, Wow, these people *hate* each other; this is not gonna work. Bringing people together like this is not going to work. I'm, sadly, gonna have to segment myself.

And...I'll be working on this over here, and I do this; over here, I'll do that. I can't be my whole self in...in any of these places, because people will not allow me to. They don't want to see one another as people. And so, because I refuse to take a side, you know, then it's kind of like, you know...

And I think...it's not *bad*, necessarily, if one decides to take a “side.” I too have my ideals, and my values too. I do, kind of, “lean” more one direction (toward neurodiversity). But because I refused to

demonize the other side, I made the mistake of thinking okay, we don't *hate* other people. You know, people *are* different.

They're different from one another, but surely they can work together? Surely they respect one another, and we can all talk; collaborate and make change; surely they can look past their differences?

No.

That was foolish. I'm cringing, thinking about some, like, social media stuff where I tagged people who I had no idea like...hate each other. And like, (a time when) like I'm trying to raise money, and people are pulling out because this organization was involved. Just thinking about this, like, I was so naive. I truly thought we were just one big loving community - or we could be(come) one.

And, you know, I know better now. (Half-hearted/disappointed laughter).

**Andrew M. Komarow** 14:10:49

What, what can you do? For...and I, I feel like it's almost...almost like some sort of like "rite of passage" for the vast majority of like, adults who are diagnosed later in life to like, have like a six month to a one year where, like, they attack people like Eileen, right? Now, or that's how they feel? Or like...

**Morénike Giwa Onaiwu** 14:11:16

Maybe that's a white autistic thing? I'm not saying that people of color don't do it too. They drink, like, a lot of the Kool Aid. (All laugh.) But, I've never understood that. I actually thought you were gonna say a six month to one year period where you're like, honeymoon and love. Where you think the whole autistic community is all, you know, peace and love and harmony. Because that's (once) what I truly thought - that I'd finally found my people. (Sarcasm.) La da da di da. Now I think about how (some disability) parents discuss "forever searching" (exhaustively seeking out help for their children, only to be ignored/disregarded).

So yeah, so like, it's shocking to me to hear about (what has been stated about autistic adults attacking Eileen or others). Because actually, when I first came in (into the world of autism several years ago), a lot of the things, you know, happened. And *I* was being attacked left and right, by (non-autistic autism parents).

Because (of things like) I was a (volunteer online autism group) moderator saying things (to parents) like, "Why did you put that video (online) of your child doing this?" Or whatever, you know. When these things happened, I now had to go and message someone (to say): "Hi, I see you posted this. I am one of the moderators. I'm going to hide this (video you posted) because this is too invasive." *And then I'm getting cursed out* (by non-autistic parents of autistic children). I was told things (by non-autistic autism parents) like, what do I know? I'm (apparently) a "high functioning" person and (therefore to them) I'm "only mildly" autistic.

(The parents argued that) *I don't know anything about them; I don't know anything about their child; I "don't know anything about autism."* Blah, blah, blah. I mean, just the way people (autism parents) would just come at us (autistic adults). Raw, you know...horrible.

But I've also seen, you know, I've seen the flip side of that. I've seen someone go into...I've seen where Eileen will, you know, post something, and I've seen people just, like, lose it! And I don't get it.

**Andrew M. Komarow** 14:12:38

No. And I actually think you bring up a really interesting point. I actually think that a lot of the...you know, let's call that honeymoon period, really can go either way, right? Or like a bit of both and even or a lot of self, you know, discovery? I don't know. So, I really don't even know what my point there was anymore.

**Morénike Giwa Onaiwu** 14:12:59

No, but I actually want to say something. Because it was a good question, and I kinda sorta went tangential...which is hard not to do being autistic and ADHD. (Laughter.) But I want to say this. So...I...there *are* a few names like that you hear in different communities in your life when you hear the name you like cringe because it's like Voldemort, right? So, so...apparently, you know, Eileen Lamb is supposed to be one of those people, and I guess to some people, you are too, but not for the same reason. (Laugh.)

**Andrew M. Komarow** 14:13:21

What? (Half jokingly.)

**Morénike Giwa Onaiwu** 14:13:29

You might be (perceived by some as Voldemort) also! Our people think, you know, every, there's a certain way that activism *has* to be done, and if it's not done that way, oh, you're a "sellout." You know what I mean? Like if you're not talking about certain things, or if you're not using the *loudest* voice, you know? I'm being sarcastic. (All laugh)

But...But, but so everyone was like, basically, I don't remember where, but I remember reading, you know, what I read wasn't positive about this person (Eileen). And so I almost always make my own conclusion. Well, I mean, it depends; if we're talking about (Adolf) Hitler, I don't need to. I don't need to research that for myself; I can go ahead and go with the majority...he's a murderer. So, but, I'll research things that are not like that, things that I don't know about, 'cause I need to know for *myself*. I need to research for *myself*. I need to come up with my own conclusion.

So, I started researching this person who is supposedly so horrible, such an "internalized ableist," you know, and blah, blah, blah, and all this kind of stuff. And...and I didn't see the things that they were talking about. Because, like I've seen autistic people who have *tons* of internalized ableism. I won't say names, but there...there are some people who seriously need their therapists to like, move in! (Laughs.) You know what I mean? Like, there's people who have major hatred of themselves and have

issues and are really, really inappropriate. And I read (some of Eileen's writing), and most of what I read was stuff / could have posted.

I see this person posting about her beautiful babies. Her boys...oh, my gosh - freaking adorable! And I see someone posting about their thoughts and their ideas and what they're dealing with. Talking about, you know, different manifestations of autism; different...you know strengths and challenges. And sharing things. I didn't see...I didn't see anyone going "over the top."

I didn't see Eileen posting (pics or videos of) her son crying and having a hard time, and then, instead of comforting him like a mother should, she wants to get this footage so she can put it online and everyone can say "Awh, you *poor* thing, *how* are you dealing with *this*? Oh my gosh!" I see someone that, you know, shares reality. Good things, and bad things, but in a tasteful way, not in a way to...where any of her children are going to one day grow up and be horrified about what she wrote about them and said.

I *do* see some things I disagree with. (*Eileen laughs.*) Because I have been in this longer, you know, and because, you know, there's things, you know. Because my graduate degree is in special education, so I have a certain context about things that, you know, that, you know, that Eileen doesn't. And my kids are older, too, you know. And so...

But for the most part, there's only - that I can see, and *I haven't read everything* (that Eileen has ever written) - but there *was* one thing (that I read that Eileen wrote) that I found completely, totally, totally, like, ridiculous and wrong, and trash. But other than that, other stuff is just more like feelings. Differences of opinions, different stuff. And *some* of it is the same opinion. And it makes me sad that our community...I'm like, make up your *own* mind. Like, are you going to *not* eat something, or stop someone, or do something just because someone else hates it? How do you know *you* hate it? Did *you* read it for yourself? Did you come up with your *own* opinion? Did *you* ask this person - to see if that was what they felt, and what they meant? Because maybe you'd have a better understanding if you did that instead of just being a follower.

**Eileen Lamb** 14:16:40

Well, I thank you. Just..first of all, thank you, for you know, not just believing what you read online, and, you know, trying to, to have your own opinion about things. Because you...you nailed it. I think that's a big issue right now...it's that there is like a "hive mind" type of thing going on?

**Morénike Giwa Onaiwu** 14:16:58

Yeah, oh my gosh, yeah.

**Eileen Lamb** 14:16:59

Yeah, people don't try to have their own opinion about things. That, if, you know, someone says, "Let's go hate on that person!" (*Makes a fast "swooshing" sound, like running*) We're just gonna go do it. Well, I won't, but...It's...there are a lot of young people in the, you know, young and self-diagnosed, or diagnosed as adults, and it's a very vulnerable time for people. And you know, when you're young...10

years ago, honestly, I would have been like...so happy to belong to, like a community. Before having kids, I feel like I would have been that person, if I'm being honest.

Just like...because it feels so good to be part of something. (*Morénike murmurs in agreement.*)

And, you know, if you tell me this person is bad, and I'm like, 20, you know? I may go do it.

**Morénike Giwa Onaiwu** 14:17:45

They are gonna go "have their back." (*Eileen states, "Yeah," in agreement.*)

They see it as all your life, you know, people like you (collective "you" referring to the hypothetical autistic people in the example) have been beaten up on; attacked. And so you see it (mass posting to support a colleague online) as you "circling the wagons," to use that phrase, around your own (to protect them); (therefore) you don't (think you) need to know the (whole) story (before you act/involve yourself in the matter).

It's kind of like a joke about Black people. When, if one of us...one of us starts running, or if we see people running, we just start running! While we're running...we might be like, "Why are we running?" But we don't (stop and) wait to say...

(In a mimicking tone) "Why are we running? What's going on?"

No, you can get shot for asking stupid questions like that! Run first, ask later! (Laughter.) Like...you react, because that's how you stay alive. You don't need to know the reason, you know? You'll figure out the reason later; survive first.

And so (with adult autistics online), I think they...a lot of them see it as survival. Our people (autistics) are (perpetually) gaslit and disenfranchised...so, you know, mistreated (in society). We're so disregarded as autistic people that you know, that (like when you're a hammer), "everything looks like a nail," you know? Because that's what they're accustomed to seeing. Or whatever the phrase is.

**Eileen Lamb** 14:18:41

So...let me ask you: what's the best therapy for autistic children? Is it ABA or not?

**Morénike Giwa Onaiwu** 14:18:47

Okay, so I would say the *best* therapy for autistic children is **love**. That's what I say, first, and then (second) I'd say it's something that's individualized. But I'm going to talk a little bit about these things. Because I think that when people...often people are actually talking about "apples and oranges." And sometimes, they're talking about oranges and basketballs when they're communicating with one another (when they are debating ABA, whether for or against, with one another)!

I've done a lot of research on this. As I mentioned, my graduate degree is in special education and my concentrations were child development and neurodevelopmental disabilities. I've done a predoctoral fellowship in it; all that. And...I'm a big nerd that likes to read everything. And I'm a parent who has one

child who went through ABA and one who did not. And before autism, we had developmental disabilities in my home (already). As I mentioned, I have a child with intellectual disability; a lot of times when people are saying things about “profound” autism, I’m like, take the sensory stuff off, and you’re talking about *my kid!* (All laugh.) I mean, like, I can understand a *lot* of these things.

But this is something I *will* say. First, I’ll concede points to “both sides.” I hate to even say there are “sides,” but that’s what they are. I mean, that’s what it is.

So, when people (usually, but not exclusively, autistic adults) say things like, “The origins of ABA are problematic,” that *is* the truth. I mean, that’s just the truth. I mean, like, that’s, you know, just like I could say, “Okay, umm, America came in and stole this country from, you know, indigenous tribes.” That’s the truth, too. I mean, it may not be the way people want to see it now, but that *is* factual. So, the origins (of ABA) are problematic, period, you know, for a variety of reasons, you know, we can all figure out for ourselves.

I can also say that when parents say, “Well, that’s *not* the kind of ABA my kids get,” they’re also being honest. There’s been so many, you know, like, more “natural developmental behavioral interventions” that incorporate more of the, you know, things that are a little more developmentally friendly, that utilize the natural environment, that use preferences, you know, that are more play based. There’s even some people trying to introduce (into ABA) some trauma informed, you know, things, to where it’s really more of an eclectic process. Really, the ABA that a lot of people’s children are receiving today is what people will say that is called, quote unquote, “not ABA.”

And that is true in some cases, and is not true in some cases. Because if insurance is only going to pay for “ABA,” then you’re going to call whatever you got “ABA” whether it’s truly ABA or not. It might have some ABA data; principles; or whatever. But really, a lot of what younger people are receiving today in “ABA,” you know, is different from what people had, you know, several years ago, you know, many years ago.

There are still people doing the kind of, like, “discrete trial training,” old school aversive, whatever-type-of-ABA. That *does* appear. But...but you’re less likely to find that. Most, you know, BCBAs and most, you know, registered behavioral technicians (who implement ABA) are younger. They come from a school of thought that’s different. And they’re...they haven’t like...they don’t... They understand that you can incorporate concepts from other disciplines. They just...the problem is, they call it all “ABA,” so it confuses people.

It also is true that there are certain things that are...that are easier or more effective with ABA. I mean. I’m not saying that (skills learned in ABA) can’t be taught in any (other) kind of way. But I’m just going to say that, I’ll just give this example. So my family is, you know, West African. I was born in the Midwest - my parents were attending college there. We later moved to the South; I live in the South now. And growing up - it’s not like this now...you know, when I was growing up, you would *never* see a Black child in a store, throwing a tantrum. I’m *not* talking about meltdowns, you know, autism meltdowns. I mean throwing a tantrum because, “Mommy, I want a toy, I want a cookie!!!” You would *never* see that!



(Because, if you were a Black child in a store starting to throw a tantrum) Mom would give you that “side eye” - and you would *shut the freak up!*

Because if you embarrass Mom in that store, she's gonna grab that shoe when you all get back to the car, and she's gonna deal with you! (Laughter.) You *will* be quiet. You will sit there, no matter how much you want that cookie (if you know what's good for you).

The white child (in contrast) will be going crazy... screaming; crying: “Oh my gosh, I need the cookie!” (White child's mom replies,) “All right! Calm down.” (And the child gets the cookie.)

Like...it (throwing a tantrum) works. And it was...because... parents often... it's not that it's a race thing, but again, it's a...it's a view from the South. When I grew up, as an “Xennial,” Black people spanked their children; white people thought, “We just need to talk to them; and reason with them.”

And... and so the kid that got spanked, who (knew) they could get spanked...was not going to “act a fool.”

The kid who just might get a five minute time-out? “It's worth it; I'm gonna go ahead and have a tantrum. Five minutes in the timeout corner? It's worth it for me to get this toy.” (Laughter.)

And so, sometimes things are effective...that doesn't mean they're necessarily looking at the totality of a person, because while I won't say it was abusive for those parents to spank their kids, you know? Whatever. But I am saying: Is it really the right approach, or is it a “one size fits all?”

Like, could you talk through that situation with that child? Did it *have* to be a spanking? Do you *have* to coerce them into behaving like they're behaving, because of the consequences, because they've been “trained?” And is that really what is psychologically healthy?

And...so, that's why I would venture to say that growing up, I saw a lot of people who were *extremely* obedient and respectful *in front* of their parents, but when their parents weren't around them, they weren't (respectful). Then they got older...and again, this is what might have been what I saw because our, you know, our socio-economic status wasn't, you know, the greatest.

So (possibly, the frequency of the variability in discipline I observed) there could be (factors) not just (related to) race, but also income, you know, mixed into this, and circumstances. But these same people, once they got bigger than their parents, and their teachers, and whoever else, were no longer respectful. Because what you had used to govern them was fear, and now that no longer was effective; it didn't work.

And so instead of, you know, (parents) talking about, “Well, you know, this cookie is not good for you,” “You already ate a snack,” or, you know, “That toy is really cheaply made. We can go home and research somewhere else for a better toy,” or something simple, like keeping it plain, you know, like

working with them some; respecting them enough to explain your reasoning... you just say, "No," and that's just it? "You don't need a reason; it's just a no."

And so...I feel like there are certain ways to be effective that are not necessarily ethical. Slavery was *extremely* effective economically, way better...way more, you know, effective than paying people for their labor, right? But it's horrible; it's wrong. We've learned a lot of things from the horrible, abusive, disgusting, inhumane things that were done during the Holocaust for "research," but that research doesn't make it right, because it wasn't good.

So I think that it's more than, "Does ABA work?" Something can *work*; It can get results - but at what cost? So I think that if someone asked me to answer this and I had no choice - I'm always one of those people that wants clarification - if they're like, "There's a person (and a dog) tied on a railroad (track), and you've got to save (either) the person or the dog from a train, like who do you save? Well, I want to know, is this a "seeing-eye" dog? Or is the person about to die? Like, you know, they have, you know, like three weeks to live, so it won't really matter? I need to know the nuances, because I can't just say yes or no, because I can't answer.

So if I was told, "ABA - do you recommend it? Yes or no?" I really would prefer to give a narrative answer. But if I *had* to give an (immediate) answer, my answer would be, "No." Or I would say, "Can I say no, but..."

Because let me say this: I'm *not* going to criticize or demonize *any* parent that's doing what they can for their baby, to help their child. That no matter what you're doing - ABA, Floortime, specialists, PPCD, OT, speech therapy, combination of things, whatever you're doing, play therapy - you *should* be (closely) involved as a parent. Because your child is less likely to be taken advantage of and harmed if you're involved, if you're watching, if you're paying attention, if you're actively involved in the treatment plan and the goals. And so, *if* they're going to abuse somebody's kid, *it won't be yours*.

And (with any program) you (as the parent) have a right to change things or modify things, or anything. Or to pull your child out (of that program). It's *your* freaking money. And it's *your* child!

And *if* your choice is "ABA or nothing," and your child's self harming, and your child's eloping, and your child...you really don't have resources, and there's not really much to offer... Am I supposed to look a parent in the eye and say (in a carefree tone of voice), "No (ABA)! Let your child run into the street and die!"

NO. I'm *not* going to say that.

If it's ABA or nothing, and you need help, then maybe do the ABA, and maybe through some research and maybe (you will) even find some techniques or tools you could do at home. But I don't believe in demonizing parents. And I don't think *all* ABA is...is trying to, you know, "extinguish autistic behaviors," although there *are* some that do.

I do feel like ultimately, ABA is like a coercive, abusive idea, because you're building trust for the idea..for the intent of changing a person. And I know everybody...really, life is about change. But I think at the core, the concept (of ABA) is, I feel like, *it grooms someone for possible abuse. Because you're learning to be compliant; because you're learning to say what people want you to say; and that you get loved and rewarded when you do this...when you "perform."* And because, you know, anything that can't look at the internal...anything that's only looking at external factors (such as "behavior,") you're...you're always going to miss something, you know, you're always going to miss something. Just think about how many times that someone was doing ABA for someone thinking X was the reason, or the person was trying to escape...but the person was in pain, and that's why they were acting out. It wasn't whatever they thought. But...that could be the case with other therapies too (not only ABA). So, like, I try to tell people when they go all hardcore, actually, I had a thread on Twitter not long ago, and someone was talking about ABA: "It's *always* abuse. I'm never going to be for it; I never want to hear about it."

And I was like, you have to look at this in a more nuanced manner. You know, like, as a person of color. I know, and as a parent, I know - there *aren't* enough resources out there, period. Is it (ABA) a flawed resource? Yes. Like, there's a reason why I had one of my children in ABA and (later) the other I didn't. There are things that I realized once I did more research and had to take a harder look at things.

My son (who did not have ABA) will *never* freaking pass (as non-autistic); my daughter (who had ABA) does (pass). But I feel like there's certain things that he didn't have to deal with...suffering, or I don't know, lingering "after ABA" effects that aren't going to be part of his life that are a part of hers. But it meant that it wasn't as pretty a - you know, it wasn't, you know, it's not an inspirational success story situation. And sometimes that's okay, you know, sometimes the scenic route is okay.

**Eileen Lamb** 14:29:27

And also, you know, we were talking about our, with our last guest about this, you know, like she would like to see more representation in the BIPOC community. Is that how you say it? (*Morénike answers, "Yeah."*)

And she was telling us, you know, how people who are against ABA, often don't realize that for many minorities, that's the only option they have. (*Morénike answers, "Exactly."*)

And by shutting ABA down instead of trying to just make it better, you're taking that away from, you know, some people who have access to nothing. So, you know, it's better to reform it, to try to make things better.

**Morénike Giwa Onaiwu** 14:30:01

It's frustrating. Yeah, and I agree. In a lot of communities of color, and I'd say also geographically isolated locations where there may not be, you know, racial diversity - might be only a bunch of white people, but that's just like because of where it's located. There are a lot of parents and families in situations where ABA is the "only game in town." Period.

Now, in some cases, you might...a person might be able to, you know, say, Okay, well, good, I'll homeschool (instead of putting my child in ABA); I'll do this; I'll do that. I've got family (who can help me); I've got, you know, relatives; I've got, you know, patience, or I've got some understanding of the things. I know people who've pulled their kids out of programs because of concerns about ABA, and they've focused on development, or they've homeschooled, or they've done, you know, different tactics and things, you know, whatever. *People do what they need to do, you know, for their kids*; I know I have; and I respect what people do.

But some people can't do that, or it doesn't work. And there are instances where people have literally had issues with child protective services because you can be accused of "medical neglect" if you're not using ABA, the quote unquote, "gold standard" in treatment. But I feel like...treatment - any kind of treatment, any kind of program - should be individualized. And so to say that "ABA is the treatment for autism," is ridiculous. That's like saying, you know, "Stimulants are the treatment" for ADHD." Well...no. They're a treatment. They help a lot of people. But...everyone doesn't need them.

If we go back to the HIV example, there are...there used to be one thing (medication) that people would take: AZT. Now, they have several different types of classes of medications that work different ways, and (these various medicines) are options. Some work better for some people than others. You don't just randomly put people on *this* because that's what *you think* is the best. Again, it's a whole thing about when we have a hammer, everything "looks like a nail."

And so I feel like...I think also people don't understand that a lot of - and this goes back to the fact that autism is so whitewashed - when we're talking about intersectionality, communities of color have *always* had to code switch; have *always* had to pretend; have *always* had to camouflage...to stay alive. That's what you know. And I think it's true to say of immigrants as well, because I know that you're from France. So it's like, it's like you've always lived in a world that's kind of a little of both, never just one. And so as a result, you already have a kind of a broader perspective.

And so I think that there's a lot of (not necessarily pleasant) things that people (especially people of color) have already *had* to accept and do - not because they want to, but for survival. We've already had to do it in our communities anyway. So ABA is not like the worst of it.

Like, I *don't* like the fact that I had to have "the talk" with my children, you know, the ("Staying Alive While Black" teen rites of passage talk). You're Black; don't wear that hoodie anymore. Don't go out in a group unless there's only two of you. If there's...if there's more than two of you who are of color, no, don't go. Don't put your hands in your pockets. Don't do this: don't do that. I don't want you to defend yourself; if somebody spits on you, or slaps you across your face, don't retaliate. Don't ask them (officers) what their badge number is. Like, I didn't want to have that talk with my older sons. *I did, though*. I don't like the fact that my parents had to have that talk with my brothers either. My parents aren't from this country. So (growing up) their parents didn't have to have that talk with them. But I had to have the talk with them (my older sons). And I'm going to have to have "the talk" with my younger autistic child. And sadly, if he has children in the future...all my children...they will have to have that talk (with their kids). I don't *want* to; it freaking sucks, but it's necessary, whether I like it or not, whether I

agree with the concept, the premise behind it or not, I need to equip them with the information. And I think that's how a lot of people (especially people of color) think of ABA.

“Do they like *everything* about ABA?” (Rhetorical question stated in a wry tone.) When you research its origins, when you read some of the ways that people are talked about or discussed in the literature, or the research, or whether...you, you know, like, when you dig into things, they (parents) should have some concerns. Whether your therapist or provider - look, you might have a great, nice loving person that your kid grows to love; is like a part of the family; the kid loves (them) and is excited... they (the child) see them (the provider) and start flapping (for joy). You may not have a problem with that individual person (who is providing services to your child), but you might have a problem overall with the concept.

But do you have options? Do you have alternatives? Most of us don't. And until you're...that's why I push so hard for autistic people to be involved in research, you know, either as a community advocate or to go into the field. Because if - *when* we're at the table...

Like with HIV. The reason why HIV treatment has, in a few decades, has advanced so miraculously, the reason it went from a death sentence to something that literally something people (have a diagnosis of, yet) don't even qualify for disability (assistance) anymore; it's considered a “chronic illness” is because people - the stakeholders - were at the table. And they were saying this is what's necessary, and this is what works; this is what doesn't work; and that's crap. And that's great, and so on. And they were involved, and they had a *real* role, not a tokenistic role, where they could make change. Where they were being listened to because they had lived expertise, not just degrees - though some of them have that (degrees) too, and many of them didn't. And we *don't* have that with autism.

I'm like...y'all are screaming and fighting on the internet - which I'm not telling you *not* to do; it's your platform - but *where are you?* Are you involved in a role or something somewhere you're helping to develop programs that can help people? Where you're looking at concepts; where you're researching things?

Or, like you say, (if) you're trying to make ABA better, there are a lot of people who are involved in (trying to) reform it and making changes. And some people think, “No, you can't change something (like ABA) that's already totally ruined.” I venture to say that...I feel otherwise. I mean, (to me it feels like) ABA's not going anywhere. It's not going away. It's not. And so...do you want to complain about it, or do you want to make it to where it's less harmful? And I know everybody has different points of view. I'm *not* trying to, like, make it a simple thing. But ultimately...our kids are growing up. People spend more of their lives as adults than they do as children. And so...what impact?

I'm, you know, I'm a solution based person. I want to...I don't have a problem with people pointing out the problem; breaking down the problem; you know, like, giving all this context about the problem. That's important, right? Necessary for prevention. But that...that's not where I stop. I need to keep going. I need to know what's next? What can we do? What do you know?

And if you can't give me something, I'm gonna make *something*. I'm gonna figure out *something*; I'm gonna work with *something*. If your answer is "Well, I don't know whether there's anything (other than ABA you can do to help your child)," that's not an acceptable answer for most parents who love their kids and want to see them thrive.

They're gonna be like, "That's not gonna work, okay? Well... I don't want to hear what you (an autistic stranger online) have to say. I'm gonna go with this (ABA)."

**Eileen Lamb** 14:35:26

I have a question for you. It has nothing to do with this. But so you went to the White House? Um, that's pretty crazy, right? How was it like?

**Morénike Giwa Onaiwu** 14:36:13

So it was weird. All right, so I got invited, it was actually twice, but the first one was the real big one. And it was so that they were basically...there was an inaugural event and unfortunately, they never again continued a second year, but they were doing a, you know, Symposium on Disability Parenting. And so they wanted to hear from parents with various different types of disabilities, sensory, physical, neurological, etc, about, you know, barriers, circumstances, you know, things that we were dealing with, you know, and ways to help. It was just really...so, at first, when I got the email, I was like, "Is this *real*? Is this fake?" Like *what*? You know, that was really intense.

And so but it, you know, and then they have to make...make you jump through like a million hoops, before you can even like, sign up online for the thing; they do all these checks and all this stuff. And then you still have to, even when they have cleared you, and they sent you all these secure things that you have to fill out like 5 million things, and you still have to go through special clearance to even get into the building when you're there.

And so you know, and so it was just really, to me, it was just really powerful to be able to share. And it was so funny, because like I had, I had it all planned out, I had a speech written out, that was perfect that I was going to read, and then we had a bomb threat that morning! So we had to evacuate our hotel. And we couldn't go back! I'd grabbed my clothes, thank goodness. But we couldn't get back into the hotel. So...that speech that I wrote - that was so eloquent, so well written, had all these resources I was gonna cite, and sounded so intelligent - was left back at the hotel. Now I had to speak - in front of the world - with no speech! (*All laugh.*) And so, I had to just do "it on the fly."

I was *terrified*, because, of course, I did not have enough (of the speech) memorized. So, I just spoke from the heart. I just talked about, you know, a lot of the challenges I talked about the, the issue of in terms of the disenfranchisement of disabled parents, and, you know, like, just a lot of things, and it was just really, it was moving to be there with (the) other parents, and other people there.

It was also very ironic, because one of the speakers...we had to present out of order because one of the speakers (was running late because she) could not get an accessible Uber and was still waiting to try to get there, to The White House! Because of the fact that, *in Washington DC*, the person couldn't

find one that can transport their wheelchair. (*Frustrated laughter.*) So it's just like, you know, it's kind of like, wow, so bad. Like, you know, telling, again, how little accessibility there is in this world.

But to be able to speak on behalf of, you know, families at large and about, you know, about disability about, you know, how we shouldn't be ashamed, we need support, and we need more services. Like, it was just, I'm grateful. I grew up a few doors down from a "crack house" - and I'm in here speaking in *The White House*? You know? That's like...a blessing, you know what I mean?

I felt like I was giving a voice to, you know, autism families, autistic adults, racial and gender minorities. And I'm just grateful. The model for things that we discussed were - a lot of organizations took notes back, and they implemented things. I just...I think it's important for people to share their voice and their perspective, you know. *When* you can - self-care is important too. But...things can't change unless we change them.

**Eileen Lamb** 14:39:46

That's...that's incredible, though. I can't believe you had that, that experience. I mean, it just seems so surreal, from my experience, from my perspective, especially being French and being like, Oh, my God, she was like, in The White House. You know, the United States of America.

**Morénike Giwa Onaiwu** 14:40:04

I had never even been inside it. Like, you know, a lot of people do the whole, you know, eighth grade (school) tour to DC where you go when you go, you know, we had that when I was in school, I wasn't diagnosed with autism at the time, but that would have been A. too overwhelming, like, just sensory nightmare aspects of all these transitions and changes, and B, we (my family) couldn't afford it. So for those of us who couldn't afford to go on the trip, we stayed (behind at school that week) and watched movies, you know. So I had never been, you know, to, I've never been, I've been inside the state capitol, you know; the Texas State Capitol with one of the organizations that I worked with doing some advocacy, but I've never been in (the White House). So that was not only my first time speaking at The White House, but that was also my first time *inside* of it.

And I'm just in there, and I'm just looking around at history. I'm looking at the, the, you know, the architecture, and the paintings on the wall, and all these things. I'm thinking, "Wow, I wouldn't have even been *allowed* in this place, like, in another time! I mean, now I'm speaking!" It's just, it just was really moving. And it just made me think...people can do *anything*.

People *do* have limitations. People *do* have challenges. And there's certain people who couldn't be there. So I make a point...I'm like, okay. If they're not able to be here, they can't share their perspective (in person); dammit, I'm gonna share it for you, because your voice deserves to be heard. Everyone can't be ...doesn't get these opportunities. And so (those privileged to have them, like me) you can't be in a situation where you've been given this platform to be able to share, and only share your own! You've *got* to share (on behalf of all), you know, collectively, the people.

You know, I started to, you know, a few years back, I...I started something: I would not appear at any conferences that didn't have a non-speaking person/a person that was minimally speaking, or AAC using individuals integrally involved either as speakers as planners, or in some way, because I'm thinking there is a significant amount of people in the autistic community that does not speak; and our community that has intellectual disabilities. And again, those things are not necessarily mutually exclusive, you know, whatever.

I'm just saying...(to be involved/respected), everybody should *not* have to have graduate degrees and speak fluently. You know? I know that that's not the reality even for speaking people! I know, a lot of the time / lose my words. I do most of my meetings with my camera off and typing in the chat, because it's just too much; I don't have to talk all the time. So why are we presenting something as reality that's not people's reality? I don't understand.

When you're somewhere, you're autistic, and you're going on a stage or you're going on a platform, and you are...people can't discern the difference between an autistic person and the non-autistic people (present) without anybody looking it up, how are people supposed to relate or think that they can ever be that way? Or (think) their child can ever be that way? It doesn't...it's not realistic. We need to be our authentic selves. And our authentic selves need to be at the table. It's *our* table.

**Eileen Lamb** 14:42:50

Thanks so much for sharing with us. Today, I think it was our longest and more in depth podcast, and we talked about so many things, and you shared, like, some perspectives we've never heard before. And that was just, it was nice. And we did, we did it without yelling at each other. That was really cool.

**Morénike Giwa Onaiwu** 14:43:11

Okay, so now, we have to yell. I now have to say,"Oh my gosh, you're just a horrible person, your children suck. They should just take your children away, and whatever, whatever the thing that people are supposed to say." And you're supposed to say that I'm a "high functioning" snowflake." (All laugh.)

**Eileen Lamb** 14:43:28

No, no. I don't mind when people call me "high functioning." But the snowflake - that bothers me.

**Morénike Giwa Onaiwu** 14:43:36

What's interesting to me. It's like some people argue. But so like, I guess, to me, the reason why...one of the reasons I hate functioning labels like "high" and "low" is because so again, being from the Black community, there are terms that people use, like for things like in the South anyway, they were they would say, quote, unquote, has such "good hair" (which is a certain type of hair texture that's softer and curlier). And so, everything opposite of "good" is "bad," right? And that's actually what they called "bad" hair, "nappy" hair, whatever - is the texture that...that majority or...a great deal of Black people have! An Afro-type of texture like mine, is "bad" and the softer curlier texture is "good." If someone's eyes are hazel or blue or light brown, they're called "pretty" eyes. What's the opposite of "pretty?" "Ugly."



So if your eyes are dark brown again, (like) the majority of Black people, then it's ugly? And then they also had terms for...like, you'd call people "high yellow." So someone who has lighter skin, instead of saying, "This person's lighter skinned," or "They're caramel colored," or they're whatever, it's "high yellow." This is you know, I mean, people. Or, you know, "Black as charcoal," or "Black and crispy," or whatever. I don't like those...those types of comparisons. The person who is light skinned is just as important and beautiful as the person who is dark skinned. The person with this texture hair...do you have some hair on your head? Yay. You know what I mean? It's gonna be different. Different does not mean bad.

But these terms when you say "high." What's the opposite of "high?" It's "low." Who wants to be called *low*? And the people that I've met who are considered "low functioning" or "severe" kind of...I've got, you know, friends and colleagues who are nonspeaking; who have 24 hour aides and care; who have a lot of self injurious behavior; have a lot of seizures; have intellectual disability, and things of that nature. And they talk about (how) hearing themselves being talked about that way, as a kid, or even now - how harmful it was. But they didn't have the ability to communicate (then) and most of them didn't know how to use AAC and didn't really communicate in a way that people could understand. People didn't know what they did and didn't understand. I don't think they (always) didn't understand everything. No one, I think, no one can understand *everything*. But you know...so, intellectual capacity can vary, but, you know...

**Andrew M. Komarow** 14:45:48

Oh, I'm gonna interrupt you. So, but isn't that the entire reason why the IDD community, right, came up with person-first language in the first place?

Now, I'm not saying that's my preference. But again, if we want to talk about the history of some things, you know, we shouldn't, you know, pick and choose, right? The history of person-first language came from that...a good place, right, I think?

**Morénike Giwa Onaiwu** 14:46:17

It's interesting to me that people want to hold on to that. 'Cause that *same* community, those *same* people who were intellectually disabled, the same people who were very disenfranchised, that had a lot of challenges, are the same ones who demanded and wanted to have...*they're the same ones who took the lead in the community integration, you know, the deinstitutionalization movement, and, you know, the, you know, the removal of sub-minimum wage! These people were fighting for that!*

It's like people (who oppose community integration and want disabled people to live in institutions and/or not receive fair wages) are...are hypocrites. They want to be all, "(You must say) Person with autism (not "autistic person. (It) is *more* respectful!" or whatever, whatever - but at the same time, "Oh, but *these* people *must* be in an institution; that's the only way to serve such a person, we've got to have this." "Oh, well, some people *can* only work for pennies on the dollar(subminimum wage); that's all they can earn. You're taking away opportunities."

Uh...I'm like, "No!" People, *the same people that you're talking about*, said "No, that's (institutionalization and subminimum wage) *not* what the hell I want." (Laughter.) "I just wasn't able to

tell you before. Now that I can talk, type, whatever, those of us who can, we (are telling you) we *don't* want that.”

But no one (the people, usually non-disabled parents, who say that the “true” voices who are speaking “for” those who are “severely disabled”) wants to hear that (the preferences expressed by people with IDD who are nonspeaking AAC users and need 24 hour care - that they want people to respect them, to be presumed competent and paid fairly no matter their presentation or challenges, and that they want to be within the community, not segregated).

They (opponents of neurodiversity) apparently know better than anyone else (because they say) “I'm a parent.” (*Sarcasm.*)

I'm a parent (too)! But I'm *not* my child's voice! I think I know a whole lot. Not I think I know... I *do* know a whole lot about my children, but I don't know every freakin thing. They have their own opinions. You know, even my daughter, her favorite color for the longest time was pink. And now it's become purple. Yeah, I mean, I knew she liked purple. But (one day) it switched. *She* knew that. I didn't know that. Because she hadn't told me, you know?

I mean, we can't know...no one can know *everything* about anyone else. And so I agree, like, I feel like it's wrong for people to bash people for using person-first language. I personally just...don't like it; it doesn't sound right. “Person with autism. Person with autism.” When you read it, it's clunky. It takes up too much space. In English, we use adjectives and adverbs before the noun; we don't use them after. If that was (the case), it may not sound odd in another language, where they're saying, you know, where the descriptor always comes after. But that's not the case in English, it just looks to take up too much space, and it just looks ridiculous or like you're trying to hide from it.

But like I said, to me, it's the reason. If you are saying “person with autism,” because you like it, or it's what you're used to, and you don't feel that you're separating yourself from autism (it's fine). Is it this horrible feeling that makes you want to kill yourself? Then that's the thing...the hatred. You could say “Autistic” (instead of “person with autism”) all day, all night, and you can (still potentially) have tons of self hatred. You know, using identity first language doesn't mean that you're all “woke.” I mean, you just really, you know, you could have major issues.

And I think that people should *not* “police” what people want to call themselves. If someone wants to call themselves a “high functioning autistic,” let them call themselves a high functioning autistic. I don't want them to call *me* that, you know, kinda like we choose our pronouns. Let's be respectful. So I don't like how people will say, “Oh, you shouldn't say Aspie.” Don't tell them what they should or shouldn't say (about themselves)! Maybe they got diagnosed when it was still DSM IV, and the diagnosis on that paper says “Asperger's.” Are *you* going to tell them that's *not* what it says?

Because...I know, Asperger's technically doesn't exist (as a diagnosis) anymore. But again, let's not do that. Let's look at the fact that globally, things are different. You know, everyone acts like the US is the center of the world. And there's other places where things mean different things. And I tell people, you

know, instead of shaming people and being horrible, publicly tell people about the history of the puzzle piece! About you know...*not* the whitewashed nonsense that Thomas McKean says, but the *real* history before that. Yeah, I mean, and that's so that they can know that...that it has a problematic history. But then also realize, like, people may (still choose to) use it. People like to repurpose things. "Queer" used to be a *huge* slur for LGBTQIA+ you know. The community took it back, and said no, we don't use it for that!

"Black" used to be a horrible thing; (there was a time that) you wouldn't *dare* call somebody Black unless you wanted to get into a fight! We called them "Colored" or "Negro." James Brown and a lot of people like, you know, (changed that with) that whole "Say it loud, I'm Black and I'm proud!" chant. That was like, very, you know, radical.

Like...people don't understand, but (at one time) person-first language was *very* radical. And it still can be, as we see with the HIV community! It's about the *reason* you use a term, not the term itself.

And so, I think there is *no* reason to call *anybody* "low." There is *no* reason to call anybody "severe." Or "mild," like tasty sauce. (*Joking tone.*)

So, if that person can understand you, you're hurting their feelings because they understand the concept of "high" and "low." High is up; low is down. And if they *don't* understand what you're talking about, (you still shouldn't talk about) your child like that in front of other people. You have to "err on the side of caution," that is. As in, "I don't know if my kid knows that. Whether they understand it or not, I'm never going to speak about my child in a way that if they understood me, they'd feel belittled."

I'm not saying to pretend like the child doesn't have whatever gifts and challenges, you know. I'm not telling anybody to be unrealistic. I'm not saying that somebody should say that someone has an IQ that they don't. Or someone has an ability they don't. I'm just saying, find a way to call it/to say it (whatever "it" is) respectfully.

There's a book called "What to Expect When You're Expecting." I read that book. (Eileen says, "I did too.")

Yes, because that's what, that's what they tell everybody to read when you're pregnant. And when I read that book, they talked about how "more primitive cultures" carry their babies on their back, or sleep with their babies in the bed. I'm thinking..."more primitive?" They are talking about my...my African culture, and that's what they said. They talked about how you *have* to have the baby sleep on their own if you're...if you're any kind of person.

It's so interesting to me, because now...all this "attachment parenting" stuff - it's the *same stuff* that my...my people have been doing for, you know, centuries, you know.

So for thousands of years that was so "primitive," but *now* it's cool? Now people are spending three figures on buying these things to carry their baby; co-sleeping; and, you know, letting the baby

self-wean, but that was “primitive” when I was pregnant, you know what I mean? “Primitive?” You couldn’t say “in non western cultures” or “in West African cultures?” Could...do you know the hurt of that word that you're using? How cold is...is that? That word - I still remember that to this day. I was pregnant (when I read that); my daughter's now 13 (years old). And I remember reading them calling me primitive, and it hurt. It still hurts.

I remember being a little girl who picked up crayons, and they said “flesh” on them. And they didn’t look a damn thing like *my* flesh. Same thing with the (“flesh-colored”) pantyhose, or (on school) picture day that you get a comb, and it doesn't go through *your* hair. People need to think; everyone's not the same. You can speak about differences in a respectful way.

I don't have *any* love or have any respect for a parent that's going to say, “My son is nothing but a four year old in a 27 year old body,” *while that son is right there.*

Or for someone to say, “My son is stupid. You aren’t like my son; he'll never live on his own. My son smears his feces over things.”

Umm, how disrespectful! How *dare* you say that! Why can't you say, “Oh, my son has intellectual disability.” “He cannot read.” Or, “He needs a lot of support.” You know what I mean?

And the feces thing - *nobody* needs to know that; that’s not their effing business!

Would you say that about your child if they *weren't* autistic?

Would you say that about your non-autistic child after a car accident?

If they developed ALS?

Or if they had a traumatic brain injury, or got shot, and now they were incontinent or whatever? Would you say that stuff?

No, the hell you wouldn't! Why does “everything go” when it comes to autism?

I'm sorry, ya'll, I just got on a rant. With my husband babysitting the kids, I have time to do stuff. I have too much time to myself and my brain is just going.

**Andrew M. Komarow** 14:52:50

And professionally, right? That...that's why I don't like it. Somebody says there's a person who is “high functioning.” Like who wants to think of individuals as low functioning? Nobody, but like, yeah, it doesn't mean anything. Unfortunately, like in most states, it's like, “Okay, but what's the IQ?” (*Morénike answers, “Exactly.”*)

Right? And I don't care. I mean, literally, like, “Oh, it's 69. Great. You're gonna get tons of funding services and support for the rest of your life.” “Oh, it's 70. There's a 200 year waitlist?”

**Morénike Giwa Onaiwu** 14:53:20

Yeah, yeah. And I feel personally, it's so inaccurate for people who are not speaking and for people of color. Yeah. Like, there's so many people who, you know, like Sharisa Kochmeister; like so many people who are...who were supposed to be, you know, "unable" to read. And yeah, when they learned...when they are able to use AAC, people are like, "Wow, these people are actually intellectually gifted!"

Or... some are not, people; intellectual disability *is* a thing. You know, I mean, like you said, but it's like, we don't even know first of all those if those if the IQ is accurate.

When a person has communication challenges, there's so many things you can't figure out about the person. They may have a high IQ, an IQ that's average; they might have one that's below average...you might have...well, we really, truly can't know. But people assume just on the basis of communication or behavior. They assume a lot, and a lot of what they're assuming about them is unfair and usually negative.

**Andrew M. Komarow** 14:54:06

So...

**Eileen Lamb** 14:54:07

I'll do the quickfire questions.

**Andrew Komarow** 14:54:09

Yeah, okay. Yeah, we're gonna do quick fire questions. I should probably...I should probably get out there. So but, okay, I'm gonna shut up.

**Eileen Lamb** 14:54:17

Shut up. Sorry. Did I say that? *(All laugh.)*

**Andrew M. Komarow** 14:54:23

Sorry? Did you say sorry? No. Sorry. Shut up. Yes. So.

**Eileen Lamb** 14:54:30

Oh, well. So I'm going to ask you some quickfire questions. If you haven't listened to our podcast yet. Basically, I'm going to ask you five very simple questions, but that's subjective. And you give me the first answer that comes to your mind. Okay. Are you ready?

**Morénike Giwa Onaiwu** 14:54:50

I think so.

**Eileen Lamb** 14:54:52

What is the best piece of advice you've ever been given?

**Morénike Giwa Onaiwu** 14:54:56

“The master's tools will never dismantle the master's house.” Audre Lorde, but it (the advice) was given (to me) by a professor.

**Eileen Lamb** 14:55:03

What do you like to do to relax?

**Morénike Giwa Onaiwu** 14:55:06

I like to read transcripts...like...I like scripts, like screen plays. I get overwhelmed by communicator stuff. I like to listen to music, you know, a lot. I like to write. And if I have...if I'm able to go somewhere, like, I like to be at the beach; oh that's my favorite place.

**Eileen Lamb** 14:55:27

Is “glow in the dark” a color? Why or why not?

**Morénike Giwa Onaiwu** 14:55:31

Oh, wow. To me, no. I mean, it's glowing. But it could be green; it could be yellow.

**Andrew M. Komarow** 14:55:38

To clarify, that is the glow in the dark when the lights are on, right? When you see that? Is that a color?

**Morénike Giwa Onaiwu** 14:55:50

Okay, so sometimes it depends on the material, you know, there's some shirts or backpacks or wherever you can tell that it's a glow in the dark thing. Even if it's not really glowing, it has this weird tint to it or shape. So it's a kind of, you know, it's something that's “glow in the dark” even if it's not necessarily glowing.

**Eileen Lamb** 14:56:03

That's a good point, actually. So who's your favorite BIPOC advocate? And why?

**Morénike Giwa Onaiwu** 14:56:09

Oh, wow. There's so many. That is hard to select. I mean, I love...I'll name Anita Cameron because she's one of the old school, you know, like luminaries; she was in ADAPT; Crip Camp...And, you know, it was involved in all of these different things with disability, you know, as a Black autistic woman, one of those ones (who) has been around for many years. But right now, Hari Srinivasin...oh, gosh, I said his name wrong! He's often...I think it's probably someone... because I love how he...the perspective of a, you know, a very, you know, obviously, you know, obviously racialized person of color; young.

He has a lot of, you know, needs; he's minimally speaking, but he's, like, involved in things like research and he's involved in educating others, while still having, you know, needing and having strong family support. Like, I love that, you know, he...I love his example, and what it can mean for parents. I think there's a lot of people who don't think that their child will be able to go to college or do this thing or do that thing. And I think he's...he's showing people you know, that, you know, give your child a little bit more credit than you think. They might be able to do more than you think. Our kids can really surprise

us. You know, they can...they can...they can exceed our expectations, you know, a lot of times, you know, in different ways.

**Eileen Lamb** 14:57:34

So tell us where we can find you on social media.

**Morénike Giwa Onaiwu** 14:57:37

Oh, sure. So, I'm on social media, I'm @MorenikeGO, spelled like "more Nike" and then "go" like, go away. And so I'm a sporadic social media user, I should use it more. I'm totally not good about posting regularly. I may like, be off it for weeks at a time, but I am on Twitter. I'm on Instagram; I don't really use it much. I don't have the spoons for TikTok, although I like it. I have some videos on YouTube - some of my speeches. It's MorenikeGO, and I have a website and it's MorenikeGo.com.

**Eileen Lamb** 14:58:15

Awesome. Well, thank you so much for joining us today. That was...that was amazing.