

Adulthood on the Spectrum: Special education law, rights and advocacy

Andrew Komarow

Welcome to "Adulthood on the Spectrum," I am Andrew Komarow, an autistic certified financial planner. I co-run "Adulthood on the Spectrum," with Eileen Lamb. Hey, Eileen.

Eileen Lamb

Hey everyone. 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.

Andrew Komarow

Today, our guest is Michael Gilberg. Michael is a special education attorney and autistic self-advocate first diagnosed at age 18. Michael devotes his legal career to representing children with disabilities to ensure they get appropriate education that they are entitled to under the law, which he was denied. Michael serves on numerous boards and committees, including Counsel of Parent Advocate, sorry, including Counsel of Parent Attorneys and Advocates or COPAA, The Autism Spectrum News Editorial Board, New York State Autism Spectrum Disorders Advisory Board. Michael also has years of political and policy experience in government and advocating for disability and public policy.

Eileen Lamb

Hey, Michael, thanks for joining us today. We start by asking our guests what pronouns they like to use? So I'm talking about he him she her? And what identity language you use as an autistic person. So you know, on the spectrum autistic, with autism,

Michael Gilberg

it's funny because I don't think about that stuff. As much as most autistics I just think, you know, like I said, I'm boring. I'm just a regular, you know, I sometimes feel as a straight, as a straight white guy...my only, but not identity besides autism is being Jewish. I'm boring by comparison to some.

Eileen Lamb

That's a good answer. And what are your preferred pronouns?

Michael Gilberg

I mean, I never usually do it's just he and him, I don't. I'm still learning the pronoun thing myself. And I'm having to learn to be sensitive to others.

Andrew Komarow

So can you tell us a little bit about when you were diagnosed and what it was like for you growing up?

Michael Gilberg

Well, I think being diagnosed at 18, I had a lot of resentment towards it. I wanted, I was one of those not typical, but like many 18-year-olds, I just wanted to, quote unquote, be normal, whatever normal is. And so I kind of fought the diagnosis, and I resisted for a long time. And I tried to say, no, no, no, that's not what it is. And then eventually, I got to a point where I realized, you know, what, this is who I am? Well, I think I think we're, I think at 18, we're all stupid, no matter what your identity is. Otherwise, you know, 18, you're stupid. And I think as I got into my 20s, and 30s, I learned a lot more about who I am. And I get, I gained a greater understanding of my own needs, and my own self, trying to get the word, my own situation. And I think that made me a better person, and made me more able to be like, Okay, this is who I am. Accept it, live with it. That's it.

Eileen Lamb

So you're a lawyer, right?

Michael Gilberg

I'm an attorney like you said Andrew. Yeah, I represent families of children. Children on the spectrum and other disabilities, who don't feel they're getting appropriate, or the right legal services, and want something different.

Eileen Lamb

So why did you choose to become a lawyer? And why did you choose to focus on special education law? And what is special education law?

Michael Gilberg

So when I was growing up, I did not get an appropriate education. That's what the law would call a free and appropriate public education. And, you know, I got into adulthood, I went to college, I finally started in college doing better. And I got out of college trying to figure out what I wanted to do at 22 with the rest of my life. I had a degree in psychology, I thought I wanted to go become a great psychological researcher, I went to grad school in psychology and hated it. My father got sick for a little bit. So I used that as an excuse to drop out. And, you know, my mother said, from when I was little, I'd make a good lawyer. And I just realized, with all my policy work, the law was where, where I was best suited, especially given that I have an ability to drive people in credit, or drive people crazy, to get them to do what I want, which is a good skill in politics, if you're trying to change the law, that people will change the law just to get you out of their hair. And so I think that, you know, I just realized that and as I went through law school, it's something that just always stuck in my mind about special ed law because I didn't get the services growing up and I had to catch myself up when I get to college and fill those gaps. But how many people are going to have the motivation, I have to do that? How many people are going to go back and say, You know what, the system failed me when I'm gonna take care of myself. A lot of people who come out of college, haven't come out of high school, not college ready, they give up they don't do that. Then they just, you know, they end up unhappy or

underemployed. So I just said, I can make this world a better place for so many people with autism and other disabilities to make sure they have the right services and education before they get to college.

Eileen Lamb

What services did you wish you had when you were younger?

Michael Gilberg

It's hard, it's hard to evaluate yourself, especially when you're looking at things 30 years on, you know, it's this, I see stuff today that I wish existed when I was child, but it didn't. But it's hard for me to second guess, certain pieces of it. Because what I know, I know, in the context of being an attorney, in between, you know, from 2011, to 2022, and I was growing up in the 80s, early 90s, when the whole, the whole situation was just different. And so it's to me, it's almost an apples to oranges comparison to say, what do you wish you had? I don't think I can do that right now in a way that would make any sense because of the stuff I'm thinking of, in the context of today, if that makes sense?

Andrew Komarow

No, that makes perfect sense. I think that's an even more important skill is when to admit that things have changed, or you know, when to know, when things are not related. So thank you.

Michael Gilberg

You know, I always tell people, when I was growing up, autism was a kid sitting in the corner, banging his head against the wall. It wasn't people like me, or any of us who were more, you know, I don't want to say high-functioning, because people don't like functioning labels, what they call now, I believe, less support needs. And so you know, to me, the whole, the whole narrative, the whole of the whole is the word I'm blanking on the whole, you know, idea of autism has changed.

Andrew Komarow

I think pretty much everyone in the community can agree to that. Now, you mentioned you are a special education attorney, can you tell us the difference between an advocate and I'm using quotes. And a special education attorney? And where should somebody start? And what's the difference?

Michael Gilberg

Well an advocate doesn't have to have any actual credentials, anybody can call themselves an advocate. There's no regulation, it's just a word that means anything. We all advocate for different things, but there's no actual requirement. Anybody can hang up a shingle and call themselves an advocate, an attorney, you have to go to law school and pass the state bar, you can't call yourself an attorney without being barred somewhere, the difference in how they work in special ed is an attorney is brought in when things are more contentious with the district. And if you have a district, it's working with you, but you don't know what you need for your child. And you want to keep them in district and advocate works, they can help come and get good and better evaluations to modify the IEP and

things like that. If you're going to look for private placement, you'll, you'll always need an attorney and advocate can't get you a private placement. So it depends what you're looking for. If you're looking for different program and district, you can often start with an advocate. And if the school is not being works with you, granted, and if they don't work with you, and it's one of the more difficult districts, then you might have to switch to an attorney.

Andrew Komarow

So as what you're saying that it's better to always start with an advocate and maybe to get people to change it's best,

Michael Gilberg

Not always, I think if you have a case where you know, it's going to be a private placement, most bullying cases, I think you need an attorney from the start, and a lot of bullying cases, because there were so many legal issues going on there. And there were certain little things you have unique cases. I think it's a very case by case situation.

Andrew Komarow

Got it? Thank you.

Eileen Lamb

You know, I have a situation right now with my son who's on the serious side of the spectrum. And he's like, he's escaped from the school building is like aggressive towards himself and others. I mean, he needs a one on one, right? I'm getting it right.

Michael Gilberg

I've never heard someone use the term serious side of the spectrum.

Eileen Lamb

I guess, I said severe. But yes, serious is good too. Or profound or level three.

Michael Gilberg

And that and that's become a big controversy with a lot of the self-advocate community. And I've had this conversation with many of toxic. I've talked to Andrew about this, that there's this whole question about functional labels, and some people are opposed to it, some are floored, and what you mentioned about your son the whole controversy of ABA. Yeah. And right now co-chairing the task force for the Autism Society of America. They're doing a comprehensive panel on ABA and comprehensive paper. I'm one of the co-chairs representing the self-advocate community. And we've had recent town halls on ABA, and it's been contentious to say the least.

Eileen Lamb

What's your take on ABA?

Michael Gilberg

I think ABA has to be done in the right way. I think we can all agree. ABA like the Judge Rotenberg Center. I'm sure you're both familiar with it. Where you electrocute the kids not appropriate, where you deprive them dinner or you strap them to a board. To me it's matter of number one, what is the behavior is that you're looking to eliminate isn't something called that people think is weird or strange, but it's not harming anyone. And, and like flapping their hands, who cares. But your son, if there's aggression running in the street, I've had a number I've had some kids recently masturbating in class, those are issues that have to be addressed. We can't just say, Oh, he's autistic, let them behave that way. My clients have an eight-year-old girl right now masturbating in class, as she gets older, that's going to be a problem. She can't just be allowed to do that. Your son cannot be allowed to run on the street, because he could get hit by a car. So I think we have to look at what's the behavior. You know, we all have little stims we do what autistic or not. So if somebody wants to fidget or flap their hands, who cares? You know, we all engage in behavioral modification as adults who are able to do this, we all understand that when you're crossing the street, you wait for a green light and a red light means you don't go. That's a form of ABA, it's teaching us behaviors not to walk across the street, unless you see this light. So I think ABA has to be used in a very ethical way, for the right reasons. But again, things were they beat the kids or they use neg vs. And he used a lot of physical restraint is not the way to go. I think you have to use a knee in a way that teaches behavior, but it's not done properly. And I think ABA in some courts corners, has become stigma to the name. I've heard people say ABA has a marketing problem. And what they need to do is we might rename and rebrand that's,

Eileen Lamb

Yeah, I love how you put it. I think a lot of people forget that, you know, ABA is not about the little stims that are totally okay. Like, it's about some serious issues that need to be addressed. And it's not about just trying to make the autistic person normal, it's about keeping them safe, and you know, others around them too, because sometimes their behavior affects others, like when my son, Charlie hits other kids, or the teacher or the TA, you know, we need to do something about it.

Michael Gilberg

I'm one of those where I believe you can just say he's just, that's what I'm this is what I deal with school. You can see he's just artistic. It's part of who he is allowed to do that. Those kids have a right to bodily autonomy, and Charlie's autism does not give him a right to violate their personal space. Right. So he, as you're saying he needs to learn that he can't it's not appropriate to put his hands on others.

Eileen Lamb

I agree. So it's something that would help is a one on one. So what advice would you give for parents who have gone through the process, but can't get the services that would suite their child best? For example, I want an advocate for Charlie, I want to a one on one for Charlie, I got an advocate. And that didn't help. So what advice do you have for parents in my situation?

Michael Gilberg

You're in Texas, right?

Eileen Lamb

Yeah.

Michael Gilberg

I think part of it has to do with where you are and who you hire. And like anything else, advocates, they're great advocates. I just got back from my conference, which was COPAA, which Andrew mentioned, in my bio, which is the Professional Organization of Attorneys and Advocates and Special Ed. And we have amazing advocates. But again, anybody can call themselves an advocate. Anybody can go hang out a shingle and say I'm an advocate. So you have to remember that that led you to getting good and bad. If you've if you have that if anybody can do it. You can get good good advocates and bad advocates.

Andrew Komarow

And how do you tell the difference between the good advocates and the bad advocates?

Michael Gilberg

Word of mouth. Reputation. You know, that's the thing. Again, being an advocate is not regulated being an advocate. It's just, I want to be an advocate. I can call myself.

Eileen Lamb

Like, could I be an advocate if I wanted to?

Michael Gilberg

Yes, anybody can. I mean, the only issue is if you were to turn in some attorneys do this is they they don't they're licensed attorneys, but they say they're practicing as an advocate. School districts are not usually fans of that because they're saying you're trying to get around there being an attorney. Because if a school district if a parent has their attorney at a meeting, the school district has to have theirs.

Eileen Lamb

Yeah, I think the fact that anyone can be an advocate is definitely an issue but you know, I feel like most advocates here have a good reviews I mean, you know, I did alot of research and the person I went with good reviews

Michael Gilberg

Right? An advocate is just a term it doesn't. It's not like a lawyer where there is sort of certification.

Eileen Lamb

But yeah, there's no law, law background, I guess. So that might be where the issue is. Like they can't scare the district as much as an attorney could right?

Michael Gilberg

No there are times where a district will say to the parent "No, no, no, no, no," until the attorney gets involved. And that's what "No, no, no," becomes "Yes, yes, yes." You know, it becomes a different situation.

Andrew Komarow

And other than the qualifications necessary, legally, what can an attorney do that an advocate can't? I assume one is go to court. But why would that happen?

Michael Gilberg

In general, in most cases an attorney can file for what's called a due process hearing. And an advocate can't always do that, or an adovacte doesn't have the training, to conduct to run a hearing, to do a hearing. And why do people go to a court, which is a hearing is because they're unhappy with the services, and the school district refuses to budge and says, we're doing a great job. There's nothing wrong with your child, you're just, you're just a difficult mother. So I've seen cases like that, where the school will say, this child was fine in the schools and tell the mother, it's her fault. And so I think, in many cases, you know, you I've always said, sometimes, I feel like some of my colleagues I, the ones I get along with, and don't hate this up on the school board side, our job is to be an honest broker, I think, between the parents and the school districts.

Eileen Lamb

Do you think you have a different perspective on autism advocacy, working with so many different sides and seeing parents fight so hard for services for kids? Like my son?

Michael Gilberg

I think it varies, because I do have a unique perspective from my life experience. But the problem is when the parents don't agree, and what I find the biggest challenge is when the parents are going into two different directions.

Andrew Komarow

Do you have any examples that you are able to share?

Michael Gilberg

Nothing specific, but I just in general, I've had these couple of these cases, with a mother wants everything to be taken care of him looking for her daughter, and the father gets into this, my kid is not autistic. "He is not like that." "He's not like that." And I hate to break into gender stereotyping, but it's always the man holding that position, not the woman.

Eileen Lamb

Oh, my God.

Andrew Komarow

And what happens in those situations, what's the typical outcome?

Michael Gilberg

You know either the father ends up realizing he's wrong, and he does what has to be done, or the what's it called, or the what's it called, or the school district, Like the mother has to figure it out. But you know where the kid is, in some cases, if the father never comes around, the kid never gets that appropriate education. But I always say I only do what I only can do what I can do.

Andrew Komarow

So tell us a little bit more about your business. You know, the law is, well, there's lots of different aspects of the law. There's lots of different ways to help others with disabilities in the law. So tell us a bit how it started and how your business intertwines with your advocacy work?

Michael Gilberg

What do you mean?

Andrew Komarow

So what I mean, I, I mean, I'm, I'm here doing this podcast, right? Not not as my business but you know, advocacy, right? So they're, they're very intertwined, right, being, you know, an advocate, and some of the public policy is also, you know, very much a part of your profession as well.

Michael Gilberg

Right. And so I guess, I just, I bring my my unique life experience to what I'm doing for these kids. And I've had parents say to me meeting you, makes me realize my son can go to college, and he can be someone, instead of just a kid sitting on the couch, which was a problem parents still have when they're kids, you know, so I think it's a very intertwining because very often, I sometimes will talk to the kid and the parents will ask me, Can you talk to him and explain this to him? So he that he doesn't listen to us where his parents. And so I think there's a lot of cases where you can step in, in many ways and be as an honest broker between the parents and the child. And whilst not directly in school. It's, I lost my train of thought, sorry.

Eileen Lamb

What's the question that someone should ask an advocate?

Michael Gilberg

You're really into the advocate versus an attorney?

Andrew Komarow

Oh, sorry. Actually, no, I think we meant as an attorney or an advocate, right?

Eileen Lamb

Oh, yeah. yeah.

Michael Gilberg

Is this I appropriate? Is this IEP appropriate to meet my child's needs.

Eileen Lamb

Is that a good first question?

Michael Gilberg

That's a very, it's a very base question in Special Ed.

Andrew Komarow

What, what should a parent look for with an appropriate IEP and can you tell us the difference between an IEP and a 504 Plan?

Michael Gilberg

Sure, IEP. So the answer to the appropriately, the answer to what an appropriate IEP looks like. It's specific to each child. That's why it's an individualized education plan. I can't, I can't tell you what to do when you're I say, it's individualized. And so you have to follow that individualization. And so what to ask for in terms of services. It depends on who the child is, you know, what Child A needs might not be the same as what Child B needs.

Andrew Komarow

That sounds like a good way to approach it, just look at what the individual needs.

Michael Gilberg

And the IEP stands for, which is a special headline nationally, stands for Individual Individuals with Disabilities Education Act. So I think that we all are seeing the fact that, you know, there's definitely an effort now to weaken federal civil rights legislation, which a lot of people are very worried about.

Eileen Lamb

So how do you feel about the neurodiversity movement? I heard that you were previously involved with ASAN?

Michael Gilberg

I am not going to say the word previously, I've been to some of their events. Like any movement, there are people I like in the movement, there are people I dislike, you know. And you can't be everybody's friend. And there are people who don't like me. You know, I think just because we're autistic, we're still people. And there are people, you can just you can just not like, because you don't like them. It doesn't have to be because they're autistic.

Eileen Lamb

But what do you feel has changed since you started becoming involved with advocacy?

Michael Gilberg

I think that more people know what autism is now. They see it as a full of people on the spectrum can be doctors, lawyers, all these other things. And that fully functional human beings. It's not the prejudice that existed with someone like Jordan, who I mentioned, the people that are growing up, and they're totally because they're not speaking, they're never going to amount to something, they're never amount to something, they're never going to be able to be in school, because they're their too stupid. Although I had a social worker who told my mother, I'd never graduated high school. So I did go back to look at him, look him up. Now that social media makes that possible, and found he had died two years earlier. So I didn't get the satisfaction.

Andrew Komarow

If there was one piece of advice that you could give, you know, a parent, you know, starting down this road. You know, what, what would be the one key takeaway?

Michael Gilberg

I think it would be trust your judgment on your child, you know, your child best. If the school, this school says something that doesn't sit right with you challenge it be a big mouth.

Eileen Lamb

I know how to do that. Where can we find you?

Michael Gilberg

It's the parents who make the noise who end up in the most trouble.

Eileen Lamb

Yeah

Michael Gilberg

I'm sending you guys up on my website. My website is michaelgilbergesq.com. And my email for the office is, Michael Gilberg, ESQ, all one word at gmail.com.

Eileen Lamb

And where can we find you on social media? Are you?

Michael Gilberg

I'm everywhere. I'm connected with both of you in many places. So I'm all over social media, but not Instagram. To me, Instagram is just a knockoff of Facebook, the Facebook Live.

Eileen Lamb

We're gonna ask you some quickfire questions now? I mean, I will. So how it works is that I ask you a question. And you tell me the first answer that comes to your mind supposed to be like,

Michael Gilberg

I've seen this done before.

Eileen Lamb

It's okay. If you can't answer, we won't be mad. What is your favorite food or drink?

Michael Gilberg

Diet Coke. It's my, my drug of choice.

Eileen Lamb

If you could be any animal fictional or real, what would you choose? And why?

Michael Gilberg

I have no idea.

Eileen Lamb

What is your special interest or one that comes up?

Michael Gilberg

I'm very typical of people on the spectrum is that I don't I don't really have those special obsessive interests. I did when I was a kid, but I almost grew out of them.

Eileen Lamb

Special Education?

Michael Gilberg

Special interests, I don't think well, when I was a kid, I had an obsession with the dinosaurs. The US presidents and the New York City public system. New York City subway system.

Eileen Lamb

What's your favorite autistic representation in the media fictional or not?

Michael Gilberg

That's so broad. I can't even think of what I would pick. One of mine.

Eileen Lamb

Do you have a favorite quotes or saying if so, what's the quote and who said it?

Michael Gilberg

I guess it's the famous Wayne Gretzky line. "You take you take 100% of the shots you don't make." And that's why as someone who grew up behind, I always took the shots to try to get ahead. I took whatever chances I got.

Eileen Lamb

Awesome, well

Michael Gilberg

Does that makes sense?

Eileen Lamb

Yeah you did it. Thank you for coming today.