

The Think Inclusive Podcast

Season 9, Episode 1

Eric Garcia | We're Not Broken: Changing the Autism Conversation

Tim Villegas (00:00):

Eric Garcia, author of "We're Not Broken: Changing the Autism Conversation" wants you to know something about autistic people.

Eric Garcia (00:08):

Autistic people are fine just the way we are. Do we have challenges? Yes, just like every other human being does, and we should work to address those problems. But we're not failed versions of normal. And I think what needs to happen is that, the reason why I say "changing the autism conversation," it needs to change so that autistic people are included in that conversation.

Tim Villegas (00:29):

And he's adamant about letting autistic people be who they want to be.

Eric Garcia (00:33):

The world is cruel to a lot of disabled people, particularly autistic people. Otherwise I wouldn't have written this book if I thought the world was nice to them. But you can't restrict people's freedoms or their ability to have their own dignity in the name of security.

Tim Villegas (00:54):

Hey, y'all my name is Tim Villegas, and you are listening to the Think Inclusive Podcast presented by MCIE. This podcast exists to build bridges between families, educators, and disability rights advocates to create a shared understanding of inclusive education and what inclusion looks like in the real world. To find out more about who we are and what we do check us out at thinkinclusive.us or on the socials: Facebook, Instagram, or Twitter. Today on the podcast, we interview Eric Garcia about his new book and talk about the biggest misconceptions of autism, why simply existing is not inspirational, and what his dream for the future of a more inclusive world looks like. Thank you so much for listening. And now our interview with Eric Garcia.

Tim Villegas (01:59):

So today on the podcast, I'd like to welcome Eric Garcia, who is a journalist and author of 'We're Not Broken: Changing the Autism Conversation." He previously worked at the Washington Post, the Hill, Roll Call, National Journal, and Market Watch. His writing has been featured in the New Republic, the Daily Beast, the American Prospect, and salon.com. Welcome to the Think Inclusive podcast, Eric.

Eric Garcia (02:26):

Thank you very much.

Tim Villegas (02:27):

What are some of the biggest misconceptions of being autistic?

Eric Garcia (02:32):

Uh how much time do we have? I think the biggest misconception. Autism has been subjected to so many misconceptions throughout its very, very long history in the public eye. In the beginning it was often seen as something that was caused by unloving parents. And even before that, it was seen as a symptom of schizophrenia. Didn't get its whole separate diagnosis in the diagnostic and statistical manual of mental disorders until 1980, it got its own separate diagnosis. Up until that it was under this diagnosis of schizophrenia. And then over time it's gotten, you know, there's been the misconception that vaccines cause autism, which is not true then there's been this idea that it affects only upper-class white people and that was a misconception. And then there was those misconception that it only affects boy, it affects boys more than it affects girls. Then there's been the misconception that they're unable to work and that, or that there is the misconception that they all work in Silicon Valley or, you know. So it's been misconception after misconception after misconception. And that's kind of, misconception is kind of the story of autism in many ways.

Tim Villegas (03:53):

So in the book you say, "to be inspirational means to be exceptional and somehow extraordinary, but to be successful because of supports and accommodation is to universalize our success." Can, can you expound on that?

Eric Garcia (04:07):

So I really hate, I'm sure you see these stories of like "autistic person graduates from high school or college" and things like that. It is supposed to be a really inspirational or feel-good story. And I really hate that because it's like, well, why is that inspirational? It's like, well, it's inspirational because it's exceptional. It's because it's out of the ordinary. That's why it's a news story. And like, and then also my feeling is that those stories aren't inspirational to autistic people. They're meant to inspire neurotypical people. I would really love it if autistic people could be average and like, you know, we should make graduating from college the ordinary instead of out of the ordinary. If you universalize things, that might not make neurotypical people feel good, but it'll improve autistic people's lives. And, frankly, I don't care if you feel good if you're a neurotypical person. My life isn't meant to make you feel inspired.

Eric Garcia (04:58):

I'm sorry that, that, you know, like I write about it in the book. You know, when I got a job, I say specifically like, "this is the point where you might think that I get a happy ending." I'm sorry, there's no such thing as happy ending. And nobody's entitled to a happy ending except the person themselves living that life. And even then you're not entitled to a happy ending. Life is cruel and it sucks, deal with it. But, you know, I think that it's important to say that like, okay, if we give the right supports to autistic students, then more will graduate. Then it's no longer inspirational, then that's a universal thing that can happen and it's a possibility, you know?

Tim Villegas (05:35):

Right. So, so what do you think is the barrier then? Is it just a matter of mindset of like, oh, people just haven't thought about giving the supports or is there something more systemic?

Eric Garcia (05:47):

I think so. You know, I talk about it a little bit in the book. I would have liked to have done more in the book, but like for example, the Americans with Disabilities Act didn't mention autism in its original 1990 version. It was in later in the ADA amendments act, once regulations were put in place. Autism is included in the Individual with Disabilities Education Act as a disability that's covered, but you have to remember that that was a reauthorization of the 1976 Education for Handicapped Children Act. So a lot of the things about autism they get to recognize is that autism, the way we deal with autism has been grafted into pre-existing policies. And that's a good thing because it means that what we're doing, we were including them more in, you know, society. But the other thing is that it means that we're shoehorning autism into these policies that existed before and didn't have autistic people in mind. So a lot of times it's, it's always, you know, it's a paradox. On one end, you want to include them in larger within larger society, but then also you want to make sure, well, what happens if, you know, we try fitting them into something that they weren't initially built into. That's, it's a real paradox that I don't think I didn't even try to ask or answer that question in the book.

Tim Villegas (07:06):

Do you have any thoughts about what needs to happen to IDEA?

Eric Garcia (07:11):

Well, first of all it needs to happen is that the federal government needs to actually live up to its commitment. I believe the, you know this probably better than I do, the federal government's supposed to pay about 40% of the cost. And it's only ever gotten paid around 14.67% of the cost. I'm not, don't quote me on that specific number, but it's not what it's supposed to be. And one of the things that almost every democratic presidential candidate promised in the 2020 democratic primary was that they would fully fund IDEA. Or they would, not only would fund IDEA, they would increase the amount of money that the federal government promises. So, I mean, I think to your point is that know the real difficult part is that, first off, the federal government isn't giving the money that that needs to be given to even properly administer the IDEA. On top of that the question is is that promised money even enough? So the delivery of services is really dependent on that. And you know, a lot of state budgets, because states almost every state has to have a balanced budget by in state constitution, that makes it really hard for states and localities to live up to their promises. And if you don't have a good attorney, you're basically doomed, you know.

Tim Villegas (08:33):

Real talk from Eric Garcia.

Eric Garcia (08:38):

I'm telling you, I'm saying the things that your listeners probably know already.

Tim Villegas (08:43):

Yeah, yeah, yeah. Well, let's talk about... In the book you talk about parents advocating for workshops. And so I want to know, you know, what you thought. Are these the same parents and families who are saying, "well, we want our kids in a separate, special education classroom."

Eric Garcia (09:08):

They probably are. I should say I didn't look into, I should say I didn't look into that in my book. I, I probably should have. But I think that it's entirely a possibility. Like I think that it's important to remember that sheltered workshops were seen as the right thing or segregated work was seen as the right thing to do for a long time. Because it was seen that these people could probably never hold a job before, but what we realize now is that we recognize that disabled people can hold a job and they can work full-time even, you know, and we also recognize that everybody deserves a good and decent living wage, you know. And that, and I should note that a lot of people who are on the front lines of that ending sub-minimum wage are Republicans. Cathy McMorris Rodgers is a Republican Congresswoman who was in Republican leadership. Governor Greg Abbott in Texas.

Eric Garcia (10:06):

I think parents who think that, first off, they feel like, okay, well, there's a support system that comes around segregated workshops. They get driven to the place, they get supports there. They a lot of accoutrement and it also provides respite for caregivers. But the fact of the matter is that those things could come with integrated work. We just never thought of them. We never, we didn't think that was a possibility for integrated work, but that doesn't mean that they can't be done. And I think that's what matters. Is that for the longest time, parents oftentimes are afraid of the unknown and because the world can be cruel. I try to be, a lot of people will probably think that I'm being unempathetic to parents in this book, but I understand why they're afraid. The world is cruel to a lot of disabled people, particularly autistic people.

Eric Garcia (11:07):

Otherwise I wouldn't have written this book if I thought the world was nice to them. But you can't restrict people's freedoms or their ability to have their own dignity in the name of security. And that's what you're doing when you pay people below minimum wage. And what you do when you segregate them from other coworkers is you basically say they aren't entitled to work with other people. And they aren't entitled to earn the fruits of their labor. And they aren't entitled to a good job. Cause a lot of these jobs are very, very menial. I talked with Maxfield Sparrow, and they were, you know, working on cutting felts for like those puzzle floor things like it's very, very not to say that all work doesn't have dignity, but it's very much like it's assuming the low that disabled people can only do the lowest of low labor and they can't do anything more. So it's providing indignity and it doesn't give them their due.

Tim Villegas (12:10):

What do you think we can do as a country to improve, you know, healthcare for not just for autistic people, but for everyone.

Eric Garcia (12:18):

One doctor told me that, like, I can't think of a worst place for an autistic person than an emergency room or an emergency department. The thing that you had to remember is that I think because autism was medicalized for a long time, a lot of times doctors think that they are helping autistic people by

trying to kill the symptoms of autism or, you know, they're autistic traits instead of treating the things that autistic people themselves are dealing with. I think that what this requires is it requires doctors listening to autistic people and their needs rather than doctors trying to treat, but people don't want to be treated. They need to recognize that disability is not the same as illness and they need to recognize that disabled people's needs are valid. You know, I, I interviewed Lydia Wayman and she said like, doctors just thought that she was faking being sick.

Eric Garcia (13:13):

Like doctors need to take what autistic people are saying at face value. That's a really important thing. You deserve to have doctors listen to you. So I think that's, I think that's the primary thing. And also I think what needs to happen is there needs to be more research into what is actually killing autistic people. Autistic people with intellectual disabilities are very much likely to die of epilepsy. Autistic people without intellectual disabilities are, the two biggest killers are heart disease or circulatory conditions and suicide. Those are all, those are, that's a pretty big crisis. If a lot of autistic people with without intellectual disabilities are dying from heart disease or killing themselves, both of those are pretty big crises that need to be addressed.

Tim Villegas (14:02):

Eric, can you tell us more about what you mean by the fate of autistic and LGBTQ people being intertwined?

Eric Garcia (14:11):

Yeah, that is really important. And that is something, one of the things I noticed when I started writing and research about autism was how many autistic people I met were queer, lesbian, gay, bisexual, transgender, gender non-binary or something in that sphere. And what I realized is that a lot of them aren't taken seriously because they're autistic. So if they wanted to transition a lot of times, I think it would be like, oh, well you, you don't know what's good for you, you know? Or you don't know, that's, that's basically argument JK Rowling is making when it comes to trans men being tricked into, you know, transitioning, which is just really gross. You know, but like on top of that, I think the other thing that's important to remember is that Ivar Lovaas, who was the, I guess you could say the father of applied behavior analysis at UCLA was also the same person who worked on and advised on UCLA feminine boy project. Which was basically, not even basically, it's served as the template for a conversion therapy, what we know now.

Eric Garcia (15:33):

So even though, so like, and one of the things that it used a lot of the same conditioning and the same kind of averse is, and the same kind of things. So those two things share DNA and the same impulse. Even though I am cisgender and heterosexual, I have to recognize that the same impulse that wants of people who want to stop me from stimming are often the same people who don't want, you know, gay men to have a lump breast or something, or, or want lesbians to wear a dress or have trans men be women, or look, you know, present as women or trans women present as men, or what have you, or force non binary to pick, to conform to one gender or another. And the core is that it's saying that whether it's ABA or whether it's conversion therapy or something, and saying that you can only be loved if you fit into these pre-described or prescribed norms that haven't built you in mind.

Eric Garcia (16:42):

So if you are, and you know, to say nothing of, if you are queer, and I'm using queer to include everything, because that's what a lot of my LGBTQ+ friends say. So I'm just using that. So queerness and autism, they're both choosing those things and choosing to be your most authentic self are, in many ways, defiance of what people want you to do. But they're also you accepting that you are who you are and you should be and you're deserving and worthy of love as you are. I think that's the most important thing that I would say. To say nothing of how many LGBTQ+ autistic people there are, there are plenty of them.

Tim Villegas (17:38):

I want to go back to an earlier question I had that we just, I just kind of skipped over about the terms of high and low functioning. I'm wondering why are those terms problematic?

Eric Garcia (17:49):

I wouldn't say that there are problematic as much as I say they don't actually accurately describe what's going on. I mean, I'm a journalist. So that's my job. My job is to describe the world as it is with words. I think the terms high functioning and low functioning they don't, they don't accurately depict what autistic people can and can't do. So a lot of people might say, and I get this a lot in my, you know, when I'm on Twitter and it always, it always means like, well, it's really easy for you to say cause you're high functioning. And it's like okay, well I have trouble taking out the trash. I have trouble with remembering things. I have trouble cleaning out my place. I have a lot of difficulties with a lot of different things. And that kind of flattens my experience.

Eric Garcia (18:42):

In the same respect, a lot of people who would be considered quote, unquote, low functioning, which is people with intellectual disabilities or people who can't speak are seen as low functioning and that flattens their experiences and that it diminishes what they can do. It says that it prescribes what they can do and they're considered low functioning because they don't function the same way that neurotypical people think that they should. But like, you know, an example is like, oh, I'm sure you saw the Interagency Autism Coordinating Committee. They have somebody who has intellectual disabilities on the committee now. And they have somebody who can't speak, who doesn't speak. Who's nonspeaking. Ivanova Smith and Hari Srinivasan are both of them. But they had to be able to function pretty well if they can, you know, be on a government committee. But we flatten their experiences if we use terms like low functioning. And also, so I tend to prefer terms like higher support needs or lower support needs, because then you're talking about what they need and how, what are the supports they need throughout how to get the world. And it's more, it's more responsive to them than it is what our perceptions of them are. So I tend to like those terms better.

Tim Villegas (20:08):

Thank you. Thank you for that clarification. So as we look to the future what is your dream for autistic people and how do we get there?

Eric Garcia (20:21):

Well I'm on Capitol Hill right now. I'm calling you literally from the phone closet on the hill where they're debating I'm sure you know, about President Biden's proposed \$400 million on home community-based services. That would be a massive boon to autistic people to allow them to live in their community, to

live with their families and to live among and, and to be seen as members of the community. Not just live in the community, but seen as being members, vital members of the community. So that's one thing. The other thing is I would, I would really like to see is that just autistic people being included in anything. Any time that there's any discussion about autistic people, they should be included.

Tim Villegas (21:03):

So this is just for fun. Oh, I know what I wanted to say. Your book. Okay. So the book that you wrote, your titles are song titles.

Eric Garcia (21:16):

Yeah!

Tim Villegas (21:16):

And then in the body of your chapters, you have subtitles that are lyrics.

Eric Garcia (21:25):

Yeah.

Tim Villegas (21:26):

And so as a segue into the last question, you know, we know you love music. Do you have like a running list of like your, you know, top five albums?

Eric Garcia (21:38):

It changes all the time. I mean, I would say my top five favorite albums of all time. Yeah. You're going to, you know, you're going to realize you're going to really put me on this. I'm gonna say Highway to Hell has to be on there. And then this is, this is no list. Highway to Hell is on there. Jimmy Hendrix's Electric Ladyland is definitely on there. Just because I go back to it all the time and it was a big part of writing this book. Miles Davis' Kind of Blue is definitely on there. I would probably put on something else. I mean, I got into it, like when I was on deadline very, very few things help you when you're on deadlines but Straight Outta Compton by NWA. You're from southern California so you know.

Tim Villegas (22:27):

Yes, I do.

Eric Garcia (22:27):

And then afterward I think I would put on, it's a toss-up right now between Metallica's Master of Puppets or Black Sabbath's Paranoid. It's one of those two. That's usually my top five and the fifth one usually alternates a lot, but yeah.

Tim Villegas (22:44):

All right. Is there anything else that you wanted us to ask?

Eric Garcia (22:48):

Not really. I think the thing that I would just like to say is that autistic people are fine just the way we are. Do we have challenges? Yes, just like every other human being does and we should work to address those problems. But we're not failed versions of normal. And I think what needs to happen is that, the reason why I say changing the autism conversation, it needs to change so that autistic people are included in that conversation. You know, that's the only thing I would say is that that's the simplest answer I can say is that autistic people need to be included.

Eric Garcia (23:20):

And I think that one of the things I write about in the end of the book is that you're seeing autistic people being included more on presidential campaigns. You're seeing them more working in Congress. You're seeing autistic people getting elected to office. You're seeing autistic people as actors and working in different sectors of the business community. They're going to change things and make things better than I ever could. And hopefully they move things forward in a way that I couldn't. So I'm very optimist. I don't want to say I'm very optimistic because people always, because I, I should say like when I was writing the proposal it was done with, on the premise that I thought that is that it was done. I started writing the proposal in 2016 when Hillary Clinton put out her policy proposal on autism and then Donald Trump got elected. So, so you got the first presidential policy on autism, and then you got an anti-vaxxer elected as president of the United States. And that should have been a harbinger of how he would have handled a pandemic. But in the same, so I don't want to say I'm optimistic because, you know, I'm usually Mr. Doom and gloom, that's just who I am. You can ask any of my friends. But what I am hopeful is... If I'm not over for humanity at large, I'm hopeful for the autistic community. So that's what I am hopeful for.

Tim Villegas (24:50):

So, Eric Garcia, really appreciate your time on the Think Inclusive podcast. Is there a place that people can buy your book or follow you on social media?

Eric Garcia (25:01):

You can follow me because I tweet way too much about politics and anything else <u>@EricMGarcia</u>. You can buy my book <u>"We're Not Broken: Changing the Autism Conversation"</u> wherever books are sold. And you can always, you know, DM or message me anyway after that. And you know, I will gladly be a guest on your podcast. So, and then also I'm a correspondent, I'm senior DC correspondent for the independence. So follow me, even though I'm not British, I wound up being a senior correspondent for a British newspaper. So so yeah, so, you know, that's also what I do.

Tim Villegas (25:41):

Eric Garcia, thank you so much for your time.

Eric Garcia (25:42):

Thank you.

Tim Villegas (25:56):

That will do it for this episode of the Think Inclusive podcast. Subscribe to the Think Inclusive podcast via Apple podcasts, the Anchor app, Spotify, or wherever you listen to podcasts. Have a question or

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Tim Villegas (26:57):

This podcast is a production of MCIE, where we envision a society where neighborhood schools welcome all learners and create the foundation for inclusive communities. Learn more at mcie.org. We'll be back in a couple of weeks to talk with Genia Stephen, host of the podcast The Good Things In Life.

Genia Stephen (27:20):

All kids being educated together. Not just being placed together, but with real attention to all of the isms, you know, to real attention paid to ableism and racism so that kids aren't just placed in a physical space together, but are truly educated together as a community.

Tim Villegas (27:42):

Thanks for your time and attention. Until next time. Remember inclusion always works.

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