T·H·I·N·K INCLUSIVE

The Think Inclusive Podcast

BONUS EPISODE
Remix: Supporting Autistic People to Create Understanding and Acceptance with Julia Bascom

Audio Transcript

Tim Villegas
From MCIE. Happy spring break to those who celebrate. I totally wasn't going to produce an episode this week. My name is Tim Villegas from the Maryland Coalition for Inclusive Education, and you are listening to Think Inclusive, a show where with every conversation we try 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. You can learn more about who we are and what we do at MCIE.ORG.

It is so great to be back in your feeds this week. Can we have a little check in? How is everyone doing? We are just over 20 episodes this season. It is unbelievable how time has flown. And we have some excellent content for you this month but for the first week of the month I want to try something a little different. Sometime you'll hear a bonus or remix episode like today or sometimes we will have what we call in the biz a "feed drop." Where I introduce you an entirely new podcast by playing one of their episode in our feed. I've already got one lined up for May.

Okay. On to today's episode. I'm going to replay an interview I did with Julia Bascom, the executive director of the Autistic Self Advocacy Network. This interview is from 2017. Wow. That is almost six years ago.

Here's what I cover with Julia Bascom in this episode:
The importance of self-advocacy for autistic people and how it can help create a more inclusive society. The challenges of autistic people having to advocate for themselves, and how they are often left out of conversations that involve the disability community. The need for allies to step up and support autistic people, to create understanding and acceptance.

So if you've been with us for the last few episodes you've heard about our sponsor TogetherLetters and how we are using the newsletters to keep in touch with our Think Inclusive patrons. But have you gone to TogetherLetters.com and setup your group yet? If you have 10 people or less it is FREE. You can't beat that! Try our TogetherLetters with the people in your life today and then let us know how you like it!

Thank you so much for listening.

And now, it is my pleasure to play our remixed interview with Julia Bascom.

Julia Bascom
So ASAN is a national grassroots disability rights organization. And we are a self advocacy organization like it says in our name. And that means that unlike most other autism organizations, we are run entirely by autistic people ourselves. So I'm autistic, all of my staff are autistic. The majority of our board members are on the spectrum, and so on and so forth. We're also the only autism organization that focuses exclusively on the needs and priorities of autistic adults. There are lots of other organizations that focus on families or kids or researchers or what have you. But the needs of adults continue just to be neglected overall, we mainly do policy advocacy and systems change. And we bring a civil rights framework to that work, which we find to be frequently lacking in a lot of other autism groups. So in layman's terms, that means we don't really talk about awareness or about autism for autism sake, we have specific changes we want to see are for our community in terms of inclusion, employment, housing, health care and other policies like that. And I want to take a second to just really emphasize the importance of us being self advocate run, we believe very strongly that the best experts on autism are autistic people ourselves. There's a tendency in our society to talk about autism that actually involving any autistic people into the discussion. And that's a huge problem. And it causes a lot of misinformation about autism and stereotypes and other barriers for autistic people. That's why ASAN's motto is nothing about us without us. First and foremost, we believe that whenever autism is discussed in the media and the halls of power and research wherever people need to be at the table leading the conversation.

Tim Villegas
So that really sets you apart from other organizations. I don't really know of any other organization that has such a, at least for autistic individuals. The focus on self advocacy is is there any or any other organizations so that you can highlight, you know, I mean, it could be autism organizations or not the off the top of your head that focus that their focus is self advocacy?

Julia Bascom
So there's the Autism Women's Network, and that, really is the other main self advocacy organization, they are also self advocate run, they focus specifically on the needs of women and girls. And so they don't have like an adult specific focus. And they do, obviously, a lot of work with families. And if you want to talk to autistic girls, you need to talk to their parents and their families as well. They're a great organization, we do a lot of work with them. There are other self advocacy organizations in the developmental disabilities community. So we do a lot of work with Self Advocates Becoming Empowered, which is for people with intellectual disabilities, for example. But in autism, that is us an AW button. And then there's some state and local groups that are getting bigger and stronger, which is really exciting to see. And hopefully, we'll see some more national groups as a result of that as well.

Tim Villegas

That's fantastic. Now, let's see think inclusive has been around for about five years. But how long has ASAN been around? Because I believe I mean, I feel like it's from the very beginning. There was that I knew about you guys, but and gals. But do you know when did it start?

Julia Bascom
So as an as an organization, this is our 11th year, we had our 10 year anniversary last November, the self advocacy movement, obviously has been around for decades. And then there were there was artistic activism and artistic advocacy before us. So there was Autism Network International and some other organizing that happened both locally and nationally, and even internationally. We've only had an office and a bank account for five years now. Okay. We are still a lot younger than people tend to think. All right.

Tim Villegas
All right. And you are a nonprofit, is that correct?

Julia Bascom
Yes. We are a 501 c3. Okay. Great.

Tim Villegas
So in saying all that. And because we are that, you know, we are I guess celebrating autism acceptance month here at think inclusive? You know, maybe let's talk about one of the biggest misconceptions misconceptions about autism, in your perspective. Sure, don't pick one. Oh, many? Oh, just yeah, just you know, throw a dart. Yeah.

Julia Bascom
Okay, so there are a lot to choose from. I guess sort of, like an overall pattern that I see, one of the things we see happen a lot of the time, is that people hear such scary things about autism. And then they meet narcissistic person, and they hopefully in that interaction, notice that we are people, and that don't quite know what to do with that disconnect between us, you know, being a person, a real person in front of them, and everything they've heard about autism. And so they'll say things like, you know, like, you're autistic. But autistic people don't have feelings, or they don't talk or they don't grow up, or whatever the stereotype might be that they're that they've interacted with. Like I still remember the first time someone who I considered a really good friend said, but you have feelings in my face after finding out I was autistic. And like, I'm not, I'm not sure how someone's supposed to react to that, right. And I think we have this problem where the reality is, there are a lot of different ways to be autistic, just like there are a lot of different ways to have a brain or to be a person. And it doesn't make sense to think that autism is only one thing that that seems to be where a lot of people are at right now.

Tim Villegas
Okay, well, that brings up a good point, because, you know, you have people who say, well, Julia Bascom can articulate herself very well. And she can explain all these wonderful things about autism and you know, how she experiences the world. She is not like my child, my child is nonverbal. Nytro my child, you know, stim so much that, you know, he, he or she hurts himself

or other people, you know, my child has challenging behaviors might you know, so, let's talk briefly or not So briefly, I guess if you aren't what you know, what would you say to people who I'm sure you get this, say, Well, you know, how can you speak for the Autistic community? You know, you are anything like my kid.

Julia Bascom
So, I think there are a few different things to say about that. The first is it's my job. to explain autism and explain autistic people and explain my community's priorities, and I'm good at my job. And I'm sure that many of the people who say these things wouldn't want to say that being autistic precludes someone from being good at their job. Beyond that, it's a pretty common thing in the Autistic community. That is, it's important to remember what you don't know, when you're encountering someone who's able to argue with you about autism, for example, all you know from that interaction is that they're able to have that specific conversation at that specific time, you don't know anything about their medical history, about their developmental history, about what their life is like outside of that interaction, and so on and so forth, we get the kind of emails you're describing pretty frequently. And like, I gotta say, I have yet to see a description of someone. In those emails that doesn't match my life, or the life of one of my staff members. At some point in time. We have board members who are not speaking we have staff who don't live independently, I'm not going to comment on my personal abilities and support needs, since that's private information, but it just doesn't match reality. There's, the reality is that autistic people who support ideas, like disability rights, and neurodiversity, and autism acceptance, and that's most autistic people have a really diverse range of backgrounds and disability experiences, some of us can talk, some of us can't, some of us can live independently, some of us can't, and so on and on and on. And there's this idea that people with a certain kind of disability experience would naturally feel one way about their autism. And people who see more visibly disabled should feel a different way than and in its extreme form, that belief looks like what you just described. And it looks like people saying that if you have any sort of positive, or even just neutral feelings about your disability at all, that you can't be disabled. And of course, that's ridiculous. But it's been a really persistent myth. And I think it's important to know that that's been around for long before AASA. And it's been said, since the self advocacy movement started. And I think it's important to remember that the self advocacy movement was originally led by people with intellectual disabilities who were institution survivors. So this has been around for a long time, regardless of you know, the reality that it is attached to, right. And I guess the last thing I would say is that, I wouldn't say that ASEAN ever speaks for any specific person. But we do speak out, for example, on the right of every person to have a robust communication system, so they can tell us what they think. And I'm pretty comfortable with that, I wouldn't say that I represent every single autistic person in every thought they will ever have. But I am comfortable saying that I represent our communities, right to have these conversations about ourselves.

Tim Villegas
Right, right. Do you do you think that? Do you think that because that, you know, parents, because I'm assuming, I'm assuming and correct me if I'm wrong, that the emails or the pushback that you get from certain people are, or they are advocating or speaking for their

child, right, or for somebody who they know that has that is autistic. And they can't see beyond? You know, what their own experience is? So therefore, they don't have that experience. So then they're saying, well, they're they're trying to reconcile that. Is that Is that fair?

Julia Bascom
That's a challenging question. I think that might be true for some people. And I think that's certainly how a lot of folks perceive that the neurodiversity movement gets a lot of pushback, specifically, from people who believe that vaccines cause autism. Right. And I think that gets a lot more complicated. And then we also overlap just with, you know, the fact that people have bias against people with disabilities. And it's difficult to untangle that.

Tim Villegas
I think it is, I think it's it's definitely difficult. I mean, part of part of what I hope, you know, this conversation and almost everything that we that we publish on the on the site will do is give another perspective so that people can see that there's a wide range of, of perspectives in the disability rights movement. And, and, as far as I mean, that's why that as far as I think, the idea of inclusion, right, we want, we want to have a big tent. You know, we want to have, we want to have discussion. We want to have respectful disagreement and And I want to be able to hear from people who just don't, who just don't understand why people don't like, you know, Autism Speaks. Now we don't, you know, we've been very vocal about that. Some people may not like that about, about us in particular, or and I know that you, the ASAN has spoken out against them as well. But we're, we want people to come to the table and at least listen to each other. So that's why I wanted to have you on because I think it's really important for anyone who's listening to say, look, you know, your experience is different. And that's okay. Here's a person whose experience is different. That's okay. Let's listen and see if we can learn something. So let's lead into this question about awareness and acceptance. So what what do you think, in your opinion, is the difference between autism awareness and autism acceptance? Sure. And just

Julia Bascom
really quickly, I want to say, No, I think having that big tent is important, and we want to reach as many people as possible, but it's also, and I think this gets lost in a lot of our cultural conversations about autism and the way we talk about it as this abstract thing, it is important to remember that we're not disagreeing over pizza topics. We're disagreeing over people's lives and people's rights and how people deserve to be treated. And I think that does require us to think about the conversation a little bit differently than we would think about other kinds of disagreements. In terms of awareness versus acceptance, I think that awareness often lacks some really important context like, Okay, I'm aware of autism. But what does that mean? What do I do with that? Over the last decade, we've seen a lot of awareness campaigns focus on making the public know a few stereotypical facts or alternative facts about autism in a scarier way as possible, like I'm thinking about the on the omnipresent Autism Speaks posters in DC right now, where you see a child in black and white looking away from the camera. And I don't understand why we're trying to make people scared of a kid that's away from the camera. And I

think the consequence of a lot of awareness campaigns is that they do influence how people think about autism. And then when that person has an autistic child, they have already been sort of primed to be scared of their child and scared of that child's disability. And that's the kind of thing that's going to have a huge impact on the parent child dynamic on the kind of life that child has on the expectations that that parent has, and it sets things off just on a really, a really needed and really dangerous starting ground. Acceptance, on the other hand, is, tries to correct for a lot of that, I would say that acceptance is more active, and more clearly values driven. So acceptance means that you know, that I'm autistic, or you know, about autism, and you know that that's okay. Acceptance is about respect, and inclusion and community building. As opposed to thinking, you know, the warning signs for me, and hearing that having a kid like me is more common than being in a car crash or being hit by lightning, or all of these other terrifying things. Does that make sense?

Tim Villegas
Oh, yeah, yeah, definitely. So what is the is it? I guess? What are the current I guess? rates of autism? I don't know how I don't know the best way to say that incidence of autism? Because I believe the CDC, I think the most current is one in 68. Do you feel? Do you feel that is accurate?

Julia Bascom
I think we're getting closer. So a couple of things that will usually say about rates. One, the evidence is pretty clear that we're not seeing like an increase in the percentage of people who are who are autistic, we're seeing an increase in the percentage of people who we are identifying as autistic. Right. And we know and I think this is important to know when we think about specific numbers, that diagnostic disparities are still a huge thing. So we know that it's much harder to get a diagnosis. Once you're an adult, even if you're an adult who's experiencing a significant disability. We know that women and girls are dramatically under diagnosed. We know that children of color are dramatically under diagnosed and often a get diagnosed later, and B are more likely to be diagnosed with other disabilities incorrectly, like intellectual disability or mental health disabilities and so on and so forth. Or seen as just problem kids who get funneled into the school to prison pipeline. I think the numbers are better than they've been in previous years. I think we're getting closer due to having an accurate number, I would expect to see the number go up a little bit more as we correct for those diagnostic disparities, but one in 68 is a lot closer to the only real population level study that was done in South Korea. And that suggested it was one in I think, 38 kids, I can find the study and send it to you. Oh, yeah. And so I think we're gonna get a little bit closer to that. But the numbers have stabilized recently. And I think that's just reflective of the progress we've made and understanding what autism is and identifying people correctly. Right.

Tim Villegas
So let's talk about, let's talk a little bit about recovery. That word recovery, because I know that. And I don't know if you know this about me, but when I first got into working in special education, I actually was a behavior therapist, and I did that for a year. And this was zero, you know, experience working with anyone with disabilities at all. And that that was short lived. And then, you know, fast forward a few years, and I wanted to become a teacher. And looking

back on my training, a lot of the training that I was given was about recovery about students, how do we get our kids that we work with to be and there's this, there's this quote, and I think it's a low vos quote, actually, it's that these kids are going to be indistinguishable from their peers. Right? Yeah. Right. Okay. So it was a going through my teacher training, which was fantastic, because it was really more about more, much more inclusive, as far as how do we look at disability and disability is a natural part of the human experience and stuff like that. So looking back, and going, there's a strong, I guess, way of thinking that, that you can recover from autism. And if you do these things, whether it's, you know, behavioral training, or whether it's diet, or it's, you know, any other medical procedure, that you can get the autism out, or something like that. So do you, do you first of all, think, I mean, I know the answer. But I guess what would you say to people who believe that people can recover from autism, and then also for people maybe who have experienced it themselves and say, Hey, I, I recovered from Autism? I don't know if you get that.

Julia Bascom
So as a matter of science, I think the evidence is fairly clear that that recovery is not a real thing, research on people who have, you know, quote, unquote, lost the label, as that tends to be said, still tend to describe these adults as dealing with anxiety and depression and attention and executive functioning impairments and sensory issues. And a lot of other things that sound like a whole lot of autistic adults that I know. And in reflection of that, the DSM five criteria, also, you know, says explicitly that you can meet criteria based on past developmental history. So you don't have to actively be showing a specific trait in adulthood to count. And that's more in line with how people work. I think you're absolutely right, that recovery is the stated goal of Applied Behavioral Analysis. And that's one of the reasons that ASAN and self advocates generally have such strong objections to it, because just because someone is able to put on a good show, and act indistinguishable from their peers doesn't mean that their quality of life has improved. Or that they aren't experiencing disability or that they aren't still artistic and just really good at faking it. And that's also not like an ethical goal. And it's not a goal that we have for other people. I think it's worth pointing out that I have are a lot of us is other projects with something called the effeminate boys project, which tried to have those same goals of recovery for young men who were thought to who are thought to be gay and young boys. And as a result of that, that became you know, conversion therapy and our society has come a lot further. And I say this is a member of the LGBT community and saying, Well, that's not okay. And that's not ethical. And so it's very confusing to me. That is not necessarily agreed to be ethical anymore for someone to spend a lot of time training me to act straight, but it is okay for them to spend a lot of time training me to also act like someone I'm not, and suppress really natural and fundamental ways of interacting with the world and thinking and being and communicating so that I can act non autistic, that just, that just isn't an ethical thing to do to someone. Right. Right. In terms I mean, you asked about individuals, and I would never argue with an individual who refers to themselves as recovered. That's not my place. But as an advocate, I'd rather focus on the culture that makes people feel the need to say that about themselves.

Tim Villegas

That's a good point. Yeah. Why don't we, let's pivot to inclusion, and inclusive education. Because along with that discussion of, I guess, training students or kids to be, or act a certain way. I think that when we're looking at inclusive education, specifically for autistic students, there is a big baby. With them being included in any sort of general ed setting, behavior tends to be the thing that everyone is kind of, up in arms about or afraid of, or tends to be the challenging issue. Because while this student is either, you know, having, you know, quote, unquote, meltdowns, or they're making a lot of noise, or they're having a hard time with, you know, XYZ. And, and so, people will say, you know, to me as an inclusion advocate, wouldn't these kids be better served in a self contained environment where they're comfortable, you know, safe? You know, and stuff like that? What I guess what is your opinion about inclusive education? And do you feel like there's a any sort of reason why you would want to have a separate environment for autistic students?

Julia Bascom
Sure. So in terms of, of inclusion, we think, and I think this is a really important baseline for us, generally, there's not some sort of bar people have to meet before they deserve to have their rights on it. So inclusion is a civil rights in this country. And we would argue that it's a human rights. And so conversations about whether or not someone is x enough to be in an inclusive setting, we tend to find not a useful way of coming at that. If people we know that people who are having a lot of challenging behaviors, and so on and so forth, are reacting to something, they're not doing things for no reason. And that usually, what's needed is either medical support for an issue that's gone undetected, and this causing someone to be in pain. And or, and it's usually access to a functional communication system to some alternatives. Besides to be to when people have those tools, they tend to be able to regulate a lot better and to participate more. From an advocacy perspective, we know that segregated or substantially separate environments just breed more segregated environments. And often these settings get introduced or excused as Playstations. And places for people to get more training and get up to some sort of bar. You know, we've seen that historically, but we also know, since we've been doing this for a while that it's exceedingly rare for someone once they've been segregated, to be permitted back. And that's just not a thing that happened when you look at the whole picture. So as a matter of public policy, as civil rights advocates, we really just have to be essentially unilaterally opposed to those separate environments, because it's really hard to ensure people's rights otherwise. At the same time, I mean, it's not a secret that most schools are 100% inclusive, and that students and teachers and families are often asked to make the best of a bad or even just an imperfect situation. And I think that's a more personal decision.

Tim Villegas
Yeah, yeah, I definitely see that. I mean, I see that every day. And I as I've seen that every day since I've been an educator. And and what I typically do is if if I am with a family who, and we're lucky Seeing towards more inclusive placement or setting and the family is 100%. And then then we're going to do that. But there are also times where parents and families don't want that. And they they like the system the way that it is. And they sit and they say, No, I don't want that. I want my student in a self contained classroom, and I want them to get, you know, X amount of attention and, you know, X amount of support. So as a as an advocate for inclusive

education, in, I have a lot of cognitive dissonance, because I want certain things from my family. And I see, you know, like, like what you said, the bigger picture where, you know, I see a world where it's just not an option. So then, therefore, we have to make it work. And because it is working all around the country, and that you can point to certain schools and certain districts that are doing that. But you can't, you know, force I can't force my administration or the district or the state to make the changes that I want to see. And so, so yeah, it's a very personal decision. And fortunately, we have I mean, we have the Individualized Education Program, which is supposed to be an individual and personal decision. Based on based on theory, it's a beautiful theory. That's right. Yeah. But, but no, that I think that clarifies pretty well, you know, your position on that. And I would say that we're very much aligned in that in that respect. So if you don't mind can maybe let's talk about, I guess your personal experience with autism. And so I mentioned an IEP. So is that something that you experienced when you were growing up as an autistic person? Or did you get diagnosed later? Or what was it like growing up?

Julia Bascom
I actually don't usually talk about that publicly on media just because often a self advocate. Once you start talking about that, that's all you're allowed to talk about. So I've drawn that line. Okay. I'd be happy to talk with you about that offline.

Tim Villegas
Okay, no problem. Can we talk about the maybe some of the other questions about about? So you don't want to talk about any of your personal experience with autism? Okay, that's fine. No worries. So let's, why don't we do this? Let's, let's, I guess, close our eyes and travelled 20 years into the future. And let's say what kind of world would you want to see? We know when you open your eyes and you traveled with the work with ASEAN has done the work with other disability rights advocates? You know, what kind of world would you want to see in 20 years?

Julia Bascom
Sure. Okay. So, first, I'm hoping for a world where parents have stopped letting their kids get sick and die from preventable illnesses because they're so scared of my disability. I'm hoping for a world where autistic kids can grow up, loving themselves and feeling safe in their bodies and seeing autistic adults living lots of different lives, and having lots of different kinds of jobs. I'm hoping for a world where autistic people living great lives and also meeting day to day support, or communicating without speech is unremarkable, and normal and honestly kind of boring, where we've really gotten past that idea that you can't have a good life and also the support. And I'm hoping for a world where my community can live freely without fear of violence and the all of the amazing and beautiful possibilities that we can be. I don't know if we'll get there in 20 years, but I think we can get closer.

Tim Villegas
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