



The Think Inclusive Podcast

Season 5, Episode 1

Julia Bascom | Autistic Self Advocacy Network

Audio Transcript

Julia: Hi, I'm Julia and you're listening to the Think Inclusive Podcast.

Tim: Recording from my office in beautiful Marietta, GA...you are listening to the Think Inclusive Podcast (Episode 13). We are starting a new series of podcasts beginning with this one (fingers crossed). We would love to get them out to you every month but we will see how that goes. Today we have Julia Bascom from the Autistic Self-Advocacy Network. We talk about Autism Awareness...or is it Autism Acceptance?? Also, we travel 20 years into the future to talk about what Julia envisions for our world and autistic people. After the podcast, please stop by our brand new Think Inclusive Store (<https://thinkinclusive.us/shop>) where podcast listeners can take 30% off their order with Promo Code: POD30. So without further ado...here is the interview.

Tim: Perfect. Hello and welcome to the Think Inclusive Podcast. My name is Tim Villegas and I will be your host. Today I'm going to be speaking with Julia Bascom who serves as the Executive Director at the Autistic Self Advocacy Network. Previously, she did state level work in her home state of New Hampshire where she served on the Developmental Disabilities Council and co-led an interagency team to revitalize self-advocacy within the state. In addition to her work with the ASAN Julia edited Loud Hands Autistic People Speaking an anthology of writings by autistic people and currently serves on the Disability Equality Index Advisory Board. The 01:08 National Disability Advisory Council and the Board of Advance CLASS Inc. Welcome to the program. Thanks for being here.

Julia: Thank you for having me.

Tim: It's April which means it's Autism Acceptance Month or Autism Awareness Month or Autism something month. The reason why I thought it would be good for you to be on the program is I wanted our listeners to understand what is the Autistic Self Advocacy Network and why is it different from many other organizations that promote autism awareness or acceptance.

Julia: Sure. 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 ourself. 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, their kids, their researchers, their what have you but the needs of adults continue 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 mean we don't really talk about awareness or about autism for autism sake we have specific changes we want to see for our community in terms of inclusion, employment, housing, healthcare and other policies like that and I want to take a second to 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 is a tendency in our society to talk about autism without 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, in research autistic people need to be at the table leading the conversation.

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

Julia: There is 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 an adult specific focus and they do obviously, a lot of work with families but if you wanted 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-advocacy becoming empowered which is where people with intellectual disability for example. But, in autism, it's just an AW ban and so there is some seat and local groups that are getting bigger and stronger which are really exciting to see and hopefully we'll see some more national groups as a result of that as well.

Tim: That's fantastic. Now, Thinking Inclusive has been around for about five years but how long has ASAN been around. I feel like it's from the very beginning that I knew about you guys and gals but when did it start?

Julia: ASAN as an organization this is our 11th year. We had our 10-year anniversary last November. Self-advocacy movement obviously, has been around for decades and then there was Autistic Activism and Autistic 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 so we are still a lot younger than people tend to think.

Tim: And you are a non-profit? Is that correct?

Julia: Yeah, we are a 501(c)(3).

Tim: So, in saying all that and because we are celebrating autism acceptance month here at Think Inclusive let's talk about one of the biggest misconceptions about autism in your perspective.

Julia: Sure, just pick one because there are so many? There are lots to choose from. An overall pattern that I see, one of the things we see happening a lot of the time is that people hear such scary things about autism and then they meet an autistic person and hopefully in that interaction notice that we are people and that they don't quite know what to do with that disconnect between us being a real person in front of them and everything they've heard about autism and so they'll say things 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've interacted with. I still remember the first time someone who I considered a really good friend said, but you have feelings? MIA after finding out I was autistic. I'm not sure how I was supposed to react to that 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 but that seems to be where a lot of people are at right now.

Tim: Well, that brings up a good point because you have people who say, well, Julia Bascom can articulate herself very well and she can explain all these wonderful things about autism and how she experiences the world. She is not like my child. My child is nonverbal, my child stims so much that he/she hurts himself or other people. My child has challenging behaviors. So, let's talk about what you

would say to people who I'm sure you get this who say, well, how can you speak for the autistic community. You aren't anything like my kid?

Julia: So, I think there are two different things to say about that. The first is it's my job to explain a lot to some 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 saying in the autistic community that it is important to remember what you don't know when you're in encountering someone who is 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 email you're describing pretty frequently and I have to say I am 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 four members who are nonspeaking, we have staff who don't live independently. I'm not going to comment on my personal abilities and support needs and such private information but it doesn't match reality. The reality is that autistic people who support ideas like disabilities rights and their diversity, and autism accepted and that's most autistic people. Have a really diverse range of background 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 then this idea that people with a certain kind of disability experience would naturally feel one way about their autism and people who seem more visibly disabled should feel a different way. In its extreme form that belief looks like what you just described. It looks like people saying that if you have any positive or even just neutral feelings about your disability at all that you can't be disabled and that's ridiculous but it's been really persistent and I think that it's important to know that that's been around for long before ASAN 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 the reality that it is attached to and I guess the last thing I would say is that I wouldn't say that ASAN 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 community's rights to have these conversations about ourselves.

Tim: Do you think that because parents because I'm assuming, correct me if I'm wrong that the emails or the pushbacks that you get from certain people they are advocating or speaking for their child or for somebody who they know that is autistic and they can't see beyond what their own experience is so, therefore, they don't have that experience so then they're trying to reconcile that. Is that fair?

Julia: That's a challenging question. I think that might be true for some people and I think that 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 and I think that gets a lot more complicated and then we also overlap just with the fact that people have a bias against people with disabilities and it's difficult to untangle that.

Tim: I think it is. I think it's definitely difficult. Part of what I hope this conversation and almost everything that we publish on the site will do is give another perspective so that people can see that there is a wide range of perspective in the disability rights movement and as far as I think the idea of inclusion we want to have a big tent. We want to have discussions, we want to have respectful disagreements and I want to be able to hear from people who just don't understand why people don't like Autism Speaks. We don't. We've been very vocal about that and some people may not like that about us in particular and I know that ASAN has spoken out against them as well but 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 your experience is different and that's okay, here is a person whose experience is different and 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 do you think in your opinion is the difference between autism awareness and autism acceptance?

Julia: I just really quickly want to say 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 one 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 toppings. We're disagreeing over people's lives and people's rights and how people deserve to be treated and I think that that requires 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. 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 focus on making the public know a few stereotypic facts or alternative facts about autism in a scary a way as possible. I'm thinking about the omnipresent Autism Speaks posters in D.C. 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 who is looking 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 primed to be scared of their child and scared of that disability and that's the thing that is going to have a huge impact on the parent/child dynamic, on the life that child has or the expectation that that parent has and it sets things off on a really negative and really dangerous starting ground. Acceptance, on the other hand, is trying to correct a lot of that. I would say that acceptance is more active and more clearly value-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 thinking you know the warning signs for me and figuring that having a kid like me is more common than being in a car crash or being hit by lightning or all these other terrifying things. Does that make sense?

Tim: Definitely. So, what are the current rates of autism? I don't know of the best way to say that. Incidents of autism? Because I believe the CDC, I think the most current is the 1 in 68, do you feel that is accurate?

Julia: I think we're getting closer. A couple of things that we'll usually say about rates. One the evidence is pretty clear that we're not seeing an increase in the percentage of people who are autistic we're seeing an increase in the percentage of people who we are identifying as autistic 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 is experiencing significant disability. We know that women and girls are dramatically underdiagnosed, we know that children of color are dramatically underdiagnosed and often A. get diagnosed later and B. are more likely to be diagnosed with other disabilities incorrectly like intellectual disability, or mental health disability and so on and so forth. Or seen as just problem kids who get funneled into the school to break the pipeline. I think the numbers are better than they have been in previous years. I think we're getting closer to having an accurate number. I would expect to see the number go up a little bit more as we correct those diagnostics disparities but 1 in 68 is a lot closer to the only real population-level study that was done in South Korea and that suggested that in was 1 in 38 kids. I can find the study and send it to you. And so, I think we're going to 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 in understanding what autism is and identifying people correctly.

Tim: Let's talk a little bit about recovery. That word recovery because I know that I don't know if you know this about me but when I first got into working in special education I actually was a behavioral therapist and I did that for a year and this was zero experience working with anyone with disabilities at all and then that was short lived and then 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 how do we get our kids that we work with to be, and there is this quote and I think it's a Lovass quote actually. It's that 'these kids are going to be indistinguishable from their peers'. It was going through my teacher training which was fantastic because it was really much more inclusive as far as how do we look at disability and disability is a natural part of the human experience. So, looking back and going there is a strong way of thinking that you can recover from autism and if you do these things whether it's behavioral training or whether it's diet or any other medical procedure that you can get the autism out or something like that. Do you, first of all, think... well I know the answer but what would you say to people who believe that people can recover from autism and then also for people who have experienced it themselves and said, hey I recovered from autism. I don't know if you get that.

Julia: As a matter of saying I think the evidence is very clear that recovery is not a real thing. Research on people who has quote on quote lost the label as that tends to be said still describes these results as dealing with anxiety and depression and executive functioning impairment 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-5 criteria also says explicitly that you can meet criteria based on past developmental history so you don't have to be actively showing a specific trait in adulthood and that's more in line with how people work. I think you're absolutely right that recovery is the stated goal by behavioral analysis and that's one of the reasons that ASAN and self-advocates generally has 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 autistic and just really good at faking it and that's also not an applicable goal and that's a goal that we have for other people. I think it's worth pointing out that Lovass's other project was something called The Feminine Boy Project which tried to have those same goals of recovery for the young men who were thought to be gay young boys and as a result of that, that became conversion therapy and our society has come a lot further and I say this as a member of the LGBT community in saying that's not okay and that's not ethical so it's very confusing to me that it's not necessarily agreed to be ethical. I mean 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 isn't an ethical thing to do to someone. 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: That's a good point. Let's pivot to inclusion and inclusive education because along with that discussion of 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 maybe with them being included in any sort of general Ed. setting behavior tends to be the thing that everyone is up in arms about or afraid of or tend to be the challenging issue because this student is either having quote on quote meltdowns or they're making a lot of noise or they're having a hard time with XYZ and so people will say to me as an inclusion advocate wouldn't these kids be better served in a self-contained environment where they're comfortable and safe? I guess what is your opinion about inclusive education and do you feel like there is any reason why you'd want to have a separate environment for autistic students?

Julia: In terms of inclusion we think and I think this is a really important day plan for us generally there is not some sort of bar people have to meet before they deserve to have their rights honored so inclusion

is a civil rights in this country and we would argue that it's a human right and so conversations about whether or not someone is X enough to be in an inclusive setting we tend to find that a useful way of coming at that is we know that people who are having a lot of challenging behaviors and so on and so forth are reacting to something. They are not doing things for no reason and that usually what's needed is either medical support for an issue that's gone undetected and is causing someone to be in pain and/or is usually involving access to a functional communication system to some alternative besides speech and when people have those tools they tend to be able to regulate a lot better, to participate more. From an advocacy perspective, we know that segregated or substantially separate environments just breed more segregated environment and often new settings get introduced or excused as play stations and places where people get more training and get up to some sort of bar. We see that historically but we also know since we've been doing this for a while that it's extremely rare for someone once they've been segregated to be permitted back in. That's just not a thing that happens when you look at the whole picture so as a matter of public policy as civil rights advocates we really 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 aren't that 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: Yeah, I definitely see that. I see that every day and I've seen that every day since I've been an educator and what I typically do is if I'm with a family and we're looking towards more inclusive placement or setting and the family is 100% in then we're going to do that but there are also times where parents and families don't want that and they like the system the way that it is and they say no I don't want that. I want my student in a self-contained classroom and I want them to get X amount of attention and X amount of support. So, as an advocate, if we're inclusive education I have a lot of cognitive dissonances because I want certain things for my family and I see what you said the bigger picture. I see the world where it's just not an option. So then, therefore, we have to make it work because it is working all around the country in that you can point to certain schools and certain districts that are doing that but I can't force my administration or the district or the state to make the changes that I want to see and so it's a very personal decision. Unfortunately, we have the individualized education program which is supposed to be an individual and personal decision. It's a beautiful theory. I think that clarifies pretty well your position on that and I would say we are very much aligned in that respect. So, if you don't mind let's talk about your personal experience with autism. So, I mentioned an IEP 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: I actually don't usually talk about that publicly on media just because often the self-advocate once you start talking about that, that becomes all you're allowed to talk about so I've drawn that line but I'd be happy to talk with you about that offline.

Tim: Okay, no problem. Can we talk about some of the other questions? So, you don't want to talk about any of your personal experience with autism?

Julia: No.

Tim: Okay, that's fine. No worries. Let's close our eyes and travel 20 years into the future and let's say what kind of world would you want to see when you open your eyes and you've traveled with the work that ASAN has done, the work with other disclosure rights advocates, what kind of world would you like to see want to see in 20 years?

Julia: 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 jobs. I'm hoping for a world where autistic people living great lives and also needing 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 need support. I'm hoping for a world where my community can live freely without fear of violence and see 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: That is our show. We would like to thank Julia from the Autistic Self-Advocacy Network for joining us. Make sure you check out their website: <http://autisticadvocacy.org> and you can find them on Facebook and Twitter. Follow Think Inclusive on the web at thinkinclusive.us as well as Twitter, Facebook, Google+, and now Instagram! Today's show was produced by myself talking into usb headphones, a MacBookPro, garageband, and a skype account. You can also subscribe to the Think Inclusive podcast via the iTunes music store or Podomatic.com (the largest community of independent podcasters on the planet) from Marietta, GA...please join us again on the Think Inclusive podcast...thanks for your time and attention.

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