

The Autistic Life Podcast

EP02 Transcript

Host (00:28):

Hi friends, welcome to The Autistic Life podcast. This is episode two and today I'm less scared, not "not scared", I think, but definitely less scared than the last time. Thank you so much to everyone who reached out and told me that you really liked the first episode and to everyone who shared the news. I appreciate you so much because I was incredibly scared of posting that. And actually the day before posting the episode, I was like, "Nope, I hate it. I hate it. I need to do it again." but that was exactly what I was talking about in the episode that perfectionism freezes me. And I'm so glad that I did it anyway. So thank you so much for that. It means so much. Today's episode is a good one. I think, I really hope it is. I'll be talking about ways of communicating your needs and challenges to people which hopefully can lead and open a conversation for potential accommodations.

Host (01:51):

The other day I asked on Instagram, what topics you would like to listen here in the podcast? And this came, this one came up like a lot highly requested. So yeah, stick around to hear my thoughts on it. And I hope you like it. Quick shout out to Tiimo for sponsoring this podcast. In case you don't know, Tiimo is a paid subscription app that helps you organize your life, and it can help you create routines, checklist and keep up with everything going on with your life in a very visual and helpful way. While everyone can use it, obviously it was really created with the neurodivergent brain in mind. So that's why it has all of these visual ways that it can help you keep track of what's happening in your day. And it's

amazing. It's such a very app and if that's something that you're interested in, please head over to tiimoapp.com

Host (03:06):

If you want to learn more about them, or you can check my show notes for more information about them. Just a quick disclaimer, before we jump right into the episode, as with everything I put out there whether that's on Instagram or on Patreon, or here on the podcast, this is not fixed science. My experiences may be entirely different from yours, since Autism is a spectrum and there's hundreds and hundreds of factors that can impact the way Autism presents in a human. So please just take what resonates, if anything resonates and leave the rest. Both experiences are valid and every experience in between is also valid. So please keep that in mind. If any of this, if some things resonate and others are like "uh I don't agree," that's fine. You just, you just leave that and take the rest. So as I was saying the topic of communicating your needs challenges in order to access accommodations kept coming up on Instagram.

Host (04:20):

And I think that's a great thing to discuss since it's not an easy thing to do at all. This is how I understand things by the way, and what my experience tells me. So again, this is not a manual. I feel, I feel the need to clarify this a lot because I know this topic is complicated and it's impossible to cover everyone's experiences. So please, please, please please know, this is not fixed science. So, how I understand things is that I would say the first thing that we should do before communicating our needs or challenges or both is to figure those out. And I know this may sound obvious to some of you, but many Autistic people have challenges with recognizing our needs, especially if we are asked about

them unexpectedly. Sometimes people ask me things I know I know, but I can't access them when being asked about them with some degree of pressure to get an answer out of me.

Host (05:38):

My brain just kind of shuts down. So I think that's like the very first step of this journey of communicating your needs and struggles is to just learn about them. Something that has helped me is to keep track of them. So if writing something that you, that you like doing, you can write those down or take the time to discover them so that when you are asked, "Hey, what do you need?" or "how can I help?" Those questions aren't so broad and overwhelming that makes your brain shut down again. I know it sounds obvious, but seriously I know that some, some of you also get this, that you are asked something that you should know like you, and, you know you know, but it's just your brain shuts down and it happens. So I think that's very important. As I see it, when it comes to potential accommodations that an autistic person may benefit from this can include different areas, such as sensory processing, executive functioning or cognitive skills.

Host (07:04):

However you want to call those emotional processing, social interactions. There's, there's a bunch of areas that could be covered. So communicating those can bring up different conversations and different types of accommodations, obviously. I'm going to try to touch up on some of those, so you can get an overall idea of what I mean, but obviously this is a hundred percent on you and depends on a hundred percent on your ways of existing and your preferences and your own brain. So again, if this doesn't resonate, just

don't take it, that's it? Oh, and before doing that, I feel the need to say that when I say accommodations, what I mean is any possible changes that could be done to make the person feel more comfortable. So I feel like when we talk about accommodations or at least this is me, maybe this is just me, but I feel like when we talk about them, we, I, like, I imagine like a big corporate thing or maybe like college accommodations or work accommodations.

Host (08:26):

And it's just like very like it belongs to those spaces. But actually accommodations can be done at home. And if you, for example, if you have a partner, they can also accommodate you. So it's not just a thing that it can help you like in work and school environments, again, maybe obvious, but I don't know. It wasn't obvious for me. So I wanted to say that. Okay, so let's start with sensory processing when it comes to communicating your sensory needs, so you can access accommodations. I found that it can be very hard for neurotypical people to understand the concept of sensory overload. And I'm, I'm saying neurotypical people, because I know that so many non-Autistic people such as people with ADHD or sensory processing disorder, or just so many other things also experience sensory overload and they do get it.

Host (09:41):

So when it comes to bringing this up with neurotypical people, it can be difficult. Some might get it instantly but others might not, which can make the conversation a lot more complicated. From personal experience, I've found that the more examples you can provide to help someone understand what you go through, the easier it is for them to understand and to be understanding about it. So, for example, I'm very sensitive to loud noises and several voices at the

same time. And even like repetitive sounds such as typing on a keyboard like that just it's, it can be super overloading for me. And I remember that when I asked to wear my noise canceling headphones during an exam in college, that we were supposed to do it in our computers, therefore there was going to be like 30 people -- well, maybe less because it was during the pandemic, but maybe like 20 people, it was a, it was a large classroom -- but it was like 20 people all typing at the same time.

Host (11:15):

And yeah, I was not going to be able to, to concentrate and do my, my exam. So I asked, I asked to use my, noise-canceling headphones and they said, yes, they were super okay about it. But some of my classmates were curious about it. It wasn't like from a bad place. Like they, weren't curious just to be like, "Oh yeah, why do you need that?" No, it was more like, "Oh, hey, can you explain that to me? I'd like to know" which was all very cool. And I said, "well, when these sounds start to happen around me, it feels like all the sounds take over my brain and my thoughts and the longer I'm exposed it, the more focused is placed on those sounds until I can't think of anything else." And then the sensory overload happens. And then all of those physical symptoms that we experience from sensory overload.

Host (12:28):

But for me, it starts right there. Like there's a sensory input that just takes over my brain and that's all I can think about. And I said that to them and their reaction was like, "Whoa, yeah, you should use them." And they were able to empathize with me because I provided a visual image and they were able to imagine how it would feel to experience sensory overload. Of course this doesn't

work with everyone. Some people are just not very good people and won't believe you. But I found that providing an example or a visual aid helps them understand what you need your accommodations in the first place. So I would have that conversation about my sensory needs on my sensory challenges, I would start with that. I would provide examples and I would do my best to just try to help them imagine what it feels like to me.

Host (13:46):

And when it comes to what accommodations you might benefit from when it comes to your sensory needs. Well, it depends on you. And it depends on the setting and it depends on so many things. So, again, not a manual. It can't be done because every Autistic people, every neurodivergent people, we have different sensory profiles, which means that we seek different sensory inputs and we avoid different sensory inputs and those two fluctuate and change over time. And just, it's a mess, to be honest, in terms of trying to make it a fixed science because it's definitely not. So yeah. What type of accommodations? It depends a hundred percent on the person that you are accommodating. But that said some of the most common ones, I guess I would say that for example, at schools, sensory aids like noise-canceling headphones, or ear plugs, tinted glasses, stim toys, chew toys, all of those things can be very helpful since it can help us reduce like harmful sensory input.

Host (15:21):

And it can also help us regulate in case we can't really remove ourselves from that input. At least we can just, we have a few tools to, to regulate ourselves. At work we can request similar things plus maybe discussing your experience with meetings or activities that just might be too sensory overwhelming for you.

And at home, you could combine both things like for example, the usage of sensory aids and potential accommodations such as taking breaks to avoid sensory exhaustion or skipping certain activities that make you uncomfortable. Things like that. On a similar note, I think it's easier when we explain things to people in a way they can understand what we find challenging. Like why. Sometimes when we say "I struggle with this," we, we often receive very invalidating comments such as "yeah, well, we all struggle with something sometimes." And yeah, that's not how it works.

Host (16:42):

And ideally we are going to want people not to say that, but since that's not entirely realistic, because it does happen, I believe that when you provide examples, you have more chances of people understanding you. For example, when I found out I was Autistic, one of the things I told my mom was that I didn't want to go to family gatherings anymore because it was too exhausting for me. The masking, the sensory overload, just the emotional toll, the anxiety, it was way too much and simply not worth it. And I told her "for them, it's just a four hour gathering tops. For me, it's the anxiety of the days before the gathering and then recovering two days later." So it's not as simple as just going to a gathering. And she totally get that. And so I think that providing an explanation, like as to what is it that we experience it can be very helpful for people to be more understanding.

Host (18:04):

I really want to acknowledge that we shouldn't be doing that. We shouldn't need to explain ourselves. Again, ideally we would want people, if we say that we struggle with something that they just believe us and trust us. But yeah, that's

not the society we live in. And until then I think that it's important that we have these little tools so we can make our lives more comfortable. So if you're thinking, "Oh my God, that's so exhausting. Why are you even like talking about explaining things?" Well, it's because of that. I do believe that we shouldn't be doing that at all. I think that it's not on us. So yeah. I also wanted to say that because it's, it's important to say, I think, okay. So, in terms of executive functioning or cognitive skills or cognitive functioning, I don't know how you want to call them.

Host (19:17):

I really want to start by defining them just in case some of you don't know what those are. So essentially the executive functions are a set of cognitive skills that are responsible for helping us regulate and control and manage our thoughts and actions. Every human on Earth has a different executive functioning profile, which may and often does change throughout our lives. So what executive functioning englobes is all of these skills, such as attention and memory and planning and organization and emotional regulation and cognitive flexibility and impulse control. So yeah, so many, so many skills. So as you can see the impact in all aspects of our lives, all of them. Autistic people, as well as other Neurodivergents, we often have a different executive functioning profile in comparison to neurotypical people. So for example, think of our ability to hyper-focus or how many of us have this really amazing memory or some very cool organizational skills.

Host (20:48):

Some of us have great executive functioning skills but others not so much. And we may benefit from accommodations in our lives. And how I usually approach

this, these conversations is how I do the same thing. Like what I mentioned with our sensory needs. Although, I do recognize that when it comes to executive functioning skills, it's a bit more complicated because of how society is. Yeah. And period, how society is. There's a lot of pressure around what productivity should look like and anything that is below that standard is considered lazy. And that's simply not true at all. Just because someone has different functioning rhythms, it doesn't mean someone is lazy or won't get anything done sometimes in order for the person to access their rhythm, they need accommodations. So yeah, there's just, these conversations are difficult because again, not only we have that element of people not understanding that

Host (22:16):

we just process things differently. And, but also because we all have an executive functioning profile, people often think that you're just not trying enough or that you are just not putting effort on doing things. And that's not how it works. Imagine if we would tell neurotypical people like, "Hey, how come you can't hyperfocus? What do you mean you can't dive into a project and just forget about the entire world? What do you mean you can't do that? You need to work on that. You need to put some effort." It just, it makes no sense because that's not how their brain works. So when discussing these things that as you can see, organizing memory focus, these are all skills that are involved in productivity. So it's, it's really hard to talk about these things when we are being analyzed from that neurotypical standard.

Host (23:37):

So something that I did with one of my professors at college was to ask her if she could make the exam more clear and straightforward, as opposed to having

broad and open-ended questions. And I explained to her why. I told her something like, "if you want me to define a concept, cool, can you provide more details? Because my brain instantly comes up with all the ways that I could answer that question and I lose time trying to choose which one is the best because you haven't specified what is it that you want." And she understood that because I provided an argument. I provided a reason. It wasn't like, "I need more time because I say so", or "I need more time because I'm Autistic." It was more like, "this is a genuine problem that I have, and this is how my brain works

Host (24:37):

when you do these things and you don't provide enough information, this is how I process things. I'm telling you my exact thought process so that you can see that it's not how you do things so it's different." And it worked.

Host (24:58):

So, here's another reason why these conversations can be difficult to have. We as Autistics often get stuck on it, on asking, asking for accommodations, because in order to say something like that, like the argument that I provided my professor, we need to know why is it that we struggle with what we struggle in the first place. And I think many of us don't reach the point of asking for accommodations, not because we don't need them, or because we wouldn't benefit from them, but because, well, one, we are not used to having them, but that's another topic for another episode.

Host (25:41):

And two, because we genuinely don't know why some things are hard for us. So that's why I said that it's important that we know our needs and we know what

we struggle with. Because yeah, if, if we don't know why life is being hard for us we, we won't know how to make it better or communicated to others so that they can help us make it better. I found that introspection and self-awareness are two great things that can help us with this. And they can be trained like by activities, such as journaling about yourself, being aware of your challenges and going through them to understand yourself better. It can also help learning about other Autistic people's experiences so know what resonates with you and what doesn't. So I highly recommend just to keep track of that whether that's saving posts or just like keeping it in a journal or something.

Host (26:56):

I highly recommend doing that again. This is super hard, so don't feel frustrated if you are like blank right now, and can think of anything you struggle with. It often comes to you when you are in that moment, if that makes sense. Many times I get frustrated or go from zero to a hundred when it comes to emotions and it's, it's only then that I realize that I find it challenging to regulate my emotions. So if you are like, "yeah, I'm not sure what, what is it that I need" just don't stress about it. It will come to you. Sometimes, it's just seeing it reading on a post, like maybe you're on Instagram and someone puts it into words and you're like, "yes, that that's me, that's me." I'd gotten that so many times. So yeah, don't just don't stress about it.

Host (28:06):

So, some accommodations that you can benefit from when it comes to executive functioning skills can include asking for more time to do certain tasks, asking for clear or clearer instructions, asking for head-ups, for example, to avoid feeling frustrated or distressed by changes or things like that. Some

people may not understand this, especially when it comes to, for example household chores. I received messages from people that say things like, "Hey, how can I make my parents understand, or my partner understand, or my roommate understand that I can't do the dishes because it's sensory overwhelming for me so I avoid the task as much as I can." And I say, literally say that, and I know this sounds way easier said than done. Just say that exactly like that. Just tell them exactly what makes the task challenging so that they can understand that it's not you, that you are being lazy as we are often get labeled. And maybe you can offer to do another task that is less overwhelming for you. I've found that people interpret executive functioning challenges as excuses instead of an explanation. So I think that suggesting to do something that you don't have trouble with or less trouble with can help them see that you are actually open to do it. And it's not a matter of you wanting things your way, it's as genuine thing that you struggle with and that you just don't feel comfortable doing.

Host (30:06):

Yeah, and it's not a matter of being lazy or anything. It's just different wiring. And again, for the zillion time. And I think I will say more. This is super hard, not a fun conversation to have, not everyone gets it. And there's, I think that's where the raising awareness comes in. The work that many of us do is to raise awareness on these very real challenges that perhaps are not well-known by neurotypical people and are usually misread as something entirely different such as, as I said being like, "Oh yeah, you're just not making enough effort. You are not trying enough." Yeah. That's not how it works. This is a real thing. So yeah, I think that it's, again, not a fun thing to say. It's hard and sometimes we may provide all the explanations and all the visual images and just everything

and people won't still get it. It sucks, but it's true. And for last, I wanted to talk about everything that englobes emotional processing and social interactions. I wanted to add this one because I think it's important that we communicate how we process things and what parts of our divergent brain kind of make it more difficult to get our point across or understand someone else's point of view.

Host (31:55):

I think that the neurodivergent brain is so misunderstood because we continue to try to understand it from a neurotypical point of view and that won't lead us anywhere at all because, and, and I think that's the main reason why we continue to talk about neurodivergence is in general as deficits and disorders and all of these things that are very pathological instead of differences. And I think that the main thing is that we talk about it about those from that place, that place of, "Oh, you are not normal. You aren't like the rest of us." And this like standard thinking it makes people expect that the other person that they are going to talk with is going to be the same as them. So when neurotypical people encounter people like us that have all of these common traits, like literal thinking and, our differences in communication, emotional processing and so many things it can lead to a lot of misunderstandings.

Host (33:23):

For example, I've kind of gotten used to when I'm talking to someone and for whatever reason, whether that's because I'm uncomfortable or just anxious, or honestly, I want to focus on what the person is saying, I avoid eye contact. And I've gotten used to telling people "I'm not looking at you, but I am listening to you" just so that they know, and they don't jump into any conclusions because

that's something that I have experienced before people being like, "look at me when I'm talking to you." Yeah, but I'm, I'm listening. If I, if I look at you, I won't be able to listen. But yeah, people don't know that apparently. Because again, they expect the other person to be the same as they are. And we are all different. So yeah, I've gotten used to saying that. And again, for the zillion time this should not be necessary because in an ideal world, people don't make such a big deal out of eye contact or people don't assume that just because often when they don't make eye contact, it means that they are not listening to the other person.

Host (34:49):

It doesn't mean when another person doesn't make eye contact, they aren't listening to you, but yeah, we are not there yet. Hopefully we will at some point, but yeah, when it comes to these things personally and again, personally, this is what I do. So I do my best to anticipate any comment that comes from simply not knowing how Autistic, neurodivergent people can be. I know certain things such as eye contact and the tone of my voice and my facial expressions can be misread and misinterpreted by people which can lead to arguments and sadly, a lot of fallouts. So just like with the other two examples, what I do is essentially explain to them how I work and I acknowledge that it might not be something they are used to. For example, when I told my classmates that I was Autistic, I told them, "so maybe I come across as blunt or insensitive because I don't always pay attention to my facial expressions while I'm talking

Host (36:03):

I focus on talking, and many times I'm labeled as angry or moody and I'm not angry normally nor insensitive. It's just that, that's how I work. It's just a

different wiring. Please keep that in mind before jumping to conclusions." And yeah, a lot of them understood that. Some of them didn't and they continue to just take it personal. But I've learned to make amends with that, which prompts me to say this: some people just won't get it and they won't believe you. They will invalidate you. And it sucks so much. And honestly, I'm so sorry. I'm so, so sorry. If you have ever communicated your struggles, your challenges, your needs, and someone invalidated you. I want you to know that it matters. I want you to know that your struggles, your challenges, your needs, they matter so much.

Host (37:20):

And just because someone doesn't understand them, it doesn't mean they are any less valid in any way, any way. And I'm going to say it again so that it's kind of drilled in your brain in case you don't know. Your struggles, your challenges, your needs as a human being matter. Just because you are neurodivergent, just because you process things differently and we live in a mainly neurotypical-dominated world, it doesn't make them any less valid. And just because people don't understand them, it doesn't make them any less valid. Please remember this, because I think it's important and – I include myself in this – we often forget. If you ever have conversations like these with people in your environment and you request accommodations and they refuse to do so, that's not on you. It doesn't mean you don't need them. It doesn't mean that you're not "Autistic enough" to get them.

Host (38:34):

Again, this is just way bigger than us. Autism is still widely misunderstood, especially by neurotypical people. And if you pair that, that misunderstanding

with a kind of know-it-all attitude that a lot of people seem to adopt when it comes to Autism, you get harmful results that unfortunately impact us greatly. You get people that don't understand how Autism works, or honestly, neurodivergences work, in general. They have no idea. Yet, when you talk about these things, they tell you, "I know Autism when I see it," or "I know ADHD when I see it. And you are not that." And again, when you pair misunderstanding and that attitude, of being like, "I know this and you are not going to tell me otherwise" it's harmful and it's not on you. It's not your fault in any way. That's another reason why these conversations are not easy to have.

Host (39:48):

And another one is because it involves putting ourselves in a vulnerable place where we need to put our challenges and needs on display for everyone to comment and judge. And it's oftentimes very unfair. And for those of us who have advocated for ourselves in the past, and, and it has been welcomed, that's such a privilege that many of us don't have as Autistic people. Many of us do and will ask for accommodations and they will be refuted simply because people just refuse to listen to us. And that's also important to acknowledge that we are going against something that I think that is going to take a little years to understand. But I, I think that we are heading somewhere. I think that with all of this wave of advocates in the Autistic community, just like all sharing our experiences and being vocal about our experiences when we can, it's just, I feel like that's what is slowly, slowly shifting the conversation.

Host (41:08):

But yeah it's going to take awhile. Hopefully it won't, hopefully it won't. But yeah, the, the main point that I'm trying to make here is that if you try to have

these conversations and you try to advocate for yourself and you're not listened, it's not on you, it's not on you. There has to be openness. And there has to be willingness to learn from the other side too. And sometimes there's nothing we can do to change that if the person just doesn't want to listen to us, if the person doesn't want to believe us, there's, there's nothing we can do about that.

Host (41:53):

Okay, I think I'm done and I'm tired. Oh my God. This episode was loaded. I hope you are able to take something out of this. Again, please take what resonates and leave the rest.

Host (42:14):

It's yeah, it's just, it's a topic that it's, I don't know, it feels very equal parts empowering and just heartbreaking because on one hand we advocating for ourselves is just so powerful. It's just, it's amazing to be able to be like, "Hey, you know what? I'm living in a way that is very uncomfortable just to make you comfortable, so can we make everyone comfortable? Can we make the necessary changes so that we all feel comfortable? Thank you." And that feels very powerful. But when we kind of like, see the big picture of it, and we learn about people telling others, like, "Hey, I'm Autistic and this and this, and I need this, and this would make it so much easier" and they get dismissed or they are invalidated, or they just, some of us lose our jobs because of it.

Host (43:32):

It's just, it's messed up and it's heartbreaking. And it shouldn't be that way. We are changing things. We are moving towards something. I, I hope we get there soon. But yeah, I hope these tools help you in any way, shape or form. And

maybe it just, maybe you don't use any of it, but it triggers your own ways of communicating this. And if that's the case, I'm all in, I love it. You are amazing. And your brain is amazing and you're capable of doing so many amazing things. And if you feel stuck or you feel like, I don't know, I feel like we've all been there at some point or another that we felt like we were a failure. We are not a failure. We are just living in a world that doesn't accommodate us. That just doesn't take into account the fact that there are other humans that have different brains that just process things differently.

Host (44:47):

And it's not on you. It's not on you really that's. I really wanted to say that so that this podcast episode didn't end in such a bittersweet thing. You're amazing. You are amazing. Again, another drilling, you are amazing and you have an amazingly wonderful, beautiful brain. Okay. So now I'm done. Thank you so much to Tiimo for sponsoring this podcast and thank YOU, who is listening. Thank you so much for listening and supporting and following and subscribing and all of those things. It means so much to me, it means so much that you are supporting my project. I am deeply, deeply grateful for you. And yeah, I hope I see you here next time for episode three. Until then, please stay safe.

The Autistic Life Podcast is hosted by Agustina C. from @theautisticlife.

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