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Jessica Murray: Hi this is Jessica Murray, managing editor for Stairway to STEM. We're an online resource that supports autistic students transitioning to college, especially with a STEM focus. This past April, we decided to kick off the “Steps to Autism Acceptance” podcast. We wanted to give our editorial board members a chance to promote concrete actions that people can take to build, not just awareness, but greater acceptance for autistic students and students on the spectrum. What does it mean to really accept someone else as they are? We're going to explore the steps we can take now to create a culture change. In this episode, editorial board member Arianne Garcia and contributor Katie Matthews discuss communication differences between autistic and allistic people, and how to bridge that gap. And now I'm going to turn it over to Arianne and Katie who are going to jump right into this terrific conversation. Thanks so much for joining us!

Katie Newton: Well, we had been talking a lot, in a blog, about perspective-taking skills, and kind of thinking about theory of mind skills, and a little bit about, I don't want to say controversy around those terms, but the way the world thinks about those terms when it comes to people with autism. And branching into, how do we go about thinking about communication between people with autism and people without autism? And we thought maybe it'd be good to have a conversation around how to help autistic students learn social routines. But then also thinking about, how much *should* we be teaching social routines? And what's the discussion around that area especially as I think it's kind of a hot topic right now.

Arianne Garcia: Yes, yes, I agree yeah. One of the things that I find is really interesting, about learning social scenarios, is once you know like what to expect makes it a lot easier. For example, if you are going to the bank and you know that you're depositing a check and that that's all that's going to happen you can expect an outcome of that and that there's no anxiety around that, as long as you know what's going on. And it's the same thing for autistic people. The only difference about that is if there are other factors that come into play, like if I go into

the bank and I'm having a light sensitivity day or I forgot my tinted glasses or maybe there's loud noises or somebody has their kids, that creates anxiety in me. Sensory disruptions and sensory overload, it feels the same as if I was you know approaching a social situation uncertain. And if I'm not careful, I can unintentionally influence those conversations. And if I'm in a situation where I'm at the financial mercy of the teller, if they decide to uphold some arbitrary rule, or if they decide they don't want to talk to me anymore and so they go and get someone else.

I just think that part of learning social skills is based more off of like a psychiatry point of view. Like a Maslow's hierarchy of needs, like "oh no you need social situational- you need friends." Like, yes, I'm aware I need friends, you know, I know social skills are going to help me have friends, but I don't want to be anxious at the bank. I want to be able to have confidence in life skills, and I just don't see that enough. I see more research, more money, more awareness, more attention to aspects of how to help "them" deal with other people that make other people feel comfortable. Whether it be, like, if it's genetic then, finding a way to get rid of a gene. If it's, like, medicine, a cure, you know to see those "cures." And cure is such a strong word. It stirs up strong emotions in autistic people, because I don't know anything else other than being autistic.

Before there was a word for it, I was just weird. Once I had a word for it, people who were trying to figure me out based off of those cues, that people incorporate in social skills training, once they realized I was autistic, it changed things for them and how they communicated with me. And those are the kinds of things that neurotypical people don't take into consideration, and that's one of the biggest problems in this, like, you know, magnified little area where there's a clashing between autistic adults and parents with autistic kids. But, we don't agree on everything. And both sides have strong feelings and, at the basis of it, we want to learn from each other and teach each other and it can get really difficult. On one hand, we see things that neurotypical people don't. On the other hand, there's more neurotypical people than there are autistic people. So, there has to be room for compromise.

KATIE: I do agree, like I wouldn't be a proponent of a therapy, like an ABA therapy, which I think is kind of like, "oh here we'll practice this scenario over and over again." And, like you said, it's just not natural. And it's also unlikely that it's going to go exactly like this practiced, exact routine—that's not how life works. The clinic I work at, when we are working on social language, a lot of it is in a naturalistic environment. The kids are coming in and out of these gym spaces, they're playing with peers, and we're kind of focusing on skills like empathizing with someone. We're thinking about theory of mind, like reading nonverbal cues. You know advocating for your own sensory needs. And that's for people with autism and for people who don't have autism, and any person, just advocating for when, like, "oh I need some space." That's a skill that we all could use more of in our world.

And it's like you said, it's a little bit stigmatized if someone's having a breakdown and maybe they just had a rough day, maybe they just need some space, and kind of knowing when you can ask for that. So, the communication partner needs to be sensitive of that in who they're communicating with on both ends. So, I like what you're saying about collaborating and learning from each other because autistic people can certainly be teaching the neurotypical people a lot. And yet, usually the neurotypical person is the language therapist or you know "fill the blank" of whatever type of therapy a parent might put their child in. But I completely agree that I'm learning more from the people I'm working with then, maybe, they're learning for me half the time. And, I'm looking at some of the questions that we had kind of talked about, and I kind of wanted to go back to when you were talking about if you're learning nonverbal skills, you were talking a little bit earlier about how that might feel really good at first for someone but then, eventually, it could lead to burnout. And I would like to kind of dive into that and hear your perspective.

ARIANNE: The part where the burnout comes in is the masking. So, when I was learning nonverbal communication, it was on a level where people would tell me. Because I would ask, I'm like, "why are you making a face at me?" And so, I would just get frustrated like, you know,

and when I was younger, I thought that that stuff was on purpose. That's a huge thing with nonverbal communication: your understanding of it changes over time. Another example is that it took me a few years to figure out when winking was acceptable. And it turns out that it's not really! So, like, I tried it out in a few different conversations, and it just...I just, I don't talk to those people anymore [laughs]. It makes you emotional. And when the emotional parts of your brain is firing, they're going to fire at the line of thought that's trying to get to the desired outcome of the conversation. Because people don't just talk just to talk. There's an outcome, there's a reason, there's a motivation. So, you're internally getting electrocuted all the way down to the end of the outcome, and it's distracting.

Over time, your corrections, your “on the toe” corrections, create this mask. And it's commonly referred to as masking, because it's fake. You're like, “oh yeah, I'm clever, I meant to do that, yeah, that's a thing I did,” but, really, I'm just, like, “okay, that was a freebie.” At first it feels great, because, you know, “oh, look, I'm on my feet, like I feel good!” You know, you feel good about yourself that you were able to guess that quickly. And then, eventually, especially if you have to keep the mask up, and you're feeling this on the inside, it's emotionally draining and it starts to spiral downward. Like when I get close to burnout, little routines start to go.

It's super important to be aware of one's own limitations because I know once I reach that point like, “okay, I need to take some kind of break”. Whether it's like, you know, take a day where I don't talk to anyone or where I sleep all day. Whatever I need to do. If I need to take a few days. Sometimes, if something's going on for a super long time, like when the government shutdown, how long that lasted—like, I was, like, freaking out the whole time. I needed like a week to recuperate when the government came back up, but I couldn't recuperate until the government came back up because that was my primary stressor![laughs]

KATIE: Yeah, I think you bring up a good point with, like, thinking about when you go into that high stress brain. And, you know, it's your amygdala brain, and you're in that fear response and your emotions are driving your thought process—that's not a time to work on higher-level

language. And, I see that often with families, with a parent maybe who doesn't get it, might say, well, "they need to come to therapy, they need to do this, they need to do that..." And, sometimes I'm friendly with the autistic student, and I've gotten to know them and who they are and I'm advocating saying, "He's got a lot on his plate, coming to therapy for three hours a week might be better served having some time in his bed reading his favorite comic book." That might be what he needs, and it's really hard to get that message across to just let in.

And I don't think that's necessarily even for autism. I think that's a potentially something to go into like further parenting theory, but knowing when to take time for self-care, and I know we've talked about that before. But at that point when you're drained and tired and you're having these hard emotions, it's not going to be a time where you're going to be in tune with the social nuances of a conversation. And that's not a realistic expectation that we should be having as a society, and it's the same with anyone, really. If anyone's having a really rough day, like, how can we be better communication partners and stop thinking about ourselves but start thinking about the other person? And how can we try to listen and support, versus going into that fixing mode or the shaming mode, which would be toxic? But even trying to be a fixer before it's time to fix.

So, another thing I wanted to bring up that we spoke about was, say you *are* having a communication breakdown. And you're realizing it in the moment like, "okay this isn't working, like, something's getting lost in translation," and maybe this is someone you have to speak to again, and again. Say it's a co-worker or say it's a professor or, you know, even an aunt. Some of the strategies that I try to teach, like you mentioned with asking about, "why is your face like that?" or "why are you making that sigh?" kind of realizing when you're not understanding something, and I always hope that autistic students will advocate. Like, "wait hold on a second I missed that." And that's for anybody who's misses anything in the conversation. Letting someone know that you're having a miscommunication, and then kind of advocating your position to someone who is in power over you.

Advocating, maybe disclosing diagnosis, and saying you know, “That means that I might not always get these nonverbal communication.” Or, “Oh, I might have more trouble with the subtleties of language.” Or, “Oh, I might have trouble with these figures of speech or sarcastic emails.” And just kind of give them a heads up so that maybe they'll have that in their mind if there is a communication breakdown. And then another one is, advocating for the type of communication style that you prefer. So, as you said, you used to like being on the phone more because there wasn't these distractions. But, you know, now you're kind of changed, and sometimes you prefer to be in person or on video, and kind of just letting someone know that. So, like “Oh, I'd prefer if we could get these meeting notes in an email later because, you know that during the meeting a lot of it is just going to be too much, or it's too fast” or whatever, fill in the blank.

But advocating for another way the same material can be communicated, I think can be a really helpful tool for an autistic person to have. What other tips do you have? Maybe thinking about social conversations that go awry, like what could happen in those from your perspective?

ARIANNE: I agree that sometimes you just have to disclose. Especially, if it's one of those situations where it would be helpful in the understanding. Like, if someone's getting frustrated because they keep having to repeat themselves. If I'm just, like, “look I'm sorry I'm autistic I promise I'm trying.”

KATIE: But you don't even have to apologize! You shouldn't have to apologize.

ARIANNE: Well, I mean, that's also a learned thing, that society has taught me that I had to. That's a tough thing to unlearn. That's also part of mental health and part of the parent aspect. That there's things that we have to unlearn, and apologizing for being autistic is something that I'm still trying to unlearn [laughs]. Because you're right, I really shouldn't have to. I find myself doing it a lot because, like, apologizing for “inconveniencing” the other person because that's what society has made me feel like.

KATIE: Yeah, I mean that sucks. That's like, a lot of time, I hear women, in general, apologizing—so you got both going. But, you don't need to apologize.

ARIANNE: And race, too, I have to apologize when it comes to race. That affects my experience with autism as well. Especially, if there's like nonverbal subtleties. I was in Ohio, and I went to a little nail salon. I went inside, and they looked me up and down, and I told them what I wanted. And they told me, okay, go ahead, and sit in that chair. I was sitting in the chair for 30 minutes and, after like 15-20 minutes, I looked around the room and I noticed that people who had showed up after me were getting helped before me. And, I was the only Hispanic person in there. That was something I had to think about because I was like, is this a race “thing?” Like, what's going on? Maybe these ladies just do hands. Trying to think “maybe there's an excuse,” because that is what society has taught me. But no, that was race. That was a race “thing” because, at that time, and even now, there is really negative rhetoric around brown people and people of color.

I say “brown people” because I'm brown, but, you know, people of color. And that's important to acknowledge with autism, because if you look up Hispanics and autism, you only really find me and a couple of studies. There's not really a whole lot out there. One of the things that you find is a study trying to figure out why there are less Hispanic diagnoses. And that's because of the language of the questionnaires, it's the subtleties of conversation, the things white people worry about that Hispanic people don't worry about. We don't really care so much whenever our kids take forever to talk. That's not something that's, that super important to us, because bilingual children take longer to talk, that's just a given. And, in that aspect, that's not really a reliable thing to go off of. So, when they give the questionnaire, they ask the parents, “Are you concerned about delay and speaking?” Like, no, the kid's only two, what do they know about words? [Laughs]

KATIE: Well, it shouldn't be that much of a delay for learning both, I mean, I know that it sometimes happens. But, it's interesting that you bring up the difference of what's expected in a culture. There's definitely a lot of pressure on mom, well, I should say families in general, like "Oh, when is your kids saying its first words?" like have they done this, have they done that? And, just the whole milestone "propaganda" I would call it. But, that's interesting that you've noticed that difference from being part of that community.

My hope for therapy is that, say, I'm working with a young child. Sure, the child will learn some social skills. Yeah, we'll help them develop their language. Okay, sure, we'll help them with joint attention. Okay, we can work on play skills. But a lot of research is showing the biggest predictor of success, and I'm saying success not in terms of necessarily academics or hitting some milestone but success as in the person is living a satisfied, fulfilled life later on. The biggest predictor, is going back to the family, and educating the family, and thinking about what language can the family use at home. It's not necessarily even just language to facilitate lengthier sentences, or more complex vocabulary but language around problem-solving, and language around self-advocating, and language around "Oh, how am I going to cope with this emotion or this feeling?"

And it's interesting because, that's new for a lot of families. As you said, in so many cultures that's just not part of the conversation. I'm from a caucasian white family, and that wasn't really the way we were brought up either. Just, because, I was raised in the 90s, and it was kind of, "You're doing this because I said so" and so on. It wasn't a lot of talk about, "Oh, wow, I see you're feeling really upset, it looks like you might need to take some time to calm down, what can I do to help?" you know. And that language can be helpful to both help co-regulate the child back to being in that regulated state, that they can learn from. But also, provide an example of that nonverbal language so the kid sees, "Oh, mom's face looks like that, oh now she's putting the vocab to it, she's saying, 'I'm feeling upset I'm feeling frustrated.'" And, then, maybe, she's even saying why, "Oh, I'm so frustrated because I just burned the chicken," or

whatever. And then, they can go one step further, and they can talk about how they're now going to problem-solve that moment. That's such a rich learning experience for the child. And you can look at that later and say, "Wow, I just taught my child social language." But it's a little bit hidden. Maybe people don't even realize that kids are sponges and they're learning all the time. So that would be the way to really go about this helping with some of the social language. And I think, like I said earlier, it's not just for autistic people. It could be so helpful for so many people.

ARIANNE: Yeah. One of the things that I think is really great, when you're first getting into, like, self-advocating, I know for me it took some time because I already had decided I was just weird and then, once I had a word for it, everything just kind of changed. So, for example, I wear tinted glasses at work because it's really bright. I've been working since I was 16, so I've always been under fluorescent lighting. I just got this note from my doctor saying that I was allowed to wear tinted glasses inside for light sensitivity just a couple of years ago. But it has completely changed the way I work. What made me feel really good about self-advocating was that I noticed changes right away. And it made me feel empowered. And it made me feel confident. I felt like whenever I was verbalizing how I felt and I was understood and respected, everything went great. Where I ran into problems was not knowing the words for how I felt, and just knowing that I was upset. The way a conversation goes is, when you announce that you're upset, the other person says, "Well, why are you upset?" A dialog is started.

But if you don't know why you're upset, then your answer is just, "I don't know." That can go so many different ways. That can go, "Okay, well, I'll give you some space." That can go like, "Okay, do you want to talk about it?" That can go immediately into like, is it physical is it emotional? Depending on the person they, they may back off, or they may instantly go into problem-solving mode. Learning to self-advocate is just learning when to realize that, just give me a minute. I can tell that you guys can tell that I'm upset, but I'm not ready to talk about it. I

just kind of want to keep it on the down low, and let's all just kind of carry on while I think about this. Then, if I can figure it out or what have you, we can talk about it at a different time.

What are some tips for family members who want to change their communication styles to be more accessible, and do you have any therapies that might help, since ABA is really controversial?

KATIE: Yeah, I think in terms of types of therapy I personally like to go with a more naturalistic approach. Which would kind of be for young kids, like the floor-time model or anything that's like a play-based DIR—that stands for “developmental and individual differences relationship” therapy. Those types are usually highly focused on how the parent engages and interacts with the child, and then how the child interacts with their worlds. And, it's child-lead. Which, that's kind of a key for me when it comes to young kiddos and treatment. I think that anything that's kind of attachment-focused therapy—so if you're looking at a center and you either see that they're attachment focused or sometimes sold as a trauma-informed care model, those are usually kind of “person-first places” that I really like.

Also, if the clinic has a sensory-integration “lens” on it, that's usually helpful because that gets into them being aware of some of those things you were talking about with noise sensitivity or light sensitivity. You need to think about those things before you can talk about subtleties of communication. A lot of parents will get the option of receiving therapy through the public school system. And I think just having a strong conversation and dialogue with the particular therapist and asking them, “What is that therapy like?” “Who's in their social group?” because social skills groups are just so different. It could be great, it could not be great, so you really need to ask the questions and kind of figure out what's really going on there.

And if there's that lens of emotional intelligence training within it, so that it's not just about, “How could I communicate?” but it's also about “How am I going to react to different things?”

You can only really control your own emotions and your own reactions. So, giving the skills and building that toolbox so that when there's a miscommunication, or when you're feeling frustrated, or when you're not getting your needs met, it doesn't have to be a big blow up. It can be something that feels more controlled and feels like you're empowered. And, that, you're like, "Okay, this is something I know I can take control of, and I can use these tools that I have." Maybe that tool is that you just need some space, and maybe that tool is, "I need to go tell an adult about XYZ," but it won't be helplessness. And that I think is really valuable, because the parents are not always going to be there. You asked about what ways a family can kind of help?

ARIANNE: Yes, with their communication styles to be more accessible. Are there any just tips in general?

KATIE: Yeah, sure. I was giving the example before about narrating the way that you communicate with other people can be huge. So, I love to use examples, like, children, and even young preteens, even high schooler or anyone, really love a good story. And if you can teach through these social stories about yourself that can be really powerful. So, instead of, you see your child is upset and you're like "Why are they upset, what's going on?" Instead of going hard with the questions, talking about yourself and making a story up. Like, "Oh, man, I was so upset earlier." And then kind of jumping in and seeing like what happened. It can be—I don't want to say, "make up a story"— but it can be a slight white lie. Just kind of thinking about, "Oh, the lady at the checkout counter, she didn't know that I had this coupon," and just kind of going through, like, where the breakdown was, how you responded to it, and then kind of letting the story end up teaching a lesson in a way or just showing the way. Maybe it worked. Maybe it didn't work. Maybe you're like, "Oh, I should have done this differently" or "now, in retrospect, I wish I *blah blah blah*," fill in the blank. That can be nice, and it might open the door for the child or the student to share something that happened to them that was similar. Taking off the drilling of those questions, which I don't, necessarily, like.

Another strategy is, like, you're the parent and you have unconditional love for the person, and you can be someone who might let them know if there is something that's a big social roadblock and you're noticing it. You can tell the person. I don't think we have to be afraid of "Oh, we're just going to hurt feelings" or "It's going to be awkward." Because, if it's something that you're noticing, it might be helpful to bring it up. *You* can be the person who might let them know like, "Oh, when you're walking away from me and we're trying to talk, it's hard for me to hear you, and it makes me think you're not interested." And then saying, "Is that true or not? If you're not interested, that's okay, you don't have to be interested, but, like, just so you know, when you're walking away it shows me that you're not interested."

And you might know as a parent that they're walking away because they want to get a fidget to hold and they *are* interested. But kind of letting them know, like, this is how it might be perceived. So, that they are just aware. And it doesn't mean that it's wrong, it's just that's the way that a neurotypical person might perceive that. Unless you say something like, "Okay, I'm listening, but I'm going to go grab my pen while we're talking." Now, it's like "Oh, wow, look, now we understand, like, now we're on the same page!" And I think that type of thing can be powerful, because the person might not even know that they're coming off as not interested. They might be really interested and they're like, "Oh, of course I'm interested, why wouldn't I be interested?" and you're like, "Well, you were walking away from me!" So, explicitly teaching some of those things. Do you have anything that comes to mind that you think would be helpful?

ARIANNE: I mean it's difficult for me to say because the way I learned to cope, a lot, was just being really pushy [laughs]. So, it's not something I recommend. It's one of those things I'm learning.

KATIE: One other thing a family could do, I can just add on, is talking explicitly about the message you're providing and not using a lot of idioms and figurative language. But, if you do, making sure that you're also teaching it because, it's not obvious. So, thinking if I use a phrase that isn't familiar with a child, that I'm saying "oh, what I meant was, [fill in what you meant]"—so that it's clear, and that there's an opportunity to learn a new phrase. Sometimes, you might unintentionally confuse them, and they might not know, and they might not check. So, kind of thinking of, like, how specific can I be? How explicit can I be? I wouldn't advocate watering down everything and talking to them like they're younger. So, if you *do* use a higher-level phrase, then just explaining it and talking about the social connotation of something. You don't want to accidentally have them saying something rude that they might not even realize is rude because it's a phrase that they're not familiar with.

If the parent wants a behavior to change, like the example I was thinking of is if a child is constantly standing really close to you. Instead of being like, "back off" and snapping, the parent could say something like, "When you stand that close to me it makes me feel uncomfortable because I like to have more space around me. Can you please move back?" You might have to be that clear instead of just pushing your hand away, the child might not have the nonverbal communication reception. So, no "oh they're showing me to get away." So, you might have to say it. You might have to say things that you think are obvious. They're not going to be obvious, but they'll eventually learn them and it's not going to be the rest of their life. But they might not know what you, what slapping your hand away means. When you're like, "I told you seven times to get away" they might be like, "wait what you didn't say it once" [laughs]. So, kind of just thinking of, what have you actually said, and just over-communicating, maybe.

[Music] JESSICA: This is Jessica Murray again, thanks for listening to this episode of the "Steps to Autism Acceptance" podcast. For links, bios, and more information on this episode, plus additional resources for autistic students transitioning to college, visit stairwaytostem.org. Again, thanks for listening and keep tuning in!