Stairway to STEM presents – Steps to Autism Acceptance Podcast

Episode Two: Editorial Board Member Arianne Garcia and Rem S. on Managing Limitations and Avoiding Shutdowns

JESSICA: Hi this is Jessica Murray, managing editor for Stairway to STEM, an online resource

that supports autistic students transitioning to college, particularly in the STEM fields. This April we decided to kick off the Steps to Autism Acceptance Podcast. We wanted to give our editorial

board members a chance to promote specific 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 somebody as they are? Our editors and their guests are going to explore the steps we can take now to create a culture change. I want to introduce editorial board member ARIANNE Garcia. ARIANNE thanks for being here and for leading this episode of the Steps to Autism Acceptance podcast

ARIANNE: Thanks for having me.

JESSICA: Absolutely. Listeners have you ever had difficulty managing limitations or wanted insight into preventing and addressing shutdowns? Arianne is here to help us address this problem area. In addition to working as an editorial board member for STS, what's your day job and who's going to be your guest for this episode?

ARIANNE: I work in health care. I also do work with the National Coalition of disabled Latinx. I'm in the leadership team right now. And my guest today is Rem S., and he's an autistic college student.

JESSICA: Terrific, thank you ARIANNE, I'm really looking forward to listening to this episode.

ARIANNE: Today we're going to be talking about managing limitations and avoiding shutdowns and shutdowns in general. So, Rem, what do autistic people normally experience during a shutdown?

REM: If I were to put it simply, it's like everything in the world is just happening while you're,

like, basically a vegetable. In a way you get put into, you become a statue almost, even though there are bunch of gears going on inside your head.

ARIANNE: I completely relate to that, that happens to me like when I'm hungry when I'm tired. How often do you experience shutdowns?

REM: The only time I really experience it is in school, mainly school, but it does happen a few

times. Like, I guess, if you read an article that really hits you at your core, anything that would hit you at your core, but you can't really defend or refute I guess, really just…

ARIANNE: Like an emotional kind of hit-you-at-your-core, like, something, like an emotional

response that gets you to not verbally articulate?

REM: Yeah, or even, like, something that you've held on to for, like, a certain belief that you may have had, for a long time, and then you all of a sudden feel differently about it. You question if, like you question your identity in fact at that point—like did

I really believe in this? I've believed in this so long but this other thing’s right, so am I?

ARIANNE: And all the while that this is going on in your head, you’re kind of just sitting there and there's not really like a physical response.

REM: Yeah you just, you just can't move. In a way like the brain just forgets its bodily functions.

ARIANNE: That makes sense. So you said you've experienced shutdowns at school what do you do, what happens that you reach a shutdown at school? Like what sort of things put you in the

shutdown mode?

REM: Mainly when I'm thinking about all the homework that I have to do and really just in class. It's just wasted time honestly, I feel. You're just listening to someone yammer on and yet they really just care about the work that you're doing, the homework, and you only care about the grade. That's the whole thing, and that's why I love online classes. They give you just the freedom, there's no middleman. There's no like, “you have to be here or we'll take off points for you.” It's just, okay, here's your assignment, here's what you gotta, do this is the time you got to dovit by.

ARIANNE: Yeah, yeah, I completely agree, I know exactly where you're coming from with that. I, I myself have experienced shutdowns at school to the point where I just was like, I can't do this, and then I tried online for a little while and I was having troubles with that. And I learned

I learn differently than traditional methods. When you experience these shutdowns do they

happen like during class, or do they happen like during your breaks or like when do you kind of

experience?

REM: It's mainly during class, but just like if I'm on the campus it hits me cause when I'm not on the campus ,when I'm not like at class or doing anything, I feel more liberated— like I can do stuff, but it's also the fact that I have to do a commute to the school and from. I don't have a car, so I take the bus, which takes a long time in and of itself. What I hate is that idle time that I can't, like, it's not my idle time. It's just time I'm forced to go through, and I feel like I could be doing something else. I could be doing this work and just not being able to do it makes me shut down. It feels like I can't do anything so that just resonates in my whole body.

ARIANNE: Yeah oh my goodness, I know exactly what you're talking about I do drive and I do have a car, but I did feel that way when I used to have to take the bus. Like it felt like wasted time and that would upset me and then, like, on top of it, just sitting there like sometimes like the bus noises, the bus smells, the bus people—like, it just, it would get to me, and it would just it would upset me and set me off, like put me, it would put me, like, in a bad mood and set my day like in a negative direction sometimes. So I know what you're talking about with that. What do you what do you do when you reach that point?

REM: Really, I do like one of two things: one, I just kind of accept the shutdown and just sit

there for a while and let myself sort of reboot in a way I feel like I'm rebooting. The other thing sometimes is I kind of embrace it in a way, like, hey ,I got nothing to do right now so I'm going to, if I got my like my phone with me I'll plug in my earbuds and I'll just browse YouTube. I'll say like okay this is idle time, I'm going to use it as idle time. I'm gonna surf the web, and if there's something, like, I've been thinking about before and haven't had, like, the time to do it, but now I can, like just look at some random article online or to find something, I use that.

ARIANNE: So that kind of helps you just kind of like vegging out and just like watching YouTube videos and like and kind of puts you like in a in a different headspace? sSo you're not experiencing the shutdown negatively?

REM: Yeah, it's kind of like using time, your brain basically tries to use time against you, but what you have to do is use time with you. If you're in a situation that you can't really control, you kind of have to go with the current and then you can start getting, then you can start feeling that control back. Like you have to use the current because if you fight against it it's just a losing battle.

ARIANNE: How do you know whenever you're reaching your limits or your threshold when

you're like when you're about to shut down? Do you do you know like when you're about to when that's about to happen to you?

REM: Well it's kind of weird that when it happens. It sort of happens in stages it's, it's almost like the grief process, or it follows that same pattern of the grief process. You don't know that you're in it, you deny that you're in it, and then it takes a second for you to realize that you're in it. Once you get to the point where you realize that you're in the shutdown, usually like it’s in it’s prime, it's like you're just stopped, you're frozen. It's sort of an out-of-body experience

if you will. You're sort of watching yourself just like you're kind of the passenger to this, and it's kind of like in Inside Out, that movie where all your emotions are there but you're the

one there, so you kind of have to let go around the console and fix things yourself, do it manually.

ARIANNE: Oh my gosh! I say that all the time, oh, my god, I’m doing this manually right now. When you're in class and you're kind of starting to shut down, do you leave class like to go

to the bathroom to walk around? Or do you like do you kind of just like, like do you have your computer with you?

REM: And well for college, which is a good thing, you can leave, it depends on the situation itself, kind of if the teacher is like really cool and they'll let you leave. You can leave early and

you know you could talk about it later, and you just explain your situation to the teacher. If they understand, then everything's good, and you just like you say, you're sorry, you say, like, I'll do

this, and you'll, and life goes on. If it's a really bad teacher, well, they'll try everything in their power to make the situation worse. That's basic basically, they’ll say no, you can't leave you, have a responsibility to this class and that just adds more and more.

ARIANNE: Yeah like more like more to like, more pressure and like more feelings like I'm

like I need to leave, and I can't.

REM: Yeah, and like even if you do leave, they'll say like well then, I'm going to have to

count you absent for this or you you’ll get a failing grade for the day. It's like dude I can't, do you want me to just sit here and be a rock basically like wouldn't I just be like disrupting things?

ARIANNE: Yeah like I'd be more useful to you if you let me like come back like next time more like I would like I'll have everything together yeah.

REM: It’s like Darwin said be flexible because then everyone wins, if you're not flexible whether it be you or I know the person in question has a problem so really, it's more or less getting aid

from the teacher himself if you gotta leave, you gotta leave—there's no 1 or 2

way about it.

ARIANNE: What other things exacerbate you?

REM: In a way I say the brain itself exacerbates you I say with people; I firmly believe that there's a soul because there's a lot of things the brain does but you say you don't like. So the brain itself is like your internal enemy it will do everything in its power, to it will say like whoa what about this homework that you have can you even, even if you do read it in time will that be like a good grade and you're constantly having to fight with yourself about this.

ARIANNE: Yeah like is it like forcing yourself to do your homework you're forcing yourself to do the reading?

REM: Yeah and that's a real it's really a pain just having an enemy you can't get away from because it's literally a part of yourself and you, in fact in a way you have to get someone. Like what I did was I talked to my mom and she, I said like I'm getting a bit overwhelmed here and she had really good advice she said like first off you have to categorize like your work itself.

First off put it in a line and don't let your brain just throw the papers at you, you have to get it organized and then you gotta see what needs the most attention what doesn't need the most

attention and then what's like the easiest to get done and then what's the hardest. Like if you find a bunch of easy stuff to do and let, you can get done like in a snap do those first because if you take away a bunch of pebbles then the rock doesn't seem that bad.

ARIANNE: Yeah, I know exactly what you mean like in my head I have like, like for me it's less like a line and more like a list and so like I find that when I check things off of my mental list it

gives me like a little more it takes a little bit of that burden off of like pending I guess the pending things that are just going on and I'm able to concentrate more on the stuff that requires more mental energy. So, do you have any like external stressors like environmental like is there like when you're in class do you have any like sensory issues that sometimes distract you or kind of put you over the edge like anything like that?

REM: Well I guess it's just again the brain making Itself, like trying to add more stress

like I could be fine with a chair like any other day but when I'm in this mood it’s like oh this chair is unbearable to sit on man, this is warm or like

ARIANNE: Like, I'm never gonna sit in this chair again. I feel like that.

REM: And more or less just the other students, one of the things that I most hate is group work.

ARIANNE: Oh, okay, yeah, I hate group work, yes.

REM: It's not just so much as like the burns with everyone it's the fact that I try to do stuff but

if it's not good with the group they’ll like, they won't straight up take the paper away from me

but sort of like gradually take over the thing. and the thing is I'd rather, and in fact recently in one of my projects I almost got a bad grade because the two people in my group didn't do anything.

ARIANNE: Oh yeah that's a common thing that I hear about, like um some of my friends that are in college or my friends that went to college is yeah like a lot of the group work like half

the group or most of the group won't do anything and it's kind of like one person is stuck doing everything and they all get the grade.

REM: And like not only that it's really just creatively, what's the word like the opposite of stimuli, repressive, that's it.

ARIANNE: Oh, creatively repressive?

REM: Yeah like it's bad enough that you have to do the assignment but if you can have a little bit of fun with it like why not do that? It makes it less of an assignment and more of an art project. and I try to do that and then I just get like oh that won't get our point across or something like that. And I'm like alright then we should all do this by ourselves then succeed or fail on your own time.

ARIANNE: So that kind of adds to it too it's like a like a an either/or situation like look like we can like yeah, I know I know exactly what you mean it's hard like to try and like get other

people to be on board with the thing you're trying to say if they aren't open to understanding what you're trying to say. and that's that is one of the things that I find most difficult is

that something that you that you have issues with like in group projects?

REM: Yeah, they just uh, talking with, and the thing is they aren't like people that you're

familiar with its strangers and you're being forced to do this which is even bad. it's even bad just to force people to learn something. When you learn the best is when you want to. Like say if you're building like a thing like maybe a car and you're really bad with math but you have to use the math to build the car and you want to build the car that's when you learn you start to learn like on your own time you learn out of necessity.

ARIANNE: You learn like the things you need to know to make the car.

REM: Yeah it feels less like learning and more like you know you're going forward.

ARIANNE: Like you're moving towards your goal of making a car yeah and you say like oh yeah all of a sudden, I know all this math. Do your professors know about your diagnosis?

REM: Some not all, in fact it usually takes like half the semester

ARIANNE: Before they get used to you or before they realize or before you open up?

REM: Before like a shutdown will happen or something. Because like honestly you do it

at the beginning they'll look at you differently anyway and that will just make things a bit more difficult so it's more it should be more of an organic like getting to know each other thing.

ARIANNE: And then like later once they're already used to you like you let them know like I'm

autistic.

REM: Yeah because then they will have gotten to actually know you without looking at you through rose-colored glasses.

ARIANNE: I've had that same thing at my last job I had a director she didn't know I was autistic

I had myself just found out like a few months before she even got there but you know I've always been autistic so every time we would have conversations she would tell me that she like she would she would tell me there was always some phrase that she would say at the end of the conversation that made me feel like it wasn't a typical conversation that she had with people you know she would say something like your responses never cease to amaze me or like or like just things along those lines things that could be ambiguous like it's like amazed you like bad amazing like good like what does that mean you know and so it made me feel self-conscious a little and so one day she gave me a book it was called like What Got You Here Won't Get You There and it was meant to be like a book to help like regular employees like

shed the behaviors that keep them from being in leadership. I didn't know what she was

trying to give me this book for so I asked her I was like I’m autistic, I don't know why you gave me this book can you just tell me so that I know what to look for here as I was reading it and

I was like these are all me does she want me to shed my whole personality or do I just need to

tone it back tone it down a little like. I wanted to know what she wanted me to get out of reading the book. So I know what you mean by the process needs to be organic and by the time that she that I told her that I was autistic you know for her it all made sense and she was able to talk to me like different like she was she wasn't saying those things anymore like those, like you've never ceased, like you see you never cease to amaze me kind of stuff you know and it became more of a natural relationship between an employer and an employee so I guess that so that kind of thing I can definitely see happening in a teacher-student relationship. So the teachers that you do tell like how does it help you?

REM: They're a bit more they usually get a bit more relaxed give me a bit more, they'll understand more. But again, it depends on the person kind of some will start viewing you as a problem others will actually start dealing with you better. It really just depends, like I have a I’m in a human sexuality course and the teacher is very new very young and she really understands about it like the whole class is about sexual identity and stuff like that which at the end of itself is already psych psychological, so like if she knows like I'm autistic then she's like okay and it's not a degrading thing it's just the fact that she now like knows.

ARIANNE: Understands in case you need to leave class in case you need like extra help or in case something is you know something that requires her to give you more attention it just helps you.

REM: Yeah, it's less fear you know the teacher like they don't know they they're afraid like one of the students is that really bad so if they act non neurotypical it obviously sets off people but if they if you give them like the exact reason it'll be better. But on the flip side the coin for more like old school teachers which is like in my other class they just will like they'll take it like a brick wall basically.

ARIANNE: Yeah like it's not an excuse sort of thing and then then when you're having trouble, they’re, they're the first ones to tell you like no you need to be like at this level. What sorts of things help you help you manage your limitations so like when you wake up and you don't feel good it like it's hard to get it's hard to like make yourself like do all the things that you're supposed to mentally do in order to not shut down in order to not meltdown in order to not be rude to people in order to not it just feels like so much extra. So, what sorts of things do you do to help you manage like your limitations?

REM: I usually get like reinforcements.

ARIANNE: Reinforcements like people?

REM: Well there's something simple like the fidget spinner itself, like you start feeling,

like there's a bunch of chaos happening you need to fill it with stuff make it a bit orderly.

ARIANNE: So, like stimming? What are your favorite stims?

REM: Uh mainly video games. I even like to create stuff. It's fun to create stuff a lot of people don't like the quiet the absolute quiet in just your thoughts so instead you do something like constructive that reinforces the idea that you're still able to do stuff.

ARIANNE: Oh, okay I know what you mean, I know what you mean. So I kind of like, if you're feeling like, oh, I can't do something, creating something will help you like, will help ease that tension of like, I can’t do things just right now, I'm having an issue.

REM: Yeah even if it's something completely off-topic, the fact that you did it, like, that’s your achievement. It feels good to you the achievements, you know.

ARIANNE: So, what were the biggest setbacks for you when you were transitioning from high school to college? Like, did you have an IEP program or do you have anything like that that you don't have in college anymore? Like, what was that like for you?

REM: Uh it's just not a good process, this could be in and of itself a whole other podcast. Like what's the biggest problem getting from high school to college? Like well I guess first off the

professor's you know they aren't it's not a salary thing it's a it's a whole new ballgame basically.

ARIANNE: Like between you and your teachers?

REM: Yeah, it's a it's a public it's more of a public place to be rather than a state-funded thing to be less rigid and organized and there's

ARIANNE: So that like less organization that less rigidity sometimes like when like when

it works for you like getting to like needing to leave class and you can sometimes it also works against you.

REM: Yeah, and there's less like people you can go to since you're not things you're not

really well I want to say you're not forced to go here but in the modern world that's not true, you're forced to go there so since you already have to go there but they take away a lot of the

I guess you could say perks of standard Education, like you don't have a counselor you don't have people you can make alliances with.

ARIANNE: It's the disability offices are kind of hard to find, that kind of thing?

REM: Well it’s a bit better in Community College. But in like regular college you're on your own. There's also one other thing, when you get when you're out of high school there's no one else holding your hand you have to choose you start choosing but you start choosing every single

thing like you're just thrown into the wild it's like living in a castle then all of a sudden the King says okay now you have to live in the forest and learn how to hunt your own food.

ARIANNE: Oh okay, so like every, all of a sudden, like everything just comes at you and it's

all your decision and it's all your responsibility?

REM: Yeah there's no growing process and no one like helps you and for the life trainers that cost a million bucks not everyone has a million bucks.

ARIANNE: Yeah, yeah what was the first thing that you did when you realized that it was just you?

REM: Well, first find shelter. You basically have to find a place that you feel good whether that be the bathroom the Student Center or just some place like no one cares why you're there.

ARIANNE: Like the library or something?

REM: Yeah, someplace that like a safe place a safe zone if you will okay and in fact it could even be something mobile like a phone just if you plug in your headphones then you're good.

ARIANNE: Okay like something that will like allow you to have like a personal space.

REM: Yeah like some people feel better in, going back to the analogy it's better to feel, do

you feel better sleeping in a tree or a cave kind of thing.

ARIANNE: Yeah do you have any advice for teens that are transitioning from high school to college?

REM: Um if I had to say get your screaming done beforehand make sure you have a lot of contacts. Because we sort of live in that neptocratic world if you will which stinks I'd rather it be a meritocracy but nepotism, as Squidward said, “nepotism is alive and well.” And also

trying not to freak out so much, just take things one problem at a time.

ARIANNE: Thank you so much for talking with us today, this is Rem S., an autistic

college student and thank you so much for being here.

REM: Anytime

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, visits Stairway to STEM dot org. Again, thanks for listening and keep tuning in.