

Stairway to STEM presents – Steps to Autism Acceptance Podcast

Episode One: Editorial Board Member Susan Woods and Dr. Eric Endlich on What Institutions of Higher Ed Can to Support Autism Acceptance on College Campuses

JESSICA: 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 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? Stairway to STEM editors and their guests are going to explore the steps we can take now to create a culture change. Without further ado, I want to introduce editorial board member Susan Woods. Hi, Susan. Thanks for leading this podcast episode.

SUSAN: Hi, Jessica. Thanks for having me. I'm delighted to be here.

JESSICA: Listeners, have you been thinking about what kinds of things higher education institutions can do to promote acceptance of autistic students? Susan and her guest are here to help us address this issue. Susan, in addition to working as an editorial board member for STS, what's your primary role and who's going to be your guest for this episode?

SUSAN: I'm a recent retiree from the community college system in Massachusetts, where I was the Associate Dean of Student Support Services, overseeing a fairly large operation supporting about a thousand students identified as having disabilities as well as alternative programs. I'm also currently an adjunct faculty at two community colleges, and have launched a consulting [professional development practice](#) providing support and training to high schools and organizations on helping with the transition from high school to college. But with me I have a new collaborator, a new associate, Dr. Eric Endlich. Eric is a licensed psychologist and co-author of "Older Autistic Adults: The Lost Generation," which is soon to be published by AAPC, and he also helps spectrum teens transition successfully from high school to college through his firm, [Top College Consultants](#). Eric, also, is an autism dad and identifies as being on the spectrum himself, and I'm delighted to collaborate with Eric. Welcome.

ERIC: Thanks, Susan. Thanks for having me on the show.

JESSICA: Well, thanks to you both. I'm so excited, and I'm really looking forward to this episode.

SUSAN: So, what we've been talking about and thinking about for this topic is, what can higher ed institutions do to promote acceptance of students with autism? And one only needs to open your local paper or listen to a newscast or NPR to read and hear about the challenges facing institutions of higher education lately. Along with shrinking enrollments of public and private higher education institutions, financial sustainability challenges causing some schools to shut down or merge, low graduation rates—particularly at smaller liberal arts colleges—and increased competition for a pool of students to be accepted, this paradigm shift leads us to consider and advocate for colleges and universities to be prepared to engage, recruit, and enroll a diverse student body. And, I think this is particularly important

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for the significant number of students pursuing college degrees and credentials who identify as autistic. The institutional priority should be to develop and implement strategic efforts and programs to create a welcoming and accepting environment using approaches in communication which provide robust and meaningful support to students while also creating a culture and climate of acceptance. So, that being our jumping-off point, I'm going to turn to Eric and ask his opinion. How does a college or university create and achieve a climate and environment of acceptance?

ERIC: Well, I think it is something that it is important to do at all levels. You mentioned shrinking enrollment and low graduation rates. As folks may know, the college-going population, demographically, is starting to shrink, and students on the spectrum in particular have low graduation rates from college. Unfortunately, about one—one out of three students—graduate, ah, autistic students graduating high school goes on to college, but of *those* only about one—one in five—is on track to graduate from college five years later. So, umm, that's concerning. And, so, on top of being the right thing to do, to give these students the best outcome possible, it's also in colleges best interest to increase their graduation rates, their retention rates, to help these students succeed.

Honestly, I would love to see this being addressed even before students go off to college, by helping high school students, high schools, and their families be more aware of the challenges that lie ahead in the transition in terms of all the college readiness skills. There's so much focus on getting good grades and getting good test scores that it's easy to overlook that there's a lot more to being ready for college than just being able to handle the academics. Such as being able to get along with a roommate, being able to live away from home, to prepare foods, to get up on time, to advocate for yourself with professors or with disability centers. So, there's a lot of things that students need to do to be ready. And I'd love to see some of that work being done even before they leave high school. On top of that, I'd love to see more inclusion and autism acceptance at the high school level. You know, we have—really—I think, as a society, society come a long way with other minority groups. For example: the LGBTQ plus population. You see GSA's in many schools (gay straight alliances), but how often do you see an Autism Club at the high school level? Where students can get together, feel comfortable, feel welcomed? So, I think there's stuff to do even before college.

SUSAN: I wholeheartedly agree with that. And—and, in my work with high schools, that message needs to be sent out, and I think families appreciate hearing that message. So, in that conversation, there's a lot of stakeholders involved with this, and I guess my thoughts are—you know—what are the priorities that should be established within an institution? Having worked at a college, I know that a lot of effort is being made around the whole sort of notion of diversity, but when I had those deeper conversations with folks, they didn't really recognize students on the autism spectrum as part of their priority. And that troubled me. What are your thoughts about the institution in a broader way and the stakeholders involved?

ERIC: I'm struck by the same thing. I—I tour a lot of colleges, I try to tour at least 50 a year, and frequently when admissions officers are describing the college to prospective students, they will mention diversity, and if they don't mention diversity, if someone in the audience asks them about diversity, they usually have a ready answer. And they have the statistics at their fingertips, and they will

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talk about geographic diversity, where the students are coming from; they'll talk about racial diversity, perhaps, maybe one or two other things. But, I have yet to visit a single college where they mentioned neurodiversity or disability diversity, and I think that needs to be on everyone's radar screens. And, I think it's a, it's a vicious cycle. If no one's talking about it, then audiences aren't thinking about it, audiences aren't asking about that. Colleges aren't thinking about it. Everyone *needs* to be talking about it, to get—to get it into front and center, onto everyone's radar screen.

In terms of stakeholders, there's multiple levels. There's the perspective student, there's the students at the college, there's faculty, there's staff, and let's not forget that some of the faculty and staff may be on the spectrum, too, and I think they are often not part of the—the equation. When you're creating initiatives to embrace neurodiversity, to increase autism acceptance, I think it's critically important to have people on the spectrum involved in those initiatives. So, you may have heard of participatory research where—in the case of research on autism—some of the research, some of the folks involved in the research design, are on the spectrum themselves. I'm actually involved in a group with City University of New York that's doing some participatory research, and I think that's a great model because they are going to pick up on things that non-spectrum researchers may not think about. So, the same I think applies to creating diversity initiatives. Neurodiversity initiatives. I think it would be very strange if—if a college was trying to create something to increase, let's say, improve policies on sexual assault or sexual harassment, and there were no women on the committees for those initiatives. And, so, likewise, I think people on the spectrum need to be involved in designing those initiatives.

SUSAN: That's an excellent point Eric. And I, again, from based on my 27 years working at a community college, sometimes I was preaching to the choir on this, but sometimes people were looking at me askance when I talked about the diversity mission. And part of the work that I think is important, and I agree with you, is that—you know—the Disability Services Offices at colleges/universities *typically* get it. The folks that may need more enlightenment are the admissions department, enrollment department, the leadership, the, the whole sort of institutional climate. I think that people need to consider this, and—you know—there's a number of ways that, that some colleges and university have been very successful in creating welcoming environments. And one of the things that I speak about a lot and, and— certainly, Stairway to STEM has focused on—is embracing the notion of Universal Design for Learning. And embedding that into all college and university activities: not just the classroom, but also open houses, events. Things like signage, things like communication all have to be thoughtful and thought about within, sort of, the construct of designing things universally. So, having said that, can you imagine or envision the whole college approach to raising awareness and identifying the particular challenges which made the experience better for their students who identify as autistic?

ERIC: Yes, and I'm glad you mentioned Universal Design, because I think it's a great model for—for neurodiversity inclusion in the sense that while I really want to see colleges and other institutions embracing neurodiversity, embracing individuals on the spectrum, I think it's important for colleges not to just target one group and say we're going to be really inclusive for this group, but to think broadly about how can we be more welcoming and inclusive in general. And if you have that sort of universal

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design mindset applied to inclusiveness, then you're going to run less of a risk of excluding or alienating particular groups. So, you might be welcoming to autistic students, but there's no reason why you

shouldn't be welcoming to students with any disability, students who are transgender, or other minority groups.

SUSAN: Absolutely, and I, again, just to reiterate, I think that this is part of the diversity work, and—you know—a lot of focus certainly is on ethnicity and nationality and sexual orientation and religion, but I think that sometimes folks' diversity missions are not broad enough. So, jumping off from that, I guess my next question to think about is, where and how might a neurodiversity focus expansion of these diversity events be achieved to integrate activities focused on embracing the diversity of autistic people and other neurodiverse population groups? And I guess what I'm thinking about there is—you know—colleges and universities run a lot of events, there's a large connection to their community, what actions might they consider in, in sort of expanding their—their diversity mission.

ERIC: Well, this might be an odd response, but my first thought is, where would you *not* include it, where would you not apply it, why wouldn't you apply it at every level? In other words, on the website, in the promotional materials that are being printed up, in the admissions events, in the disability centers. I walk around colleges, and some of them have photos up of diversity as represented by the students. Here's pictures of students in different races. Here's a picture of a transgender student, so you can see what people look like from different groups. But, again, I don't see a whole lot of photos of people with disabilities, people with neurodiverse backgrounds, so I'd love to see that as well across the board. I don't think that institutions need to reinvent the wheel. There are a couple of colleges that are, by design, very neurodiverse. For example, Landmark College in Vermont and Beacon College in Florida. They're both essentially serving a diverse population of learners as their mission, and so they are deeply involved in these efforts. And, I think colleges can communicate to each other, with each other. There's the College Autism Network, which is a group of college autism support programs, and they communicate online. And then there's an Annual College Inclusion Summit, where, if you are a college and you're looking to augment your services for autistic students, you can go to this summit and learn what other colleges are doing. So, again, I don't want to see people feeling like they need to come up with these ideas all on their own. There's a lot being done out there already.

SUSAN: And I think there's some good things happening. One of the things that I've seen emerging is colleges creating some sensory-friendly spaces and practices. You know, again, Universal Design campus signage to aid in navigation, faculty and staff professional development focused not just on Universal Design but on autism. Teaching people about autism, I think, dispels some of the misconceptions. And I know a few colleges, I know Tufts University had a disability support group that was started by an autistic student. So, just as a follow up, there's also, and I know you're very aware of it Eric, a lot of autism support models across the country. Are there specific areas—programs—that may be developed to achieve that, that goal of supporting students with autism?

ERIC: Yes. There's, there's a number of different ways that colleges and universities are tackling this. In some cases, they have a comprehensive autism support program with academic coaching and social

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skills groups or social events and many different components. Frequently these programs entail an extra cost. It may be another five or ten thousand dollars a year on top of the cost that families are already

paying, so that is not a trivial consideration. I've created a list of what I call "autism friendly colleges" and put it on my website, topcollegeconsultants.com. Where anyone can go and see a number of these programs, and one of the pieces of information I've included in this table is the—the fees because, for families, that's a significant consideration. And although I mentioned some colleges in—involve a significant fee for these programs, there are some colleges where there's no fee at all for the programs. And, the amount of services or supports available varies tremendously. There are some colleges that have, for example, an autism club or a spectrum club, different names they have for them, and that's typically free if it's just a—a student club. But, it's a good thing for students to know about.

And then there's everything in between. There's, and there's a lot of colleges that have good learning supports that may not be autism-specific, but are still good for someone to know about if they have challenges with executive functioning, with time management, with organization, and so on. It's good for them to know that this college will provide them coaching and resources to address those issues, even if it's not called an autism program. So, it really depends on what the student's needs are, and it's important to match the student's needs with what the college provides. And not all—not all autistic students need special support programs. I don't want to give the impression that all students need to seek out these colleges. They may or may not have those needs, and there's a lot of other considerations, too, in picking a college, such as geographical location, the majors available, the size of the college, and many other factors.

SUSAN: Thank you. So I have one final thought, and that is sort of the overarching theme of this, is can you think of where an institution can have the greatest impact across departments to promote an autism friendly campus?

ERIC: Well, it'd be hard to—to pick one thing. I think you alluded before to some of the different things that colleges do, like sensory friendly spaces. It's important to remember that being on the spectrum affects many different aspects of how you interact with the world, so it may affect your dietary needs, it may affect your sensory sensitivities in the dining halls. So people who work in the dining hall should be educated to be sensitive to the needs that someone might present with if they're asking for something very specific. It's great if they can be—adapt to that similarly in the residence halls. Someone might have a need for a single room or a quieter part of the building. And, so, it's great when institutions can be sensitive to that and make accommodations. So I guess, in general, I'd like to see staff and faculty educated about what it means to be on the spectrum and be as accommodating as they can within reason for those students. And there's another concern we haven't touched on, really, which is mental health. And as a psychologist and parent, it's a particular concern. For example, a recent study of over 3,000 college students found that the rates of suicidal ideation in the past year for students on the spectrum was around 54 percent. And you compare that to the rate of suicidal ideation for students in general, in another large recent college study, of 6 percent. So the rates of anxiety, depression, suicidality, are really high and this is thought to be—not necessarily—not just a function of autism, per

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se, but of what happens when autistic people interact with a majority neurotypical culture. And, I think, a lot of the challenges that people on the spectrum experience are similar to the challenges any marginalized minority group experiences in interacting with the larger society. Being bullied, the rates of bullying in autistic children and teens are extremely high, much higher than the general population. And, so, if you are treated as different, and treated as less than, it affects your self-esteem, affects your

ability to advocate for yourself. It may affect your optimism about your ability to succeed socially, academically, in the workforce. And we really need to address these things coming from multiple directions to provide more welcoming environments and supportive services so that autistic students can be less—less inclined to suffer from these conditions.

SUSAN: That's an excellent point. So, again, I appreciate your insight and your thoughts on this. And I'm going to close out our podcast with a small quote, and this was articulated by Scott M. Robertson from the College of Information Sciences and Technology at Penn State and R.A.D. Newman from the Autistic Self Advocacy Network. They wrote an article back in 2008, but I think it resonates about autistic acceptance at college campuses and technology and the growth of neurodiversity in society and academia. And what the quote is, "The spirit of autistic acceptance on campus should focus on embracing autistic college students' diverse gifts, talents, and abilities while acknowledging and respecting their autonomy, individuality, and rights and responsibility. This also means that members of a college campus must strive to empower autistic college students and foster their personal growth rather than seeking to normalize them." Thank you again, Eric, for joining me, and thank you to Stairway to STEM for sponsoring this podcast.

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](http://StairwaytoSTEM.org). Again, thanks for listening and keep tuning in.