

Supporting College Students with Autism through the Illinois Neurodiversity Initiative (I-N-I)

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Host Sal Nudo: You are listening to the family Resiliency Center podcast. I'm your host Sal Nudo. The family Resiliency Center is a transdisciplinary research and policy center at the University of Illinois Urbana-Champaign.

In this podcast, I'll be talking with Jeanne Kramer, the director of The Autism Program on campus and a teaching assistant professor in the Department of Human Development and Family Studies. Jeanne is with me today to discuss a new program at the university that will support incoming freshmen with autism spectrum disorder. The first cohort of students in this program will start in the Fall 2022 semester, and these individuals will be supported on many levels while they're attending the university after they graduate.

Jeanne, thank you for joining us today to talk about this exciting new program at the University of Illinois.

Guest Jeanne Kramer: Thanks for having me, Sal.

Host Sal Nudo: The official title of this program is Illinois Neurodiversity Initiative, or INI for short. Can you explain the term "neurodiversity" and also talk about some of the other conditions besides autism that can make someone a neurodiverse into?

Guest Jeanne Kramer: So back in the 1990s, there was a woman who started using the term neurodiversity to talk about people who have brains that work differently. We've noticed that throughout history throughout all history, there are people who clearly think differently and have different strengths and weaknesses in their brain. As far back as Michelangelo they can go back and look at, historically, what was written about him. He was a very odd character. He had emotional outbursts and he was so focused on his work. And this was clearly different than the people around him.

It's postulated that Einstein is someone who had a neurodiverse brain because he had things that his brain did so well, and then other things that were odd or eccentric about him.

So, we are all neurodiverse because. Our brains all work differently. The caution we need to take when using this term is that we can then minimize conditions that can cause a neurodiverse individual difficulties in functioning in a neurotypical world.

Neurodiversity, in its simplest terms, is brains are wired differently as we're talking, current vernacular neurodiversity is used to describe conditions like ADHD or dyslexia apraxia. There are conditions where the brain can't do math that can't conceptualize quantities can't write easily. Agraphia it's called; even things like anxiety and depression. OCD bipolar disorder are all considered different ways that the brain is wired and different expressions of how the brain works.

Host Sal Nudo:

The I-N-I program will support neurodivergent students from the time they move in on campus through the time they graduate and eventually get a job. They'll be supported academically and socially and will develop skills on the realms of mental health and the workforce. Jeanne, tell us about the ways all these great things will happen.

Guest Jeanne Kramer:

To be honest, Sal, we are writing the script as we go along. We're very clear that this is a pilot year and when I met with each student before making a mutual agreement that they would participate in the program. I was very clear that we want their input into what is going to happen from day one through their fourth year, so we have some things established.

Now things that we've been trying over the past couple of years and have figured out are helpful and work, but we need to try them out with these students. And so, I'm going to tell you what we're offering next semester, but this very well could change after we get their input.

There's a very common saying out there right now among people on the spectrum, and the saying goes, 'Nothing about us, without us.' So we are really trying to design this program. It will be designed by the students, for the students, with the guidance from leadership that we hope to provide.

So, with all of that as a caveat, we hope to have the students involved in weekly mental health checks with the Ph.D. students over in psychology. That will look different for every student based on what they need, but we will be making sure that if they're on medications, they're taking their medications, that they're eating. That they're getting along with their roommates and their professors will be plugging them into campus resources should they require something like counseling.

I know that accountability is really helpful for all students at the university level, so they might be an accountability partner, but that's one portion, the mental health of these students is something that we're really going to always focus on.

Another aspect is that academic success that you talked about. This first semester all the students are enrolled in a class that will concentrate on the skills that it takes to express your intelligence. These can be things like staying organized, meeting deadlines. But also things like how do you communicate with professors? How do you get yourself into a study group? How do you plan a project? How do you work in a group? These are all things that may not come naturally to a neurodiverse brain, so we hope to address it this first semester with the course and then we will support that throughout the upcoming semesters, and how we do that will be largely determined by the students and how we support them academically.

Parental involvement is going to be a huge part of this program. The research has shown that parent involvement is a key indicator of success in college. These students require support. It's part of the diagnosis of autism and getting support from parents is very important, so giving parents guidance in how much or how little to be supporting their students and how best to be supporting their students by meeting with them once a month, we'll have a virtual meeting and it'll be a support group-type format with a lot of education about how the students are doing as a whole and answering their questions and concerns socially. The plan in place right now is that we will be meeting once a week throughout this semester as a group to go through a curriculum called the Peers Curriculum, which is an evidence-based curriculum on social development on making and keeping friends. It was developed at UCLA, and we'll be taking them very slowly through that curriculum.

Part of the curriculum is that you have a social coach. We would like to use university students as social coaches, and the goal of this semester will be to get them through enough of the curriculum that they will by the end of the semester be established in a group or organization with other students who have similar interests they do because the research shows that we make friends with people who have similar interests. So, by the end of this semester, they'll have this source of people where they can make friends.

A lot of people are talking about how this group of students, how great it is for them to come together and for them to be social with one another. It very well could be that this group of students has a lot in common and that they mesh and they're able to provide social support to one another. But neurodiversity in and of itself is not a common interest, and I think that's very important to realize going in that it's not a given that this is going to be their social base. We want them to be spreading out throughout the university and really finding their people with their interests, so we'll be providing social activities for them, but

really, that's the training ground for them to go out and use that with other people across campus.

As far as workforce development goes right now and over the past four years, we have been contacted frequently by corporations that recruit heavily from the University of Illinois and who are looking for neurodiverse talent specifically, because it's starting to really come to light and there's beginning to be research out there about it that autistic individuals, when working in their area of high interest, can be up to 80% more productive than their peer who doesn't have the same brain wiring and their ability to look at problems differently, not get involved in office politics, their loyalty to companies. Those are all great assets that they bring to the workforce.

Along those lines, hopefully this group will be offered a lot of opportunities to grow in their employment skills. The corporate entities that are interested are really wanting to engage with them to work on things like interview skills and resume writing, but also to offer them specific opportunities with internships or job shadowing experiences as they go along. We also plan to address this directly through either workshops or coursework that will help them maintain their identity as a person on the autism spectrum, while being valuable and being able to demonstrate their value to corporations who are recruit.

Host Sal Nudo:

That sounds great. So, the autism spectrum is wide-ranging and some students in this cohort may need more assistance than others. Can you talk about that element of the program?

Guest Jeanne Kramer:

That's actually a really interesting thing to address, and I'm glad that we're addressing it here.

Autism is a spectrum, and everyone on the spectrum does indeed have different strengths and weaknesses. But in order to get accepted to the University of Illinois—and these students did get accepted on their own academic merit—most of these students will have a lot in common. A lot of these students will pass as neurotypical students. A lot of these students will have a very easy time learning course material.

For instance, when I was interviewing these students, their perception of being surrounded by other students on the spectrum, oftentimes was, 'Well, I'm doing pretty well and I don't want to be around students who maybe aren't doing as well as I am.' And what I could assure them of is that if you got into the University of Illinois and you're on the autism spectrum, you're doing pretty well, and so you're high achievers and you're highly intelligent and have a lot to offer to the university and to the program. All of these students are very high achieving individuals or they wouldn't be here at the University of Illinois.

What's going to be different about them or make it spectrum-y about them is that some of them will be stronger in a specific area and weaker in a different

area, so there will be different strengths and weaknesses among them, but there will not be a different level of intellect, which really does oftentimes tend to separate out people on the spectrum.

I really think that these students will have a lot in common. As far as just like everyone across the university has that in common, they're intelligent and high achieving individuals.

Host Sal Nudo: How many students are in this cohort?

Guest Jeanne Kramer: I just finalized the numbers yesterday and there are 10.

Host Sal Nudo: Tell us about the selection process for this first cohort of students with autism.

Guest Jeanne Kramer: For this first cohort, we were looking for students who were able to say that they could meet certain expectations. The first expectation was that they would be interested in receiving and participating in the supports that we want to offer for the full four years while they're in school. They're not obligated to stay, of course, if they don't need the supports anymore or if they're feeling like it's not a good fit, it's not an obligation, but we were really looking for students who are in it for the long haul, who really want to see that success from the time they move in all the way through to getting that first job and graduate.

Another thing we were looking for were students who are interested in giving us feedback on what they want and what they need in a program. These students all our students who I think will be able to come in and say, 'This isn't working, this isn't helpful. I have an idea this might be helpful.' We were looking for students who are motivated to really help us kind of build the program.

Ultimately, the most important thing we're looking for students who had the recognition that the supports that we were offering are the supports that they need. If a student was not convinced that they needed what we were offering, that was something that we wanted to have a mutual understanding. That yes, I do need this help because we all know the first step to receiving help is accepting that the problem is there and that you need the help in the first place, so that was really the biggest factor.

Host Sal Nudo: How many people were involved in the selection process and who were some of your colleagues with that?

Guest Jeanne Kramer: I was the one who filed through the applications and interviewed the students afterwards, but it would really be remiss if I didn't acknowledge how the College of Engineering worked with me in this process. Of recruiting applicants, they have been on board with this process from the very beginning and offered me a 3- to 5-minute spot during every freshmen orientation that they offered this summer, which was three full weeks. So, Monday through Friday I would show up during their freshmen orientation and I would be in the portion when the students and parents were both in the room and I would give my elevator pitch

and we ended up getting probably at least one-third if not half of our cohort from that recruiting pool, so I'm really grateful to them.

Host Sal Nudo: The University of Illinois Urbana-Champaign is historically known for supporting students with disabilities going way back, and now this program for students with autism will begin this fall. How cutting-edge and historic do you think the Illinois Neurodiversity Initiative is?

Guest Jeanne Kramer: I think at last count there were 75 universities that in one way or another in the United States are giving support to autistic students. There's actually an organization called the College Autism Network, and they've been meeting over five years, probably 10 years, with a national conference every fall. They have a communication board where people are communicating with one another on supports. So we are not, as far as the nation goes, the forefront of this. We're not at the tail end either, because if you look at what's going on in the Big 10, for example, I do not know of a program or a university that is in the Big 10 that is offering supports to this extent.

And you also have to understand that every university, if they're developing a program, is developing one that's tailored to the needs of their students. So there may be some programming out there that exists at different Big 10 universities, but I'm not aware of a coordinated multidisciplinary program like this that exists in the Big 10. So there's this wave of interest and wave of things that are happening around these programs and we are riding the wave. We're right in the center.

Host Sal Nudo: Well, I can't let you go today without giving you a chance to talk about The Autism Program, also known as TAP. Tell us about TAP, which got its start on the Illinois campus in 2005.

Guest Jeanne Kramer: So, The Autism Program, or TAP, is actually the vehicle that got us here. TAP is a statewide organization that's funded by the state of Illinois and has 15 to 20 different facilities across the state, many of which are full service autism clinics. So they offer things like psychology assessments, neurobehavioral assessments for autism, ABA services, speech therapy, occupational therapy counseling. This branch is a university affiliate and began about 17 years ago, and we have been largely a training center for university students who are planning on going out and serving in the field of autism.

We also provide programming for the community for families who newly receive a diagnosis of autism to help them begin their journey and understand what that all means. We have a full-service Resource Room here that has a library and creates materials for free for teachers, for offices, for families that provide information and visuals for people on the spectrum because that's a huge support for them.

But all of that being said, we were working in that community realm, building capacity within our community for autism services, helping to bring ABA providers here to our community and building relationships within departments in the university and clinics around town. We were minding our own business when Microsoft came to campus and they started what was called the Accessibility Lighthouse Initiative. And as part of that initiative wanted to build a pipeline of autistic talent to Microsoft because they hire so many University of Illinois students. So I think that someone Googled University of Illinois autism and TAP popped up, so we were part of a number of departments that were involved in the initial task of developing this pipeline of autistic talent, and we have been the ones who have been able to persist in that because of the structure of the autism program.

Kind of undergirding everything that we do, we're able to just think every day, all day about autism, which many of our other programs like Disability Resources and Special Education and Psychology can't because they have to diversify and think of all the areas. We're able to just think about autism, so yeah, it is absolutely an integral part. They are the ones who are funding this program this year and should be given credit for that. Just to mention, they fund for services 0 to 22 for families and children with autism. And our incoming freshmen fit into that age range, and this is the age range, kind of this transition age from school age to adulthood where there's the least amount of services and the least amount of attention paid, so it's been fun to kind of fill in that gap and really has been wonderful how that's all come together.

Host Sal Nudo: Well, Jeanne, thank you again for your time today. We look forward to hearing about the successes of the Illinois Neurodiversity Initiative and seeing how it will develop.

Guest Jeanne Kramer: Thanks for having me. I'm anxious to see those things too!

Host Sal Nudo: For any questions or to learn more about the Illinois Neurodiversity Initiative, contact Jeanie Kramer at jjkramer.illinois.edu.

You can learn about the work The Autism Program does by visiting the website at theautismprogram.illinois.edu. I'm your host, Sal Nudo. Thank you for listening.