



ADALIVE!

EPISODE 63: INTERDISCIPLINARY OUTREACH IN THE POST-SECONDARY ENVIRONMENT: NOTHING ABOUT US WITHOUT US

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STEVE KUUSISTO: Hi I'm Steve Kuusisto.

DIANE WIENER: Hi I'm Diane Wiener and we're with the Burton Blatt with Syracuse university. You're listening to ADA live.

BARRY WHALEY: On behalf of the southeast ADA center, the Burton Blatt Institute and the ADA National Network welcome to episode 63 of ADA live. Hi everybody I'm Barry Whaley. I'm the director at Southeast ADA center and I'm your host for today. Today we're going to be talking about interdisciplinary outreach in the postsecondary environment. We're going to focus on a new initiative at Burton Blatt Institute. The office of interdisciplinary programs and outreach. Before we begin. As a reminder ADA live listening audience if you have questions you can submit them anytime through our website ADA live.org. The Burton Blatt institute housed at Syracuse University College of Law recently announced two scholars have joined. They're charge with launching a new initiative known as interdisciplinary outreach. They're Steve Kuusisto, university professor and Diane Wiener. Steve is no stranger. He was our guest last spring talking

about his great new book “Have Dog, Will Travel.” In their new positions Diane will join as associate director of the office of interdisciplinary programs and outreach. Steve who's a university professor will serve as the director of the initiative. So, it's my pleasure to introduce today's guests. Hi Steve and Diane. Welcome to the show.

DIANE WIENER : We're delighted to be here thanks for having us.

STEVE KUUSISTO: Thanks Barry.

BARRY WHALEY: So I'm interested if you can tell us a little about this initiative and how it complements the mission of Burton Blatt institute.

STEVE KUUSISTO: I'm going to defer to Diane and then I'll sweep in.

DIANE WIENER: I think one of the exciting things about this initiative is that we have the opportunity to think critically across an array of different locations in terms of disability justice, cultures, identities and the concept of disability as one that moves through every arena of life and something about which one might have a sense of pride and not shame or over coming but rather ways we might think about disabilities in addition to wellness, adaptive and inclusive athletics, employment, disabled vets population. People returning from multiple environments after being in the service specifically. Disability arts and culture issues of recruitment and retention of disabled students and certainly things that connect with disability, cultures and faith and secularism certainly also the music and coesais. Pretty much anything you can think of information and connection technology. All kinds of different aspects of life in which disability interfaces and unfolds. Those are some of my thoughts about the importance of the initiative and how we're going to collaborate with people among our students faculty, staff, alumni, community members, etc.

STEVE KUUSISTO: This is Steve here. You know it's interesting disability is really everywhere once you learn to look for it. So we think about disability many of us who have been in the field of disability advocacy and disability rights we tend to think of it as being co-determinate with the disabilities act. But it's also that disability is in the arts. Frederick chough pan had disabilities. We know Beethoven did. Disability enters into American

and world literature in all kinds of complex and interesting ways. Disability is a form of thinking that is to say we use the fancy word we use the word you epistemology. A way of knowing really. Disability is in fact as we now understand through great remarkable research being done and advocacy being done by people who are neurodiverse that disability and imagination function according to talents revealed by disabilities. So we're in a really remarkable moment where one can actually enter into any area of human inquiry and find a disability focused reflection or dynamic and that's partly what we want to be focusing on is opening the doors to dialogue, engagement, by scholars and students here at Syracuse university and around the United States.

BARRY WHALEY: I'm wondering. Putting all those things together Steve and Diane, we know and Diane mentioned recruitment and maintaining students with disabilities and we know that students with disabilities who enroll in college very few of them actually complete a four year program or get a degree. How does your work then assist those students in completing a college program?

DIANE WIENER: I think one of the things that's really important is supporting students without condescension as contributors to the campus community and as contributors to the world at large. Often times we think about disability in a main stream way, some people call it a pity party or having to do with trying to make better or having a curative orientation. In this case it's really about encouraging people as Steve alluded to just now, ways of knowing specifically disability oriented ways of knowing how do the students get to get connected in such a way that they understand that they are contributing to the campus that they are not you know an energy that is disrupting life but in fact a necessary and central part of campus life. So we enhance the tapestry of divergence and that the students understand that they're in the position to be leaders and moving university forward in a way that's about inclusion and belonging not Just in some linguistic sense but in a very practical way. Encouraging the faculty and staff and leaders of the university to work in partnership with the students so the students have a sense of centeredness and primacy is very much a political project and a culture change project and that's one way that I can answer among others that I would suggest right now.

STEVE KUUSISTO: Yeah and this is Steve I would jump in and add that one of the reasons that students with disabilities don't make it all the way through a four year undergraduate experience is, has to do with the very critical tension between studying, being a student, and financial aid. That in other words in other words for instance I'll speak in personal terms here I'm blind. I went to college at a liberal arts school where I was able to go to college for free. My father was a senior member of the administration. That allowed me to take classes or not take classes. Drop a class if it was above my abilities given the time constraints and difficulties. I could take incompletes. I think I still hold the record for the number of incompletes. I can't prove this but it surely has to be true. So it took me five years to complete college rather than four and I came out with no debt. More over I didn't have to have a job as a secondary dynamic to getting an education. So one of the things that I'm interested in seeing to it that we achieve is more undergraduate and graduate fellowships and scholarships for students with disabilities who wish to attend Syracuse university and that would be regardless of what it is they choose to study. If we could help take the burden off of the financial struggle and free students with disabilities up just to study then they're going to have I think a better outcome.

BARRY WHALEY: I have a question. How does the office of interdisciplinary outreach reach. How does this interface with the academic strategic plan of the university?

DIANE WIENER: The academic strategic plan is invested in a strong interdisciplinary orientation. There's an emphasis on globalization and on the idea that students from all over the country and all over the world will find in Syracuse's iconic class offerings and opportunities to have majors and an array of different interest areas and disciplinary focus and certainly professional skills development. The opportunity to really broaden their understanding of what it means to live in inclusive global society. So I feel that this initiative interfaces precisely with the different perspectives on when someone graduates from Syracuse university. By the time they've graduated how might they on the job market for example be understood as recognizable, as having graduated from Syracuse and one of the ways that that individual who will have graduated is identifiable arguably by the time all of this comes to fruition will be that they understand the relevance and

importance of disability as part of the ways that people understand the complexities of our current global society. So I think that in all the different points of reference in the academic strategic plan, in term of academic excellence specifically that again disability is not an after thought or something you have to deal with or requirement or that subject or that again but on the contrary it's really a rich engaging and as Steve often talks about an imaginative way of living in the world. Neil Marcus famously said that disability is an in genius way to live and many people who are disabled find ways to manage out of requirement because the world wasn't built for us. People find ways they have to manage as a way to cope. But that orientation is also advantageous. Rather than having it be that we have to do that because we don't have a choice, because of discrimination, because of marginalization and oppression, rather that people might have this approach just because of creativity. I think that is part of the academic strategic plan is the orientation toward academic rigor in addition to creativity interdisciplinary and inclusion.

STEVE KUUSISTO: I would add sometimes people ask me do you have a better term for disability. My response is yes, citizen. I think if we really imagine the disabled human being as a fully functioning fully fledged and fully included member offsite then the world disability ceases to have any merit. It's an old world. It goes back to the 19th century. The first person to use it wildly was carl Marx. He used it to designate people who were injured and not capable of working in factories. The term from it's very beginnings has to do with economic in capacity. An embodies economic in capacity. We keep playing around with this word because we're the inheritors so we say things like we're differently abled or whatever and the fact of the matter is if we just use the word citizen and we really mean it, that all citizens are equal as Thomas Jefferson avowed then that's one of the desired outcomes of an ambitious university curriculum. That looks across disciplines, across units of engagement and is at it's core designed to make people better civic parents. And disability is going to be part of that at Syracuse because of this initiative.

BARRY WHALEY: That's well said. Certainly a powerful role is that of student. So in thinking of those roles, those student roles that those students with disabilities play how do you see them as being part of this initiative? How do those, how does your plan for

research projects, teaching, collaboration, all the activities that surrounded this program, what roles do those students play?

STEVE KUUSISTO: I'm going to defer to Diane in a second. But I would say that the Burton Blatt Institute already has a stopping commitment to hiring and involving students with disabilities in the research work that the program does. We have several students with disabilities both at the graduate and under graduate level working on important projects through the Burton Blatt institute. So from the very beginnings BB I you know more than a decade ago began with that principle in mind. So we seek to involve students in all kinds of scholarly activities and research activities but as we've already alluded to one of our goals is to bring more students in and to do that through engaging with different units on the campus who may not even already know that they actually have an interest in disability. For instance we have architects here who know that universal design is an important thing and that it's connected in some respects to the origins of disability thinking in the 1980's and 1990s but they may not know that working directly with students from other units at the university on imaginative ideas involving new ways to engage with accessibility and design are indeed possible. So that's one of the things we want to do. To be involving people who may have an interest but don't know the extent which that interest might be translatable into really interesting work with students and with outside organizations that provide resources and funding for research and now I'm going to pass my imaginary baton to Diane who is well positioned to answer some parts of this because she's been directing our amazing disability culture center which really does reach across the campus in all kinds of ways.

DIANE WIENER: Thank you very much. I think that one exciting thing about this is thinking about the history of the university, the history and ongoing work of the Burton Blatt institute and the fact that we have so many different disability rights groups that exist already but as Steve just noted there is simultaneously this presence of energy where not everybody necessarily is oriented already toward thinking about disability as part of the work we're doing. How do we connect the people who are very invested and very awake or woke as some of the students say, I guess I'm allowed to say that, people who are woke about disability already and people who may not necessarily have that in

mind when thinking about inclusive pedestrian dodgy for example. There are so many illustrations of this. We have this outstanding collaborative design initiative and program in our visual arts program VPA. There are people who collaborate with students as end users in a variety of projects that have to do with disability inclusion and universal design and what would it mean to create course work for example or a pedestrian logical opportunity where the students who have been end user folks who have been part of those projects might help create new courses with each other, maybe they'd be taught in different departments including within VPA. There are also people who do all kinds of work in the college of education and the school of education excuse me who are committed to inclusive education obviously and we have a long history of that at this university and in Syracuse and so how do people create writing initiatives in the community in partnership with people who have a background, direct experience with disability and how that might affect how courses are taught. Not Justin terms of how the curriculum is designed but the actual content. There's a poetic seminar and there's always going to be poetry available in multiple formats. But also the poets selected might be student poets who are in the middle of creating a new journal on campus because they feel empowered to do so. There are lots of examples we can give. I think that we collaborate a lot with one of the oldest disability rights graduate student groups in the country that was 17 this fall. We have under graduate disability rights called the disability student union. There's a new very cool emergent autistic rights group called on the spectrum which was created by our students working with alumni and staff as well who identify with on the spectrum. We also have people from the disability loss society and many other student groups active minds as a mental health rights organization. So between the disability student union as the under graduate realm and all these other groups of specific commitments to certain kinds of disabilities. There are the general and the specific. I think we have tons of opportunity for collaboration with students at the center of the conversation.

BARRY WHALEY: That's interesting. There's such a richness on the Syracuse university campus of groups. Several of which you just mentioned. A couple observations. Number one we certainly have a legacy at Syracuse Burton Blatt for instance. But even today how we have carried that legacy forward in just the amazing

work that's going on today. Now the other thing I wanted to mention is Diane you are the first woman I think I have ever met who used woke and pedagogy together in the same isn't.

DIANE WIENER: Well we're here to please and delight berry.

BARRY WHALEY: Let's shift gears. Obviously you and Steve have a very comfortable relationship. How did you two meet?

DIANE WIENER: It was the F train at midnight. No that's not what happened. What happened Steve?

STEVE KUUSISTO: Well when I came here in 2011 to direct the honors program Diane came at exactly the same time to direct the newly created disability cultural center. We are the first university to actually have a disability cultural center and she came on board and she reached out to me and said let's get together. And so we did we met at the universities Goldstein faculty and alumni center and we had a lunch together and we began talking about disability culture, disability history, disability ideas, the arts and you know pretty soon it was very clear that we were basically siblings from another mother. That was the origins really of a great friendship. That was really the start right there. I think it was kind of like John Lennan said to Paul McCarthy "any of you want to join my band?" It was pretty much that kind of thing.

DIANE WIENER: I think what's interesting too is one of our first meals because it was there and it was a sharing of ideas and of food happen I think pretty much immediately we started talking about this series we created which has existed ever since called disabilities as ways of knowing a series of creative writing conversations. And this was a collaboration across the different schools and colleges led by Steve and by me and our students. And the disability studies program, the disability rights clinic. The Center on Human Policy on Inclusive Higher Education. Obviously the Burton Blatt institute and so many examples of disability justice work engaging research activism, we have just so many opportunities here. So the first conversation we talked about a lot of that. But we talked about writing. We began to talk with each other. I was actually pretty

intimidated because I thought oh my god I'm meeting with Steve Kuusisto, who's name I didn't know how to pronounce. I thought this guy is amazing and we're going to be very close friends and take up some cool opportunities to do weird things that are impactful and connected with all kinds of other folks. You know the art series that we created and the poetic series I think is in many ways one of the grounds of this new initiative. All of those programs are recorded and captioned and available on the YouTube channel.

BARRY WHALEY: Diane we're familiar with Steve from previous episodes. We know he is an accomplished author but you just published your first full length poetry collection. Can you tell us about that?

DIANE WIENER: Well thank you for asking about that. I guess the short answer to a really wonderfully weird thought around this question is that I had an encounter with this understanding of this Jewish mystical energy who is connected to the cab law and Jewish mystic in a broad way and this golem came to chat with me I'll say energetically and we began interacting in my imagination and I wrote a poem in the after math of the experience and then Steve, I wrote another one and Steve said well keep going. So if there's anything good that was accomplished here Steve is at least partly blame worthy. Because he encouraged me to keep going and I did and I ended up writing over a hundred poems all connected to this character who's my interlocker, my companion. Some people conjecture other symbolism here but it's really just friendship as far as I'm concerned. And we go on these different add ventures together that involve tear dactyls and roller coasters and carousels. It's one of the weirdest things I've ever written for sure but I think it isn't really about me at all. I think it's really about other people's experience of it and once you write it and share it it's for the world and people do with it what they will. It was published by Nine Mile press in Lafayette New York and Bloomsday all hail James Joyce. James Joyce and Thomas Jefferson neither of them not necessarily perfect in their ways but both mentioned in our conversation with you today.

BARRY WHALEY: We need to stop for a minute for a break. ADA live listening audience if you have questions for Diane and Steve about the office of interdisciplinary programs and out reach at the Burton Blatt institute or if you have a question about poetry or about using woke and pedagogy in the same sentence you can ask that question or a question about any other ADA live topic by submitting your question to ADA live.org. So let's stop for a minute for a word from our sponsor the office of interdisciplinary out reach at Burton Blatt insurance constitute at Syracuse university.

BARRY WHALEY: Welcome back everyday we're talking about Steve Kuusisto and Diane Wiener about the newly launched office of interdisciplinary programs and out reach at Burton Blatt Institute at Syracuse university. So Diane and Steve, considering your many aspirations for this new endeavor what are one of your best hopes or a keep them to or dream that you're thinking about to accomplish in the next six months to a year.

STEVE KUUSISTO: I'm a baseball fan. Like all baseball fans I like to think about home runs. There's nothing better than a home run. But the real truth is if you're a winning team you've got to get a lot of singles. The home run only has value if there's a lot of ducks on the pond. Lots of people on base. I'm hoping we can start this Institute out by bringing people together and creating initiatives that will later generate much larger and more impactful opportunities and resources. I want to hit some singles. Those can be as simple as bringing faculty to the table that don't know they're interested in disability and getting them turned on and bringing together students across the university who haven't historically interacted with other students. Both disabled and nondisabled students to think about contemporary issues having to do with disablement. For instance to give you an example right now I'm teaching a course in the honors program here the title of which is DNA in popular culture. That title doesn't necessarily suggest what it's about. What it's about is the capacity we now have through extraordinary research that's been done at the university of California and Berkeley that allows us now to actually modify the human genome at the most intricate levels. Research led by Jennifer Doudna at Berkeley means we can now actually modify in utero infants before they're born and actually transform their DNA. That's an exciting processes in the fact that it

could conceivably lead to the capacity to cure multiple sclerosis or devastating pulmonary cystic fibrosis disabilities like that. On the other hand it is also alarming because it opens the possibility to designer baby ease, equal opportunities in health care, what we would call a disability studies eugenics two point oh. The capacity to further devalue or eliminate people with disabilities. There are really pressing issues that are really right now knocking on the door of what we call bioethics or social ethics. Bringing people together around the table to think about what it means to be human is now actually a marriage of science and really profound contemporary research but also ethics and medicine and embodiment. That's the kind of thing we're thinking about here.

DIANE WIENER: It's interesting you were asking me about the poetry earlier and the goal in many ways is imagined in different literary representations as disable # D in the fact that a golem when it's created from the mud and the blessings and implications that are spirit wale utilized is not able to speak for it. The poems I wrote, the status of disability in this character is [inaudible] but one of the things that's interesting is Mary Shelley when she wrote Frankenstein which is widely recognized as the first example of science fiction of course written by a woman, when she created the representation of so called monster that monster some people have wondered whether it was in many respects based on Jewish history of the creation of a golem. It's very much about protection from innovation and being undermined. So people who are disabled are stereotyped in all kinds of extreme ways as a threat to the normative society as not belonging in some way that is not understandable by someone who doesn't share that experience. Eugenics is not extreme anymore if we really do have the capacity to do the kinds of things. That we actually are living in a world where people can decide who is worth living, whose life is worth living and whose life is considered monstrous and under what circumstances. So I agree with Steve's assertions here and we have all kinds of literary history to support why it's important to really forward these conversations and interdisciplinary way.

BARRY WHALEY: I'm wondering we've been focusing most of our discussion on the Syracuse campus. But we have a very broad audience. I'm wondering how work you're doing can be replicated on other campuses?

STEVE KUUSISTO: I'm going to pass the baton to Diane who's involved in this.

DIANE WIENER: One thing is that we have to gather together virtually and in person and in lots of other ways the commit that's we know people have all over the country and global he a. For example people want to start disability cultural centers all over the world and how do they operationalize that or make that come true. So maybe a simplistic way to answer you berry but one way is that people don't know about each other's work. So I think people need to actually meet each other. So there's this wonderful conference I want to give a shout out to Wendy Harper who used to be here, The Associations for Higher Education Disability who helps coordinate the National College Center for Students with Disability and the conference Disabled and Proud that had historically been at SU and is now housed and created through initiatives with those spaces I just mentioned. The National College Center for Students with Disabilities. So they all work together to create Disabled and Proud which is a university structure but really it can be any place. It doesn't have to be housed in an institution where disabled students meet each other and talk about what it's like to be disabled and talk about what it's like to create models where they're really engaged and how they might start a disability cultural center or a club or work with faculty who maybe teach in what is not officially called disability studies but is something that has to do with an understanding of disability again is not a triumph but part of the human experience. There is now this incredible group of people from all over the country and globally who are being introduced to each other through these different opportunities so I'm really interested in making sure people find ways to connect. Steve and I have been talking about creating a portal or a global set of tool kits all over the country and all over the world. How do people know what resources they need to create opportunities like this? In a parallel way what kinds of things can people do at other campuses to create interdisciplinary programs and outreach with disability at the center. I think that the kinds of models that we're going to create would absolutely be adaptable and able to be used in multiple contexts. At universities, at NGOs, at DPOs, disabled people organizations all over the place. That's one way to accomplish that.

BARRY WHALEY: Thank you. We are running out of time. So I want to stop here Steve and Diane and ask if there's anything else you'd like to share regarding this new initiative or any other plights you may have.

STEVE KUUSISTO: Oh dear. Flights of fancy. Yes I would like to say that this conversation should to listeners out there really be an invitation. We're open for business. We're open for ideas. We're open for imagination. I started this off by saying that disability isn't merely a matter of law and advocacy around the law but that it is also richly conversant with every area of human activity and engagement and history and culture. That being said if someone out there in pod cast land, remember when we used to call it aid radio land has an idea for thinking about disability outside the box as we like to say, let us know. Contact us. Be in touch. That's my flight of fancy.

BARRY WHALEY: That's an excellent one. Go ahead Diane.

DIANE WIENER: I apologize that is an excellent one. I think that when Steve and I first started talking about this I started to think about the excitement around the possibilities here because it is certainly work that will be connected to the mediacy of our populations here at Syracuse University but it really is an invitation as Steve said to work around the country and around the world. I have ideas about creating documentaries where disabled people are at the center of the creation of reproduction. And that we partner with already existing film series and creative writing programs and arts initiatives and faith training initiatives in the sense that people are learning about divinity or secular humanism. How do they think about that in making the spaces go beyond compliance and in many the law exempts some faith locations from having to abide by inclusion. So what can be done about that. So we create a more welcoming society. There are a lot of people working on matters related to this all over the country. Engraving about issues like food scarcity and food access. The history of the way disabilities described, the overall history of people who have lived through different experiences before since the AD ashes was ratified. Really it's across the board very many wonderful opportunities for innovation, engagement, again centering disabled expertise always and the wonderful adage nothing about us without us, being genuine. There should never be a

conversation about disability where disability are not at the heart of the conversation from the beginning.

STEVE KUUSISTO: Very true.

BARRY WHALEY: Thank you Diane. Thank you both so much for being with us today. Listeners our guests have been Steve Kuusisto, director of interdisciplinary programs and outreach and Diane Wiener research professor and associate director of the interdisciplinary programs and outreach at the Burton Blatt Institute. Thanks again for being with us. Listeners as always we thank you for Joining us. This episode and all previous ADA live episodes are available at our website ADA live.org. All our episodes are archived in a variety of formats including streamed audio accessible transcripts. You can also download as pod cast. It's as easy as going to the pod cast icon on your mobile device and searching for ADA live. Again you can submit your questions at any time, ADA live.org. And if you have questions about the Americans with disabilities act you can contact your regional ADA center at one 800 nine four nine four two three to two and remember those calls are always free and they're confidential. ADA live is a pod cast of the southeast ADA acceptor. Our producer is Celestia Ohrazda, along with Beth Harrison, Mary Morder, Emily Reuben, Marsha Schwanke and me Barry Whaley. Our music comes from four wheel city the movement for improvement. We'll see you next month.

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