

That's Inclusive!

Episode 19 Transcript

Episode title: Access to Science with SEE Science Center and Unchartered Tutoring

Vanessa Blais (VB): Welcome to That's Inclusive! Where we talk about disability and what it means to live a full life, engaging in our communities.

What does that look like? And how can we work together to make our world a more inclusive place?

Chase Eagleson: Hello and welcome to That's Inclusive podcast hosted by the New Hampshire Council Development to Disabilities. I am Chase Eagleson. I am the policy and planning coordinator for the New Hampshire Council Development. This is today. I am joined by:

Peter Gustafson: Hello, everyone. I'm Peter Gustafson, deputy director at the SEE Science Center in Manchester, New Hampshire.

Shana Hawrylchak: And I'm Shayna Hawrylchak, executive director at the SEE Science Center.

Amber Nicole Canaan: I'm Amber Nicole Canaan, and I'm the CEO of uncharted Tutoring, and someone with a number of disabilities.

Chase Eagleson: It's great to have all three of you guys here. so today we're going to be talking about the importance of inclusion, accessibility in scientific spaces. And it's fantastic to have everyone here to do this because it's a topic that does not get talked about enough. So, let's just jump right into it. often in scientific space as well as pretty much every other field, we have conversations, programs, and initiatives that, circle around the idea of, diversity, equity, and inclusion, but often we seem to forget the accessibility aspect and disability aspect of, inclusion as well. how do you think we can work to include disability more in these DEI spaces?

Amber Nicole Canaan: My first thought on it is really the whole DEI thing needs to change to DEIAJ, and that needs to be just the standard conversation because, there are people have shared identities across multiple demographics, and the things that affect one person affect another.

Shana Hawrylchak; I think, we often find that people are so focused on permanent disability and really don't think about all of the sort of wide range of disabilities that occur throughout a person's lifetime. So, we might have, individuals that, are suffering from aging disabilities. and so many of us are going to encounter disability during lifetime that it really doesn't make sense not to have us as a part of the conversation all the time. This affects everyone. It doesn't affect a small population.

Peter Gustafson: And I do think that the conversation is getting broader to include, more and more individuals, across the spectrum of needs, and, and concerns. so, I'm the eternal optimist, so I feel like it's getting better. and kind of things like this will help facilitate that.

Chase Eagleson: I mean, having this conversation alone is showing that, things are changing for the better, hopefully. You know, going along with that previous question, all three of you are scientists in your own aspects. Why do you think inclusion is important in science?

Shana Hawrylchak: I'd love to take this one. So, I think, like a huge part of science, is innovation. And innovation comes when you have people coming from different perspectives and tackling a problem from a different angle. And that's where you really get a lot of those really creative solutions to problems. And if you have everyone exactly the same coming from the same backgrounds, you are just minimizing, the potential to come to a creative solution. So I think, you know, as we're looking about just all the many backgrounds of folks, especially folks with disabilities, I know I've had multiple situations in my career where I've had a problem on the table, and someone who had that different perspective was able to solve that problem in about an eighth of the time, as the rest of us, because they had a broader view of the challenge and other resources they could pull on. So, I do feel like particularly in a field that's all about innovation, you need different perspectives.

Amber Nicole Canaan: I think that's a great way of putting it. I also would say, you know, there's the whole concept of nothing for us without us. And, you know, when we conduct research that needs to happen to help people with disabilities in whatever way, whether it's testing a new device that will help someone get around, or medical products like, drugs, if people with disabilities aren't included in that conversation, a lot of abuses happen ultimately. And then, like you said, people with disabilities understand what their challenges are. They don't have to be told what they are.

Peter Gustafson: I agree, I agree. It's like, you know, a guitar player trying to invent a new kind of piano. So, it's not the right person to do the job. So, I, I agree that having the right people in the room, you kind of get a better solution.

Chase Eagleson: It does seem odd because science in itself is naturally meant to be inclusive. I mean, it encompasses everything. Kind of putting exclusion into it is making it inherently nonscientific, which is a kind of an odd thing that society's decided to do.

Amber Nicole Canaan: Well, we find that with science, a lot of the time it gets siloed in this weird way outside of other life practices, you know, from doing the dishes to gardening or, you know, putting on your clothes each morning. And if we take science out of the equation, things just don't work.

Chase Eagleson: Going along with that, you know, despite disability become an increasingly important part of the conversation in science and individual disciplines, becoming increasingly seen in scientific spaces. Oftentimes, the fiscal layout of labs or field sites and the design of instruments can render science literally inaccessible to some. And while the representation of disabled scientists has increased, some scientists will choose not to disclose the disability due to exclusionary practices and entrenched ableism in institutions. What are some ways you think that the scientific and STEM community can work to ensure that individuals living with disabilities feel both safe and welcome in scientific spaces? Kind of a big question, but.

Amber Nicole Canaan: I, I have a lot to say on this one.

Chase Eagleson: Go right ahead.

Amber Nicole Canaan: So, one of my disabilities is a form of narcolepsy called idiopathic hypersomnia. And I used to just short call it narcolepsy. but recently NPR did a great 15-minute bit on it. And now people know what it is. and I've been working I worked in pharmaceuticals at the start of my career clinical research, radio, pharmaceuticals, all that kind of thing. And ultimately, I came to a point where I could no longer grow my career because I needed to commute to Boston, and there's no way someone with a disability like mine who can fall asleep very easily when driving, could work in Boston. So, I think it comes down ultimately to infrastructure. I'd like to say that the labs are what need the work, but right now, people with disabilities at least like mine or like some of my friends, they can't even get to the places where they want to work, whether its sidewalks are blocked because cars are parking on them or, you know, in Manchester, I'm a highway commissioner explicitly for the purpose of advocating for good sidewalks and bike lanes. Oftentimes the sidewalks aren't plowed so people can't walk places, like me. and oftentimes people with disability devices are using the bike lanes in order to get around town, which is placing them very close to traffic. So, our overall, our infrastructure, things like trains, things like regular public transportation are integral to being able to put disabled people in the places they want to work.

Shana Hawrylchak: I think that there's also that, you know, issue of ableism where there's so many very small changes or, yeah, like things that we're creating barriers that just don't even need to be there. and I think, you know, one of the things that's positive coming out of the pandemic is we realized that there was a lot of just things we took for granted about work in the workplace, that we're starting to rethink. Like, do we actually need people to come into the office to do this job? you know, is it important that they come to this particular lab space, or could this be done in a different way? but there's all of these things that we sort of take for granted as being necessary that we need to rethink. Are they actually necessary to complete the job? And are there ways, you know, to make accommodations for a whole range of people?

Peter Gustafson: And speaking of, you know, scientific spaces, a hands-on museum, a scientific space, and we're working to become, more welcoming, to many different communities. you know, the way we build exhibits, if you're in a wheelchair, can you roll under them and use them, comfortably? Or can we build

them so you can roll beside them and use them comfortably? So, it's all ways to get, accessibility for different people, with different needs. It could be putting Braille, right. You were to the museum or a school for the blind. You can speak to some of the challenges there. But it's trying to recognize where you can make some even small changes that will allow someone with an issue to participate in something scientific.

Amber Nicole Canaan: Yeah, I want to add to that, too, like the small changes, that becomes really important. For instance, I, I worked for an institution that had a dress code, even for the scientists in the lab. And it unfortunately required women to wear dress shoes. And I don't know if you've been. I mean, you don't have to have been a chemist. Just a person trying to stand and do anything. You know, dress shoe is very painful. And if we can sit down and look at what, you know, what systems have we put in place that maybe don't make sense? And why should a woman have to ask for accommodations to wear a sneaker in a lab space? These things just don't make sense to me. So rethinking things like dress codes or, you know, like requiring people to be in the office at a specific location at a certain time. You know, there are people with narcolepsy that if they could work early mornings, sleep half the day, and then work late evenings, goodness, the things they could accomplish. But that's not often, you know, accommodated. So, we're not allowed to contribute.

Shana Hawrylchak: Yeah. And I think like a consideration too, you're mentioning like narcolepsy by even like physically sitting in a chair at a desk is, a very taxing thing for a whole lot of people who could very efficiently work in a home space with their own seating, which is appropriate to their body. I would also say, like, you know, one thing we focus on a lot at the Science Center is the concept of universal design, because so many of the features which would make life easier for the disability community, would also make life easier for everyone else. Just thinking of going in and out of a lab and having doors that you can open to bring your lab equipment in and out will help anyone using a mobility device. So those changes, again, are just so important. Thinking about just, the number of people who can be helped if you, you stop just doing everything as it has been done in the past. I know something we also talk a bit about at the science Center is, just trying to think, like train of thought, like, you know, those small changes that Pete was mentioning. A lot of people, I think, have this notion that it's all about making things accessible for a wheelchair and just a broader definition of what disability

is. So, people can think about some of those tiny things you can do if you can't necessarily make a huge change to your physical space, that will help a whole lot of people, engage with the science at a deeper level.

Chase Eagleson: I got, I gotta say, just on the note of the dress shoes, cause that kind of that threw me off a little bit, to be honest. I used to work in a lab that studied, emerald ash borers, which is a little pest.

Amber Nicole Canaan: You're cool. They're cool, but they're.

Chase Eagleson: I hate them. They're more, But it. Before I start working. Working the council. I didn't even think about the accessibility aspect of being in that lab. And there's so many just weird, fine-tuned, fine movement, little machines that we had to use that. But honestly, probably would have been better if we if they had more accessible tools and levers and things like that, because I couldn't even do my hands are pretty good, I hope.

Shana Hawrylchak: I do feel like too, like a lot of lab spaces, are really moving towards certain aspects being automated because there is not a good reason for human beings to be doing some of that fine work where they can contaminate their specimens. So, you know, I think there are some engineering solutions that are coming down the line. I know automation is not always everyone's favorite term, but it can be really helpful in a lab space where you don't need somebody doing a lot of fine motor scale stuff. It is sometimes better done by that machine that can infuse the sample with biological contaminants.

Amber Nicole Canaan: Yeah. And along of what you said. Right. You were, I'm trying to remember the exact phrasing. You were talking about how, the changes that can be made for people with disabilities then end up helping a lot more people. or it might help someone recognize the fact that they might need assistance and hadn't noticed it before. Things like, you know, curb cuts, like we all think of for wheelchairs. Right? But they end up helping parents and strollers and people trying to exercise on rollerblades and, like, it ends up helping a larger portion of the community. of course, I'm so very infrastructure focused, but those there's changes in the lab, too, like you said, like automation or, better, bigger equipment. Right? Like levers instead of small turn dials, might even extend the, the working capability of someone who's developed rheumatoid arthritis or the

natural aging process, like you're either disabled now or not yet disabled, if you're lucky. Right.

Shana Hawrylchak: Well, and if we think of those ahead of time, you might not get a work-related disability has been designed a lot of things that actually cause risk. But repetitive stress situations which create disabilities for individuals because of the way our workplaces are designed.

Amber Nicole Canaan: It's so true. Like you think about standing on hard floors and that back strain. And it's very true.

Peter Gustafson: I've been fortunate to take a few tours of manufacturing facilities lately, some exhibit research we've been doing, and, you know, today's manufacturing facilities, they seem like they are taking into consideration some of these issues for people. Some of the workstations we seem seeing have seen relatively comfortable and like, they're not going to disfigure people after 20 years of work. And so, I think some people are making changes because they have to. Right. Because we've learned a little bit about what we're doing to ourselves with some of these, work environments.

Chase Eagleson: I mean, that perfectly goes into our next question. thank you. what role, do you think that science can or does take in ensuring that all voices are heard in scientific discussions? We talked, a few minutes ago about how before, people with disabilities were, brought into these conversations, a lot of perspectives were just kind of left out. I mean, the same thing happened before women were brought in, before people of different ethnicities were brought into scientific spaces. So, I just love to hear all of your opinions on that. I could see already grabbing the mic go right for it.

Shana Hawrylchak: So, I think everybody, especially with AI conversations, data sets are so important and, you know, a lot of these data sets we're collecting, you know, involve everyone in the community getting in there and sharing their voices in the information and in order for us to make good decisions. And if those voices aren't heard, our data sets are bad. We get bad outcomes. so especially even more as we enter into an AI world. We need all of that data and input in there.

Amber Nicole Canaan: That's beautiful. I also, you know, I have a I don't have a 3D printer. It's in my two-year plan, but I don't have one right now. you have to take tools, you know, certain purchases, large ones at, you know, steps. but I, you know, I have benefited from people, 3D printing things that made my life easier. I like to think of 3D printers. Like, I remember I ran that event with the SEE Science Center years ago with the New Hampshire Creative Club, where we brought in all that 3D printing for that big holiday thing. And, to me, a 3D printer being accessible to a school child is really important because it's, that's the engineer's sketchbook. Like, I'm an artist, right? I work in the sciences, but I'm artist. And that my sketchbook went everywhere with me. I do things, I do things, I change things. And to an engineer, that's what a 3D printer is. And anyone who's trying to solve a problem is an engineer, right? So, they need access to tools like 3D printers, in, in affordable ways or in school labs were in museums or makerspaces, all of that. I think that's one of the biggest areas for, including people with disabilities in science, and science, in disability.

Peter Gustafson: Well, I think it does come back to what she said earlier about having, you know, more and maybe more appropriate people in the room to help solve the problem you're trying to solve. and so, including, people with challenges, they're going to help you find solutions, if you include them. And I think that's the key is, making sure that that the, the right voices are heard.

Shana Hawrylchak: I would also say that especially in today's workforce climate, none of us can afford to exclude any population at all. So, it's, you know, we all need those perspectives, but we all just we need the people. we all need those minds coming in and helping us out in these challenges and being in our workforce. So just saying that a fifth of the population we're going to ignore is just not a viable option for anyone, not just in the scientific community, but in any community.

Amber Nicole Canaan: Oh, and I want to add on to that, that is because that is so true. Like I have, for, for instance, I've heard of workplaces that, didn't have any women in their group, so they use the women's bathroom as a storage room. So, like just as an example. So, there was an infrastructure for women to be in the workplace, right? So yeah, when women did come, they left very quickly. It was weird. so, you were designing the workplace for people with disabilities before they arrive is the only way they're going to get there. You're not going to find a

car in the middle of the woods with no road leading to it. why do you expect to find a person with a disability in a in the middle of a city that's not, you know, built appropriately or in an office or a lab that doesn't already have these things in place. They're not going to come.

Shana Hawrylchak: I would also say that we talk a lot about the entire path. So, it's not just about the space, but it's how you frame how they're getting to you. So, the data, like, do you present yourself on your website or your other materials as being welcoming to these communities? Because no one's going to if they can't get to your door? They're not going to be in your building or be part of your workforce or be part of your community.

Amber Nicole Canaan: No, people with disabilities are fighting so much so already that they don't want to have to fight to have fun, like at the SEE Science Center.

Peter Gustafson: Well, and that's the point that if we're already in the C Science Center to welcome, people with mobility issues, for instance, but they can't get to the building. Right. there's a disconnect there. And bridging those disconnects is key. Important. Yeah.

Chase Eagleson: This is one of the few times I can shout out my economics degree. I just think it's really interesting that one aspect of this that a lot of people just don't talk about is how economically positive inclusion is. I mean, again, like you said, one fifth of the population, the CDC puts it at one fourth of the population. It's 25% of people that aren't working or have, limited access to working. I mean, that's a lot of that's a lot of money. That's a lot of money that can be made, can be spent. And that's a lot of stuff that that can be processed. I mean, it's, it's a whole huge portion of the population that's just it's like not tapping maple trees. So, it's bad.

Amber Nicole Canaan: That's probably the most New Hampshire idiom I think I've ever heard. I kind of love it.

Chase Eagleson: I've been in New Hampshire my whole life. It's just it's the maple syrup ingrained in my soul at this point.

Amber Nicole Canaan: It's in your blood.

Chase Eagleson: It's in my blood. It's all thick.

Shana Hawrylchak: I want to add one thing on to what both you and Nicole were saying is that, you know, as businesses and in the scientific community, as we're advocating in our own spaces, the importance of advocating about the city itself and, just outside of our organizations, because anything that makes it difficult for people to, live in thrive is going to make it difficult for them to work or play in our spaces.

Amber Nicole Canaan: Yeah, I so I'm fortunate I'm not in a wheelchair today, but I did spend a year in one and had to relearn to walk, and I would roll on downtown of Manchester and try to spend my money, but I couldn't even open the doors to get into the businesses. and that's aside from the you know, ways I was treated by the persons who then didn't assume I had a business with employees and wanted to spend money. So, like things as little as having a doorbell, at your business, you know, when I can't open the door because I'm on wheels and in a narrow alcove, and then you can open the door and I can come spend my money.

Shana Hawrylchak: I remember I had this point in my life where I had, an ACL, MCL tear, and so I was on crutches and realized too late that I could not actually exit my apartment building after my caretaker left. so, I think we all take these things for granted. and then until we don't, and we can't. so, I do think that, again, just, you know, being able to think about the obstacles we are creating for no reason, is important. And stopping and taking that time.

Amber Nicole Canaan: 100%. What did you do?

Shana Hawrylchak: I called everyone I could go to try to get out of my, building.

Chase Eagleson: You dove out the window slides, and I. I know people hear this all the time, and it's going to keep getting said, but, I mean, with an ever-aging population, these obstacles are only going to become more apparent to the public, which in a way is a good thing. but it is something that needs to be addressed sooner rather than later, or no one's going to be able to spend money or do anything, anywhere, or get out of their apartment. We're just kind of a bunch of people trapped in their apartments. This, you know, this, topic about

voices being heard and, more people having the need for accessible, infrastructure, brings into the next point of the fact that according to the National Academies of Science, engineering, and medicine, people with disabilities are underrepresented in, in STEM occupations compared at comparison with their share of the general U.S. population. STEM workers with disabilities earn less than those without as well. what in your opinions, can be done to combat these inequalities? Big question. Have fun.

Shana Hawrylchak: I think there's a lot of misinformation out there for employers. I think that they think there is going to be a larger burden on them than they're actually is with making accommodations, and it really stops a lot of people from trying or recruiting, among the disability community.

Chase Eagleson: I think that's a great point.

Amber Nicole Canaan: I, I agree with that. As someone who employs people, and I actually try to find people with disabilities to employ because, I'm putting them in front of a classroom of children who, let's say based on that data, a quarter of them will be disabled if they're not yet disabled. So, they need to see someone who's functioning, and aligned with their disability. And it's really not that hard. Like, for me, you know, they got to have a wheely cart. Maybe if they can't lift something or we stomp loudly on the stairs, so we don't shock their cataplexy, you know, it's not that hard. And most people with disabilities are trying their darndest not to be a burden. Maybe to their detriment.

Peter Gustafson: You know, combating, inequities. I mean, it takes advocacy, takes transparency. It takes people who care to speak up and say things and do things and, so those are the things that will continue to happen. As people want to see change, they have to be the change. They have to be willing to talk about it, do things about it. Hire, hire our way out of it. so, yeah, it's the, you know, the struggle for, for, people, they need to continue to, address it and speak about it so that it can be addressed, by, you know, people in the community who have the power to make change.

Shana Hawrylchak: I was going to say, I think it's also important, like as a society, you know, we've done a great job of like trying to get rid of some of the stigma around mental health. But there's also a lot of folks who, you know, there's

hidden disabilities that people won't talk about. And so, people don't think about the accommodations or, helping people through some of the struggles they may have with those hidden disabilities because we are still in a society that, pressures people to hide. And I don't think that's a healthy place to be in if we really want, effective change.

Amber Nicole Canaan: I think that that's a really, really great point. And you can edit this out if you want. But I am very open with my disabilities, and I'm going to list them here so that if anyone who has them can see me and see that they can do what I feel like I'm doing really well. And so, I've got narcolepsy. I have a walking disability due to a tendon that turned to bone. dental neuralgia, along with, various neuralgias around my body so it could be in pain at any moment. an endometriosis. So, and the potential neuralgia is one of those things that makes it hard for people to sit for extended periods, or even sometimes at all, which, you know, so now I have a standing disability and a sitting disability. Anyways, I put that out there so that people can see that I'm a productive member of society. I seem to think so. but that, you know, you can reach out to me with questions through my website or anything like that. I'll connect you with any of the resources I have able. ABLE-NH is really, really great. And I know you guys just had on Sarah. So, kudos there. but being open about the disabilities means, it could put me at risk for future employment. so, I'm, I'm hanging my jacket on the hook that I'm going to be forever self-employed and try to employ those with disabilities. Just provide opportunity.

Shana Hawrylchak: Yeah. And I think you're mentioning it before, like for kids, we see it all the time. Representation is so important to encourage them to go into the fields. And while, you know, we're focused right here on STEM, I'm pretty sure there's underrepresentation in almost every work field. with, the disability population, unemployment is very high because of, again, some of the stigma and, misinformation that's out there. That keeps people out of the workforce.

Chase Eagleson: I will say that we won't be editing that out, and that's fine. I and I dare someone not to hire you based on that. That'll be a fun fight.

Amber Nicole Canaan: Fortunately, I'm not applying anywhere. I'm looking for people to hire.

Chase Eagleson: Even better.

Amber Nicole Canaan: The tables are turned.

Chase Eagleson: All right, well, thank you all for coming. Thank you for talking about this with us today. If you'd like to, reach out to, Amber or Shayna or, I, I almost just called you Gus.

Amber Nicole Canaan: I could see that.

Chase Eagleson: I'd love for you to say your contact information.

Amber Nicole Canaan: Oh, sure. My website, Unchartered dot org, is a really great way to get ahold of me. And actually, that form goes directly to my inbox. so, you will get me directly. That's probably the best way. I'm also on Facebook and Instagram. Sometimes TikTok. and you can find me in all those places. And then if you like my personal art where I do more on disability, that's bio site creative.com.

Peter Gustafson: The SEE Science Center is in Manchester, New Hampshire. S E E Science center. we're in the mills. We're a hands-on science museum. we do summer camps, a lot of field trips, family memberships.

Amber Nicole Canaan: It's so cool.

Peter Gustafson: It is a fun place to learn and have fun at the same time with your family.

Shana Hawrylchak: Yeah. And you can get a hold of either me or Pete. Shana. Shanna at SEE Hyphen Science Center. All one word.org or Pete, same, same rest of the email.

Chase Eagleson: Yeah, yeah. I got to say, even if you don't like science, for some reason, they have a really cool Lego set that I would recommend checking out.

Amber Nicole Canaan: It's true, it's true.

Chase Eagleson: All right. Well, thank you all for coming. And thank you for listening.

Vanessa Blais (VB): Thank you for joining us today. I'm Vanessa Blais and this was a production of the New Hampshire Council on Developmental Disabilities produced by Isadora Rodriguez-Legendre, and Vanessa Blais with many thanks to Josh Hardy and rest of the crew here at Concord TV.

We love to have guests with differing perspectives. These are personal, and do not necessarily represent those of the DD Council.