DEP RRTC
DISABILITY EMPLOYMENT POLICY
REHABILITATION RESEARCH AND TRAINING CENTER
The Burton Blatt Institute at Syracuse University (BBI)

Let's Get to Work: Reimagining Disability Inclusive Employment Policy:

Knowledge Translation and the Future of Disability Employment Policy- A Conversation with Jonathan Martinis and Barry Whaley

Barry Whaley

Hi, everybody. I want to welcome you to this new season of podcast for the Disability Employment Policy Rehabilitation Research and Training Center and for the Southeast ADA Center. I'm Barry Whaley. I'm the director of outreach for the Burton Blatt Institute at Syracuse University. Today, we're going to talk a little more about knowledge translation, what it is.

You know, knowledge translation for me is to take complex information and make it understandable for the broadest range of people possible. Nobody better to do that than Jonathan Martinis, the director of knowledge translation for the disability employment policy Rehabilitation Research and Training Center, and our host today is Dr. Peter Blanck, chairman of the Burton Blatt Institute and university professor. So, Peter, I'll turn it over to you.

Peter Blanck

Thank you, Barry, for that kind introduction. And I'm particularly excited about today's podcast because at the end of the day, we are in the job of conveying information to people that is useful, robust, accessible, and in plain language to both improve disability employment policy and disability employment and the lives of persons with disabilities.

Today, we're going to talk about knowledge translation, which has been a leading effort both at the new disability employment policy, RRTC as well as at the Southeast ADA Center. The Disability Employment Policy Grant was recently awarded to the Burton Blatt Institute, and it's to study, essentially, the future of work with regard to employment policy affecting persons with disability. And we're very excited to begin this five-year journey with the support of what is the premier disability research and policy organization in our federal government, the National Institute on Disability, Independent Living, and Rehabilitation Research. So, Jonathan, I want to thank you for joining us and leading this endeavor. Perhaps you want to start with your general idea of what your job is and what knowledge translation is about.

Jonathan Martinis

Thank you so much for joining us on this and I hope many podcasts. But a quick confession to the listeners. I knew this question was coming, so I prepared an answer for it. I think Barry gave a really good definition of knowledge translation. Mine is similar, but a little broader.

I looked it up and I saw the definition of knowledge translation was as follows. knowledge translation is the active process of synthesizing, adapting, and communicating research or expert knowledge so that it influences decisions, policy, practice, or everyday life. Great definition. Also, too many words. Here's how I would define knowledge translation and what I see my job as and, frankly, the job of the entire DEP as. And that's this. Knowledge translation is a bridge. It is a bridge between what we know or what we're going to find out and what we're doing. The entire job of knowledge translation is to take information, like Barry said, and make it understandable, but, also, we hope and we intend to make it actionable, to translate information from incredibly complex and incredibly far reaching research that we're going to talk about later and make it useful, Make it be a part of the everyday work and the incredibly important work of policymakers. So just one example. We have one of

our research projects involved looking at the impact of infrastructure in rural communities on people with disabilities. Meaning, if you're in a city right now, Wi Fi and broadband are a given. But what if they weren't? What if you had to struggle to get good Internet access or good transportation access? How would you get to work? How would you work remotely? How would you be able to apply for a job on a world that increasingly does everything online? So, our research in that project is looking at the impact of things like broadband access and transportation on people with disabilities' ability to find, keep, and succeed in their jobs. What the knowledge translation of that is way broader than that, though, Because the information that we get can not only help with employment policy, but it can help with infrastructure policy. Because if people with disabilities can't access effective and reliable Internet or transportation, neither can anyone else. So, the decisions in the made based upon the information that we have, if properly translated, can help policymakers make decisions in a whole bunch of areas even beyond what we initially set out to research. So that is my really long way of answering that really short question. Knowledge translation is what makes good information into good policy and practice.

Peter Blanck

So that's a great answer, Jonathan, and a great foundation about what we're going to talk about today. So clearly, you're saying that research needs to see the light of the day and be seen by all participants and understood. What are some of the vehicles by which you do this knowledge translation, one of which, of course, is what we're doing here today?

Jonathan Martinis

Thank you for asking that too because I look at knowledge translation as a yes and situation. If you ask me if something is part of knowledge translation, I'm going to say yes and if it's something I haven't thought of, I'm going to say and that too.

But as a beginning, what we're doing is this podcast, for example, where you're interviewing me, but also, more importantly, interviewing people directly involved in our research, policymakers, leaders in our field. By the time we hear this, we'll have had a couple of podcasts already out with a couple of real titans in our field in Lex Frid and Beth Schrull, people who really can influence and move the needle, and that gets information out to people. But there's more. First, not for the last time, I'm going to recommend that people look at our website, bbi-dep-rrtc.org where you can find a lot of our methods of knowledge translation.

For example, we have eight core research projects. If you look on our website under the research section, you will find summaries of what they are and what we're doing and why we're doing it and what we hope to find. We've written up fact sheets, one pagers to give you a view of what we're doing, but we want you to be part of our journey. This is a five-year process, so we want to also, from time to time, provide updates. I'm foreseeing quick videos from our lead researchers talking about what they're learning and what we're doing and why it's important. Additional fact sheets summarizing our initial findings. And, of course, when they're done, large scale articles and presentations but there's another thing I really want to press on, um, because we're going to be doing all the traditional forms of knowledge translations. You'll get webinars, you'll get presentations, you will get fact sheets, you will get brochures. We have a periodic newsletter where we synthesize recent information, new developments, and important steps that impact policy, those not done by us, updates from our partners on what they're doing, and news you can use telling you where you can find information that is useful to you if you're a policymaker, if you're an employer. But what I want to press on is another more important thing.

Knowledge translation is not one way. It's not just us telling you things. It's us finding out things. In our newsletter, you're going to see a request that you contact me with information that could help us or with requests for information that can help you. We

want information to flow from you as well. What have you heard? What have you learned? What is concerning or interesting to you? Because that can shape the ways that we talk not only to you but to everyone else. If you're asking me what types of knowledge translation we're going to do, my answer is yes and everything you can think of and whatever else you can think of.

Peter Blanck

I, of course know that social media will be a big part of this as well. I know we're involved with a number of channels, if you call them, with social media, which I think you would say was particularly relevant, of course, to today's generation that has grown up on social media.

Jonathan Martinis

Social media is part of the yes and. And one of the great things about what we're doing is, again, if you think about my definition of knowledge translation, being a bridge, being a bridge means being a bridge everywhere one is needed. So, you're a hundred percent correct. Old hands like you and me, I mean, I am not of the social media generation. That's not an excuse not to be aware of it and be a part of it because younger adults, people entering the workforce, people in school right now, if that is a way to get information to and from them, and it is, then that is something that we need to do. That is a way that we need not only to translate information, but to receive it.

Peter Blanck

Now we're all living in times, I think it's safe to say, that national issues are almost changing in significant areas. So, this is a five-year project, and we want to hit the ground running. I know you've already hit the ground running. This is not going to take years to unfold. I assume we're going to have, it goes without saying, timely and important updates. How are you going to do that?

Jonathan Martinis

Well, first, with regard to the times we live in, I always thought it was a blessing, not a curse when the saying was, may you be cursed to live in interesting times. These are the most interesting times because so many things happen so quickly and develop and evolve so quickly. And that's something that the DEP is going to do too.

We're not waiting for our projects to be done to provide information. We are not waiting for conclusions only. There are things going on right now that we can help people understand. Peter, you and our day-to-day project director, Fitore Hyseni, are speaking this weekend, the weekend on which I am talking now. This will have happened by the time people are hearing this at a major employer and employment conference talking about the future of work, talking about what research shows about where things need to be developed, and things need to be done. That's an example of current, let's say current events to use an old school term, where we can help bring information together because that's another part of knowledge translation is synthesis. There may be thirty different sources of information out there, and that's the world we live in. We're very fragmented. But if there was someone who could synthesize those things and get them down to a set of accepted conclusions, a commonality, best practices, then think how useful that would be to policymakers and employers. Instead of having to read thirty studies, you could read the joint conclusions of all of them. That's part of what we're going to be doing all as well through our five years.

Peter Blanck

I thought it was particularly important and interesting, your idea about the two-way street of knowledge translation. Of course, many of us at the Burton Blatt Institute have experienced the living of being a person with a disability or having an association with a person with a disability. And, of course, the disability community's mantra often has been nothing about us without us. Would you say a little bit more about this particularly

interesting concept you have of this two-way street?

Jonathan Martinis

Well, with regard to nothing about us without us, amen. The majority of employees at the Burton Blatt Institute are themselves people with disabilities or family members. I grew up in a family of people with and allies to people with disabilities. Peter, you and I got our start working on guardianship cases and looking at enhancing the independence of people with disabilities. One of my guiding forces in all of that is my god son who is himself in a guardianship and my sister who is his guardian who do wonderful work together to maximize his independence and talking directly with people with disabilities and leaders in their field about ways to enhance.

I always view the conversation I'm about to tell you about as foundational in my life. I would have told you for years that I am an attorney for people with disabilities. I represent people with disabilities. I speak for people with disabilities. And one of our partners on this project, who at the time was the founder of the Autistic Self Advocacy Network, Doctor. Ari Neiman. Ari took me aside at a conference and he said to say that you are something for a person with a disability in the way that you say it, Jonathan, is dangerously close to saying that you are something instead of a person with disabilities. I've never forgotten that. That was about fifteen years ago. And that's when the phrase nothing about us without us really hit home for me. Because if we're going to talk about independence, if we're going to talk about self-determination the idea that people who have more self-determination are more likely to be employed, then we have to hear from and be led by people with disabilities from their insight, their input, their leadership.

And I will tell you that is a commitment that we have in this project, and we'll have every day that I'm here, and I know that every day that Peter Blanck is here.

Peter Blanck

Can you say a little bit about some of our partners who are working with us in the knowledge translation area? You mentioned the National Organization on Disability. Who are some of the others?

Jonathan Martinis

I mean, the answer is no. I can't say a little bit about them because there's so many that do so many great things. I could mention so many. National Organization on Disabilities, Mathematica, Rutgers University, Harvard University, Syracuse University, APSE, Association for Persons Supporting Employment First. There are so many doing so much. ILRU is part of our distribution field.

If you are in this field, the names that I mentioned are gigantic, powerful entities. Mental Health America is one of our partners. And, of course, one of our biggest partners, maybe the most important, is the National ADA Network. I've had the really good luck of working with directly with Barry Whaley and others with the Southeast ADA Center. And these are a group of centers dealing with every state in the nation working with people and professionals and policy makers across the country. Imagine the benefit of having expertise of national leaders with national exposure and national information to shape and translate national news like the National ADA Network. And there's just so many others that we're working with. I think two that really come to mind when we're thinking about really effective and really broad-based partners that bring knowledge and information and experience to us are AHRC NYC, probably the largest organization in the state of New York working with people with intellectual and developmental disabilities, maybe one of the largest in the country. AHRC NYC brings information and depth and scope in what people need, working directly with people, learning from people, what they need to live their best lives, including in work. And CSAVR, the Council of State Administrators on Vocational Rehabilitation a national organization dedicated to vocational rehabilitation. And vocational rehabilitation is so integral to the issue of work and helping people work. And at the forefront of disability

employment policy, it has been one of the most important programs for people with disabilities, and CSAVR embodies what that program is all about.

Hearkening back to my prior answer, we live what we say. When we say nothing about us without us, we are being led by, influenced by in everything we do, organizations led by people with disabilities So to have so many partners that do so many things so well is to me an honor, and I think it's going to serve the DEP incredibly well.

Peter Blanck

You know what? Many of our readers know, and it's on our website, that you were counsel in perhaps the seminal case involving supported decision making, empowering individuals in life, the Jenny Hatch case. I've always thought that that has informed you also the way you look at the importance of getting information out. That case was picked up by every major newspaper, by television stations and social media. What did you take from that that you're bringing here today?

Jonathan Martinis

Peter, you know all about the Jenny Hatch case because you were a key expert in it. Without shining you up too hard, I always said that your testimony was the turning point in the case. I described my career as I'm lucky for a living, and that case is an example of when you are around the right people and you have a chance to be influenced by and led by people with disabilities, good things can happen. For those of you who aren't familiar with the Jenny Hatch case, Jenny is a young woman with Down syndrome who lived her entire life independently until she turned twenty-nine, at which point she found herself facing a petition to put her in a guardianship.

By the time I learned about Jenny's case, she'd had one hearing, three hours, when she had walked into a courtroom with all her rights. Three hours later, she walked out with none. She was put in a quote, unquote temporary guardianship where she wasn't

allowed to live where she wanted to live, work where she wanted to live, wasn't allowed to go to the church she had gone to. Her cell phone was taken away.

And thank God, one, Jenny never gave up. Jenny was very clear. She didn't want a guardian. She wanted to live her life the way she wanted to. Similarly, thank God for national leaders like Peter Blanck, like some of our partners that we've worked with in this area who came out and spoke in favor of Jenny, who in one case submitted a brief on behalf of Jenny, and thank goodness she won. Jenny has been without a guardian for about thirteen years now and living just fine.

But the specific answer to your question is this, Peter. What that case taught me about knowledge translation is the simple message in Jenny's case was if you can decide your future, you should. If you have the ability to make your own decisions either by yourself or when you get help, and by the way, all of us need help to make decisions, you should be empowered to do that. You shouldn't look at a person and say, you look disabled. You look like you can't make decisions. Therefore, we're not going to let you.

And that message is what resonated. Since Jenny's case, just thirteen years ago, more than half the states have passed laws recognizing supported decision making, I think about knowledge translation and what I hope and expect the DEP is going to do with knowledge translation. Taking detailed concepts, what some people might call getting in the weeds, as important as those weeds are. Let policymakers see them as a meadow. Let policymakers see the main point. Letting employers see the synthesis of the research so that we're not bogged down, and we can see clearly what the main issues were. In Jenny's case, it was one sentence. I don't need a guardian. I just need a little help. That was her quote. In this situation, it could be, Work is good. Employing people with disabilities is good because employing anyone is good. And if there are qualified employees, we should do what we can to make sure that they can work.

Peter Blanck

You know, clearly, in your blood and your DNA, you are a knowledge translation person, whether as a lawyer, an advocate, a researcher, and you've always been able to put it in a format that resonates with people. I know, for example, you were early on. You created a resource center that went national with regard to support decision making, and that certainly changed the lives of many individuals. So, I guess I would ask before we pull Barry Whaley in, what are you doing tomorrow, and where are we going from here?

Jonathan Martinis

Yes, and is my answer to that. We are going not only where we think we're going. And, again, if you go to our website, bbi-dep-rrtc.org, you'll see where we think we're going. You'll see where we intend to go. Read our fact sheets. Think about what we're doing and think about the impact they can have. Again, not only on the lives of people with disabilities, but on the lives of someone you know. Then you'll know where we think we're going. But we are going so many other places, and that's why I stress the two-way street.

I would love it if the day after this podcast airs, someone emails me or calls me and sends us off into a different direction and says, you know what, John? That was really interesting information. Have you thought about the impact over here? And I would love to say, Oh my god, you're right. And get on the phone with Peter, get on the phone with Fitori and say, we need to look at this because this is going to impact people's lives. So yes, and.

We're going where we said we're going to go. We're going to do the things we said we're going to do, but, man, we're going to do so much more.

Barry Whaley

Well, thank you, Jonathan. Of course, that was always passionately said, and I think a

model which we hope to be for other such efforts around the country or internationally. One such effort and embodiment of knowledge translation is our Southeast ADA director and knowledge translation leader who's been a major figure in the disability community for many years and a shining light for us at BBI who's really led us to many new places. Barry Whaley, it's so nice to have you as well. I hope to ask you a couple of questions and then facilitate a conversation perhaps between you and Jonathan.

Barry Whaley

Yeah. Thank you, Peter. Thanks for having me.

Peter Blanck

I guess I would ask first, what's your take on what Jonathan said?

Barry Whaley

I think Jonathan is spot on. I really am amazed at the work that he has done already on organizing knowledge translation for this project. And Jonathan's absolutely right. I mean, we can put all the information we want out, but unless there is communication with the people receiving that information and that it is useful to them, then we've not succeeded in our mission. So, it's important that we communicate with our stakeholders, we communicate with policymakers, and we understand what their needs are so we can deliver on that.

Peter Blanck

So, the Southeast ADA project is among the premier efforts of the Burton Blatt Institute and has been almost twenty years, and that's a testament to Barry's team. Barry, would you say a few words about the Southeast ADA so for people not aware.

Barry Whaley

And Jonathan mentioned the ADA National Network; that's a good place to start. The

Southeast ADA Center is one of ten centers in the ADA National Network. We serve an area from Kentucky to Florida, from Mississippi to the Carolinas, and we exist to do four things. Most importantly, we provide technical guidance on the Americans with Disabilities Act and other disability rights law.

If you believe your rights have been violated or you have a question about the ADA or you're just not sure, you can call eight hundred nine four nine four two three two, and you'll be put in touch with a technical expert that can answer your question. Now some of those questions may require additional research because, again, going back to the definition that I use for knowledge translation, it's taking complex information and making it understandable. And we are finding each year that the questions we get on that technical assistance line are becoming more complex and require a great deal more research.

We also exist to provide training. We train thousands of people a year. My specialty is, obviously, is employment, Title one of the ADA. We also provide training for state and local government, for shop owners, for virtually anybody for whom the ADA touches. We provide print and electronic material, and then finally, we conduct research. The center is currently completing a five-year research project looking at the impact of disability on short- and long-term poverty, access to digital technology, and employment. One other thing to mention about the ADA National Network, we also have a knowledge translation center. I know that they are an important partner in this RRTC DEP project.

Peter Blanck

Thank you, Barry. So, Barry, like Jonathan, this has been an incredibly informative discussion. Two of the leading actors in this field. I will ask you the same question I asked Jonathan. At the Southeast ADA, what do you do with tomorrow? And in the near future, what are your goals and aspirations?

Barry Whaley

Yeah. We're looking at several things. We're looking at new and innovative ways to provide knowledge translation, which includes short burst video, animation. When we look at how people receive information, they like it in chunks, and they like it in small, digestible ways that they can understand. One of the things that we are looking at is new and innovative ways to get information out to people, policymakers, people with disabilities, family members, state and local governments. We do a lot of work with state and local governments and ADA coordinators. We want to make sure that the information is clear and understandable to them.

Peter Blanck

Again, this was fantastic, Barry. I want to stimulate a discussion between the two of you because your one and one is equal to five. What have you guys thought about what you just heard today? What are things that our listeners would be interested in hearing about?

Jonathan Martinis

I said before, I'm lucky for a living. And one lucky is for the last ten years at the Burton Blatt Institute, I've gotten to work with Barry Whaley and the people at the Southeast ADA Center. When we talk about not just knowledge translation, but knowledge generation information getting in the hands of people who need it and can use it, you're not going to do better than Southeast ADA. I've been working a little bit more closely with the folks at Southeast ADA over the last year. I would say, and just the breadth of people they respond to and the breadth of areas they address for people are incredible in scope. Barry said we may have to do a little bit of research if you call them. I have seen Southeast ADA have the information people need at their fingertips that I don't think anyone else would have.

That's how I would react to what Barry said. I would react with thank you. Thank you for what you've taught me, and more importantly, thank you for what you do for the community.

Barry Whaley

You know, when people call Southeast ADA Center, often emotions are high. Right? My rights have been violated. I feel I've been discriminated against because of my disability. I need somebody who has an empathetic ear and can give me those answers, and that's what I hope we do at Southeast ADA Center every day.

Jonathan Martinis

Such an incredible breadth of people that you work with. Again, I don't know that people really think about how large this country is or just one section of it is and how many people are there and the number of issues. Just one example. I was part of; I got to watch Barry and Pam and others at Southeast ADA guide an entire county in Florida on making sure that its facilities and its programs are accessible to people with disabilities. And it's not just saying do this, don't do that. It's working directly with people to understand what it is they do so we can help them do it better. And that's really the most baseline goal of knowledge translation. We don't tell people what to do. We talk to people who have information for us and who need information from us so that they can do what they do better because what they do benefits the entire community. And that's just one county in Florida, probably a couple ten thousand people and that's a huge number of people. Now think about that and multiply it across the state of Florida and across the entire southeast, and maybe you have a small idea of what Southeast ADA does. And I guarantee you don't. You don't know as much, and we are lucky to have them here to teach us.

Barry Whaley

Yeah. Jonathan, thank you for mentioning that county in Florida because they approached us, and that's very important because they want to do good things for their citizens. They want to make sure that their programs and services are accessible to the greatest number of people in the community. They want to modify their policies and practices for equal opportunity for everybody in that county. That gives me hope that people want to do good things. They want to do the right thing. And sometimes they need help from places like the Southeast ADA Center or the Disability Employment Policy, RRTC, to know what the right thing is.

Peter Blanck

So, Jonathan and Barry, we've discussed a lot of great topics today. You've provided resources and information. This two-way street idea, I think, is fantastic. And I'm sure many organizations do that, but the way you articulated that for purposes of our grants, Jonathan and Barry, is particularly important.

Jonathan, I'd start with you. Any closing comments for our audience?

Jonathan Martinis

Thank you. First, thank you, Peter. But more importantly to the audience, thank you. Because if you're listening to this podcast, you have an interest in this area. And this area to me is so integral to our values as a nation. Yep. We were founded on the value of equality. We were founded, and we had to grow into it, but we did grow into recognizing equality of opportunity. That's what this is about. The most basic tenet we have in economy is supply and demand. What this project is dedicated to is making sure that there is a demand for the very well qualified supply of employees with disabilities out there. If we do that, the entire economy benefits. The research that we're doing will benefit every worker.

And the last thing I want to say is bbi-dep-rrtc.org. Come frequently. Bookmark it. You'll

learn more and tell us more so we can learn more with you.

Peter Blanck

Barry, same thing for Southeast ADA.

Barry Whaley

I want to end by saying that Jonathan hit it on the head. Right? When you look at what the four pillars of the ADA are, full participation, independent living, equality of opportunity, and economic self-sufficiency, that fits very nicely with the RRTC Disability Employment Policy and the Southeast ADA Center. So, I'm pretty excited to see where this project is going to go over the next five years. We know we still have a long way to go around employment policy. There's still too many people who want to go to work, who do not go to work, too many people sitting on the economic sidelines in this country, not even participating in the workforce. I hope that the work of the RRTC DEP improves those outcomes for people.

Peter Blanck

Gentlemen, thank you, and I'm sure it's not the last time we'll be speaking. Thank you both for being with us today.

Barry Whaley

Dr. Peter Blanck, chairman of the Burton Blatt Institute, and Jonathan Martinis, senior director of law and policy at the Burton Blatt Institute. This is very important information. Listeners, I want to thank you for joining us. You can access all Let's Get to Reimagining Disability Employment Policy episodes at our website, and that website again is bbi-dep-rrtc.org. Let's get to work. Imagining Disability Employment Policy is a program of the Disability Employment Policy Rehabilitation Research and Training Center at the Burton Blatt Institute at Syracuse University.

The show is produced by Celestia Ohrazda and Jonathan Martinis. We hope to see you next episode