



ADA Live! Episode 114: Supporting Meaningful Change in Research, Education and Service: The Association of University Centers on Disabilities (AUCD)

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Guest: John Tschida, executive director of the Association of University Centers on Disabilities

Host: Barry Whaley, Project Director at the Southeast ADA Center

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John Tschida: Hi. I'm John Tschida and you're listening to ADA Live!

4 Wheel City: Yo. All right. Let's roll. Let's go.

Barry Whaley:

Hi, everybody. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network, I want to welcome you to ADA Live! I'm Barry Whaley. I'm the director of the Southeast ADA Center. As a reminder, if you have questions about the Americans with Disabilities Act, you can use our online form anytime at adalive.org, or you can call the Southeast ADA Center at 404-541-9001. Remember, those calls are always free and they're confidential. This episode of ADA Live!, we want to focus on the important work of the Association of University Centers on Disabilities or AUCD. AUCD is a network of interdisciplinary centers advancing policy and

practice for and with individuals with developmental and other disabilities, their families, and their community. We're very honored today to have as our guest, John Tschida.

John is the executive director, the Association of University Centers on Disabilities. Before coming to AUCD, he was the director of NIDILRR, the National Institute on Disability, Independent Living, and Rehabilitation Research in the US Department of Health and Human Services, which incidentally is our funder. John, I want to welcome you to the show. John, you have such a rich history of working in the disability field long before I ever knew you, I knew your name. I'm curious what led you to this work and how did you get where you are now?

John Tschida:

Thanks, Barry. First, I just want to say thank you to you and the center for the invitation. I'm very glad to be here. For me, this work is deeply personal. My life changed dramatically in September of 1993, and that change would set me on a path toward the disability field that eventually led to where I am today. At the time, I was working at the Minnesota House of Representatives as a reporter and editor for a nonpartisan weekly magazine. I love politics and loved policy, still do, and it was a great education for someone who wanted a career in the field. I was riding my bicycle to work on September 9th of 1993 when I hit a bad patch of gravel just a few blocks from my office near the state capitol and flipped over the handlebars of my bike. The lamp post I hit left me with a permanent spinal cord injury and paralyzed below the chest.

After a few months of rehabilitation, I returned to my job at the Capitol and very quickly came to see that the way policy and funding decisions were made were not necessarily in the best interest of people with disabilities and didn't always include the voices of people with disabilities. So witnessing the committee process, just the way that decisions were made and in silos and nobody was really looking at all of these services and supports as a system that were designed to help people. So after a while, I decided I couldn't just be a witness to and a recorder of the process and legislative events. I needed to jump on the other side of the fence and actively work to develop solutions. I was fortunate enough to receive a graduate school fellowship from Georgetown University where there I studied

health services research and also worked as a research fellow at the National Rehabilitation Hospital's research center. Since graduating, I've spent my career at that intersection of disability policy and research, looking for ways to make things better for people with disabilities and their families.

Barry Whaley:

Oh, thank you for that. Your work speaks for itself, John. Speaking of disability research and policy, prior to AUCD, as I mentioned, you were at NIDILRR, the National Institute on Disability, Independent Living, and Rehabilitation Research. NIDILRR, of course, is a federal government's leading applied research agency looking at issues that impact people with disabilities. I'm curious, when you were there, what were some of those important research topics and projects that you were working on?

John Tschida:

Tough question. One of the great things about NIDILRR is that it funds so many different areas of research. One of the issues that I felt strongly about when I was director, and we dedicated some research funding to do this, was better understanding outcomes measurement for home and community-based services. These are services like in-home supports for personal care attendants and direct support professionals to get people like me out of bed in the morning and assist in daily activities or day programs, service coordination, or even transportation. My goal was to try and get us closer to defining the value of these critical supports that allow people with disabilities to live fully integrated, meaningful lives in the community. There's a lot of reasons to do that, but in my mind, the two most important reasons were number one, to hold the providers of these home and community-based services accountable to the people using them and those who are paying for them, and two, to prove with data that home and community-based services are keeping people healthy and contributing to other positive outcomes like employment and quality of life.

I think if we can agree as a community and with federal funders and regulators what those measurements will be, we'll have an easier time getting funding at the state and federal

level for these services. At the same time, we were having these discussions internally to fund this. The Administration for Community Living where NIDILRR is also housed was working with the National Quality Forum to develop these indicators and outcome measures as well. There was a great committee that developed a wonderful report looking at 14 different domains in a disability context to think about how we can measure these services and prove the value of them. Of course, taxpayer funded the Medicaid program as the primary payer for the services that we're talking about here. Employer-based health insurance generally doesn't pay for any of these non-medical home and community-based services that we're talking about.

I think the home and community-based services outcome measurement is a good example of NIDILRR responding as an agency to timely issues that are happening in a policy context and putting a specific topic out there for research. Importantly, the agency is also intentional in creating open-ended research funding opportunities where it says to the field, give us your best ideas in a general research area like community living and the best scores will get funded. These more generic opportunities, if you will, allow for the needs of the disability community to come forward and be funded rather than just the government agency deciding what it thinks is important to fund. A couple other areas that I think are important are some of the longitudinal efforts that NIDILRR has really invested in overtime.

They've got 30-year databases looking at a couple of specific medical conditions. One is spinal cord injury, one is traumatic brain injury, and another is burn systems. It's designating centers around the country as model systems and also collecting common data elements at all of these different institutions that are grantees. That's created a wealth of opportunity in the area of brain injury. It's also led to partnerships with the Department of Defense and the Department of Veterans Affairs to have those large agencies also collecting these common data elements so that we can tell the story of people with brain injury over time. What are their health outcomes looking like? What are their community-based outcomes looking like? All that work started at NIDILRR. Those are a couple of the areas [inaudible 00:09:08].

Barry Whaley:

Yeah, those are fantastic areas. I do want to stay with the issue of HCB services and attendant care in particular because... So you have the outcome measurement, which gave us a lot of good information, but then how has that information changed in our current situation, pandemic, post-pandemic with the current attendant care crisis in this country?

John Tschida:

Great question. It's hard to talk about policy issues and not talk about the workforce shortage issues that are affecting people with disabilities in multiple ways. As more people with disabilities and members who are aging are served in the community, the demand for more workers to serve us in both home environments and in community service provider organizations continues to increase. We know that in this economy with the limited wages and benefits these workers are receiving, it's increasingly difficult to find and maintain qualified staff. I was in my own state of Minnesota over the holidays, spoke with friends and leaders in the disability policy world there and the situation is dire. We've used the word crisis to describe this for years now, and it is, but I heard colleagues talking about people with severe disabilities needing to leave independent departments and homes to move into licensed settings because they can't find staff. Group homes closing because providers can't find staff. Even long-term home and community-based service provider organizations shutting their doors because they can't keep the staff.

As I just mentioned, these supports are largely financed by the Medicaid program. Payments going to both individual workers and organizations providing home and community-based services are coming out of state budgets. Lawmakers are deciding what those funding levels will be. Historically, advocates have needed to fight state capital every year to get cost of living increases for these essential workers.

Barry Whaley:

Sure.

John Tschida:

There was the promise of a historic investment, hundreds of millions of dollars in HCBS funding from the current administration when the presidential transition occurred, identifying incentives for workers to enter the field, giving money to states to look at career paths and training pipelines, infrastructure funding for state Medicaid agencies to hire staff to think deeply about these challenges and how to solve them, but that investment didn't happen. I will acknowledge there were temporary funds directed to states during COVID to address the crisis, but we really need a systemic solution rather than these piecemeal approaches, so I-

Barry Whaley:

Yeah, I agree. Just to amplify how deep the crisis is, I'm sure you're aware of the lawsuit between Disability Rights North Carolina and the state in the forced institutionalization of people or the retention of people in state institutions caused by, in some ways, a number of factors, but in some ways, caused by this attendant care crisis.

John Tschida:

And I think we're probably going to see more of that.

Barry Whaley:

Which is directly in opposition to Olmstead and the intent and the spirit of Olmstead.

John Tschida:

Yes. Yes. As I think about the disability support system, I think of that three-legged stool of the Americans with Disabilities Act, Olmstead, and the Medicaid program. You have challenges to one of those legs and the entire system really is fragile. So I think the workforce crisis is a great example of some of the inadequacies of the Medicaid program, I think, and the payment structure that is not there to pay competitive wages-

Barry Whaley:

Sure.

John Tschida:

... for these positions, but also a very difficult economy that we're in with both inflation and a very tight labor market.

Barry Whaley:

Yeah.

John Tschida:

Unfortunately, lots of work to do on the advocacy fund.

Barry Whaley:

Yeah. Let's talk a little bit about your work at AUCD. In full disclosure, I worked for UCEDD at the University of Kentucky prior to coming to Syracuse and have great respect for the work of AUCD and the UCEDDs. I guess, the place to start maybe is, what's the mission of AUCD and a little bit about its history?

John Tschida:

Sure. AUCD, I like to say, is close to a \$700 million network, university-based researchers, trainers, service providers and advocates who advance policies and practices that improve the health, education, social and economic well-being of all people with developmental and other disabilities, their families and their communities. I know that sounds like a mouthful, but what it means is that there are thousands of people at universities across the country, including trainees and emerging leaders in every state and territory working with and on behalf of people with disabilities to make things better. There's a total of 142 network centers across the country that often serve as a vital link between the academic world and the local community. We are now in our 52nd year and have our roots in a law passed during the Kennedy administration. It was actually Halloween of 1963 that JFK signed the law that would start the network.

It was the brainchild of a doctor named Robert Cooke who was a pediatrician from Johns Hopkins. He had two kids himself with developmental disabilities and he developed a close relationship with Eunice Kennedy Shriver, one of JFK's sisters in the late 1950s. After JFK became president, he became a key advisor and leader on a government panel that would recommend the formation of what would later become the National Institute for Child Health and Human Development or NICHD at the NIH. The Kennedy family interest in disability stems of course from Rosemary Kennedy, a sister to both Eunice and JFK, who was born with a developmental disability. This law that was passed and signed on Halloween of 1963 had three critical elements. One was training. At that time, we just talked about workforce shortage. There was a critical shortage of qualified professionals to treat and address the needs of people with intellectual and developmental disabilities.

There was also a lack of research and data. So research and data was the second prong of this law, really bringing attention to the university level for the first time. There really were not a lot of researchers at the university level looking at these issues back in the early '60s. The third prong was facilities, so infrastructure building. There was a shortage of places to conduct the research and the training to assist people with intellectual and developmental disabilities. This first wave of centers were what were then called university-affiliated facilities. The whole point was to look at this intersection of training research to look at the complex needs of people with disabilities, not necessarily as medical problems, but to begin to recognize some of their social needs as well. They became laboratories for emerging medical services, community-based services, employment services, parent training, strengthening families, disease prevention, prevention of secondary conditions.

What was great about these first centers is that they were addressing the needs that were expressed by the parents of the kids living with IDD themselves. The parents were the chief advocates at that time. As I mentioned, it wasn't until these university programs were up and running that a significant number of universities across the country became active in IDD research. There was a progression over time during the late '70s, early '80s to really emphasize community-based services and the development of new services, looking at serving the entire lifespan of people with disabilities. Then the next generation

of centers from probably the mid '80s until the mid '90s, really focused on beginning to empower consumers. All of the UCEDDs, for example, have consumer advisory councils that are made up of people with disabilities, family members to advise the centers on what they should be doing. While our roots and our legacy are tied to the IDD community, intellectual and developmental disability community, many of our current centers are now serving many different subpopulations within the disability.

Barry Whaley:

It's interesting to me, thinking back to the origins of AUCD October of 1963, how at that time, we were so rooted in a medical model and a medical definition of disability, and then the evolution of that to the social model and how those university centers in AUCD were leading the way to that movement away from the medical model.

John Tschida:

They did help to drive that and really by looking at that interdisciplinary nature that's really in the lifeblood and the original mission of these centers. It doesn't make that artificial distinction the way we do in our healthcare system, for example, between these medical services and these non-medical services and the need within our government programs to get special attention on Medicaid waiver in order to get those community [inaudible 00:19:26] services. These centers were really designed to look across that health continuum and consider all aspects of an individual's [inaudible 00:19:34], which helped to drive the policy change over time, absolutely.

Barry Whaley:

Sure. As I said, I worked for UCEDD, which are University Centers on Excellence in Developmental Disabilities, but really, AUCD has other parts as well. I know a little bit about LEND, which is the Leadership Education in Neurodevelopmental and Related Disabilities. Really, John, I know very little about Intellectual and Developmental Disability Research Centers or IDDRRC, so it might be helpful to our listeners to talk about each of those three parts of AUCD and what their focus is and how they interact.

John Tschida:

Sure. Those three parts or prongs, if you will, are distinct programs funded by different parts of the US Department of Health and Human Services. If I break those down, we've talked about the University Centers for Excellence and Developmental Disabilities. There are 67 of those funded by the Administration On Community Living, and they really are focused on community living for people with disabilities. They have a statutory charge under the Developmental Disabilities Act to do four specific things. The first is interdisciplinary training, which includes continuing education. Second is community service including training, technical assistance, and demonstration services for the community. The third is research, which includes evaluation. Most of our centers are doing that in one form or another. That includes public policy and analysis of public policy as well, and that research prong. Finally, information dissemination. Although the law says information dissemination, we talk a lot more about knowledge translation these days.

Barry Whaley:

Sure.

John Tschida:

So it's not just pushing information out, but engaging your stakeholders on the front end of the process to understand what information they want and need, engaging them in projects and work of the centers to better define what those information deliverables should look like on the [inaudible 00:21:45]. The UCEDDs do that in partnership with people with disabilities, as I've mentioned, and we talked about the consumer advisory councils that every one of them have. Very close ties to the community. They often have close partnerships with the state DD councils and the protection and advocacy organizations that are also funded by the DD Act, as well as Centers for Independent Living and community-based organizations supporting people with disabilities. If we move to the 60 leadership education in Neurodevelopmental and Related Disabilities or LEND

programs funded by the Maternal and Child Health Bureau, this is really graduate level workforce development.

We've talked about workforce shortages in the context of home and community-based services. If we look at that medical service side of the ledger, there's often just as many shortages there. In the case of developmental behavioral pediatricians, for example, who are assessing kids with intellectual and developmental disabilities, I think there's only four in the whole state of Iowa. This is both leadership and disability competency training. It targets more than a dozen health professionals, including doctors, physical therapists, occupational therapists, speech therapists, mental health providers. Importantly, it also includes family members of people with disabilities and self-advocates themselves. There was a change in the law a couple of years ago to say that all of the LEND programs need to be including self-advocates in there, leadership and training programs as well. It's focused on building the disability competent workforce of the future, which was one of the original goals of the 1963 law that we talked about and we mentioned the workforce shortage issues challenging today's medical and social support system for people with disabilities.

Last but not least are the 15 intellectual and developmental disabilities research centers. They are funded by NICHD or the National Institute on Child Health and Human Development at NIH. Think of these folks as the white lab coat scientists looking at underlying causes of disability, studying things at a cellular and genetic level. This isn't about curing people with disabilities or making disability go away. It's about designing interventions that will help people with it, often very severe and rare genetic conditions and disabilities, lead as productive and independent lives as they possibly can. Importantly, and I talked about these as three distinct programs and they are from a funding perspective, but it's important to note that we have 16 of our universities across the country where there's a UCEDD and a LEND that are co-located in 10 centers across the country where all three parts of our network are co-located. That presents unique opportunities for collaboration and they have a wealth of resources to benefit the community.

It's our job in the Washington office at AUCD, not just to support the network's individual members, but to foster collaboration among them to share knowledge, create opportunities to come together on grant proposals, to host webinars. We host an annual conference every year that brings together almost 1,100 people now in the field and not just in our network, but people with disabilities and community organizations as well. We started by saying that the network was incredibly diverse and you can see they're embedded in medical schools and clinics as well as colleges of education, public health, other settings focused on social sciences. But what they all have in common isn't just a passion and commitment to people with disabilities, but a commitment to training the leaders of tomorrow, building the bench of researchers and health practitioners, service providers and advocates with and on behalf of people with disabilities.

Barry Whaley:

Important work. Yeah. Thank you, John. ADA Live! listening audience, if you have questions about this topic or any other ADA Live! topic, you can submit your questions online at www.adalive.org, or you can call the Southeast ADA Center at 1404-541-9001. Now a word from this episode's sponsor, the Association of University Centers on Disabilities.

Voice-Over:

The Association of University Centers on Disabilities, AUCD, is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. These programs serve and can be found in every US state and territory and are all part of universities or medical centers. They serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change. The center's purpose is the advancement of policy and practice for and with individuals with developmental and other disabilities, their families, and communities. For more information about AUCD, visit their website at aucd.org.

Barry Whaley:

Welcome back. We're talking with John Tschida, executive director of the Association of University Centers on Disabilities. John, the AUCD has diverse collaborations with projects, organizations, experts in the disability field. In addition to the ADA national network, which we are very pleased that we are partnering with AUCD, what are some of the other AUCD collaborators?

John Tschida:

Nearly everything we do, Barry, is done in partnership with one organization and often with several. Over the last few years of the pandemic, for example, we received several million dollars in funding from the CDC to assist and support people with disabilities and getting COVID shots and accurate information and resources to make that happen. Most of those dollars have gone to our network members, but also to some other key national disability organizations like the Arc, the Autism Society, the Autistic Self Advocacy Network, Family Voices, and Spina Bifida Association, just to name a few. In another CDC-funded project with our network members, we look at the effectiveness of the Learn the Signs. Act Early program, which is designed to get kids who are not hitting their developmental milestones in for assessments and services as soon as possible. Some additional funding is going to our members as well, but we're also partnering with the Morehouse School of Medicine on the NIH-funded National COVID Resiliency Network, which is designed to help address the impact of COVID-19 among racial and ethnic minority populations.

We know these populations were disproportionately and negatively affected by the COVID pandemic. If I return to the subject of HCBS services that we were talking about earlier, we are partnering with several organizations funded by the Administration On Community Living to ensure that the home and community-based settings rule is properly implemented. The HCBS settings rule first revised almost 10 years ago, but its full implementation has been delayed until this year, actually. This regulation is very complex, but part of a broader effort to promote community integration for people with disabilities and to help people with disabilities ensure that they have the same rights and choices and access to the broader community that anyone else does.

Every state needs to develop a plan to implement the rule and we are working with the DD councils, the Protection and Advocacy agencies, the Centers for Independent Living among others to engage at the state level as CMS is meeting with states to discuss these plans. We also partner with philanthropic organizations and private businesses. Right now, we are working with the WITH Foundation to evaluate grant investments that they have made to influence medical school curricula to include disability training. This is an area that they have invested significantly in over the last several years and they wanted us to evaluate how successful those grants have been at achieving their outcomes. We're also partnering with the national health plan, Elevance Health, which used to be Anthem to provide disability and equity training specifically in the state of Iowa. This gives you a taste of the wide variety of partners that we're engaging with on a regular basis, not just disability organizations, but also with providers, funders, and businesses who can benefit from not just our expertise across the AUCD network, but our connections as well.

Barry Whaley:

Great. Thanks, John. What struck me, you had mentioned a minute ago your annual conference. We were talking before the show that it was so good to be back in person, especially in the last year or so as a consequence of the pandemic. There's been a real focus on health equity for people with disabilities and I know that was the overarching theme of your conference. I was wondering before I forget to mention that, if you could talk a little bit about that.

John Tschida:

Happy to talk about that. This is directly related to issues of community inclusion the question of equity is one we have been focused on for the last few years and has been a theme for not just this last conference, but our previous two conferences as well. So I will say we lag behind other fields in equity in the disability community I think. We haven't really defined it and more specifically what it really means in a disability context. There are many definitions of equity out there, but what does it really mean when we look at issues of disability. We choose the issue of disability for our multiple conferences recognizing the need for us working in the disability field to create a national agenda.

Partnership with people with disabilities, their families, and the communities in which they live to address this challenge. We spent significant time with our board at AUCD talking about this. Many of our network centers are grappling with it as well. We know that there are groups that have been absent from leadership. Not just within our network, but in the broader disability community.

The disability research that has been done has been predominantly done on a white population. We know that we have progress to make in diversifying the staff make-up of our network centers. We are looking at ongoing action to identify and eliminate barriers that prevent the full and meaningful inclusion of individuals in groups that have been historically marginalized. And we recognize to achieve this vision we need to make investments in programming and supports to nurture the strengths of people in these communities and with these identities while also addressing their needs. In the broader disability community this is playing out in the disability justice movement, which I think has been healthy.

Historically we have looked at disability rights as civil rights, that's always been the framework. But this Disability Justice frame also acknowledges the systemic barriers and the absence of voices at the table in identifying priorities as well as shaping policy solutions. That is an overarching priority that I think is at the forefront of many organizations including ours and needs to be.

Barry Whaley:

Definitely agree with you. Thank you. As we come to the end of our time today, I'm curious. Pull out your crystal ball, John, and what are our challenges moving forward? Where will AUCD be focusing their work next?

John Tschida:

I think the equity conversation area we're having is both a challenge and an opportunity and that's a top priority for us. If we look at the current political and economic context to think about future, I get a little nervous. As I mentioned, we're in a very tough economy, a very tight labor market as we've discussed with divided government at the national level .

We've also got a very different supreme court than we did a few years ago. We have made tremendous and steady progress in shifting funding from institutional based settings to community based settings, to support people with disabilities over the last few decades, not just in the disability context but in aging context.

There has been more choice and control and meaningful social participation that has resulted because of that. More competitive jobs, increase civil engagement, faith and volunteer opportunities - all the things that people without disabilities look to for happiness and meaning. I talked about the three legged stool of the ADA, the Olmstead decision, the Medicaid program, and the potential threats there.

As a disability community I think we need to be vigilant, proactive and not just preserving what we have. Continuing to push to make things better. We're going to be spending a tremendous amount of time as an organization in that Medicaid context trying to really move the needle on things like competitive integrated employment. There's pending legislation, some of that is in the Medicaid context, some of that is getting rid of our segregated work settings.

Barry Whaley:

Great. Thanks, John. What struck me, you had mentioned a minute ago your annual conference. We were talking before the show that it was so good to be back in person, especially in the last year or so as a consequence of pandemic. There's been a real focus on health equity with people with disabilities and I know that was the overarching theme of your conference. I was wondering before I forget to mention that, if you could talk a little bit about that.

John Tschida:

There's been great progress at the state level related to that. Many states shutting front doors or developing systems to do that to eliminating sub minimum wage and also creating a path for those organizations who host those programs to change their business models and have an opportunity to succeed as well. We need to look at and reflect on the last few years of this COVID experience, the good and the bad, I think to take advantage

of some of the good and make things better in some of our communities system of supports for people with disabilities. We saw tremendous flexibility in government programs granted during the public health emergency that is still in existence. But in all likelihood that distinction will be eliminated in 2023. How can we preserve some of those flexibilities like telemedicine. Like more decreasing the need for face-to-face visits for recertification for eligibility for medicaid program. For example there is a lot of administrative pieces in there that make life difficult for people with disabilities and as a result they can fall off the program and lose their supports that are vital to their independence and the participation in the community. I think preserving those after the public health emergency is a way that we can unite as a community and continue to make progress.

I think the unity is important. We often create in our silos or our own areas of interest. In this current environment, I believe this is the perfect opportunity for us to unite the deaf community, the blind community, the community of people with physical disabilities among others.

You know we all have our unique and individual issues, but there is so much we have in common, especially in a home and community-based context. I think you are absolutely right and using forums like the National CCD in order to do that, the coalition of disability organizations operating at the National level can only make us stronger.

John, I want to thank you. I want to thank you for being our guest today, but personally, I want to thank you for your leadership through all the years. You've just been great. Thanks for telling us more about the Association of University Centers on Disabilities.

John Tschida:

Thanks, Barry. Great conversation.

Barry Whaley:

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4 Wheel City:

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