ADA Live! Episode 132: Nurse's Guide to the ADA: Understanding Responsibilities in Caring for Patients with Disabilities

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Guests:

- **Erin Vinoski Thomas**, PhD, MPH, Research Associate Professor Interim Co-Director, Center for Leadership in Disability (UCEDD)
- **Sydnie Smith**, M.Ed., Project Manager for the Georgia Statewide Disability and Health Project
- **Patricia Lawrence**, PhD-prepared nurse practitioner, educator, and researcher at Georgia State University. Stacey Peace, State ADA Coordinator’s Office – Georgia State Financing & Investment Commission

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

**Recording:** [adalive.org/episodes/episode-132](adalive.org/episodes/episode-132)

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**Sydnie Smith**

Hi, I'm Sydnie Smith,

**Patricia Lawrence**

Hi, I'm Patricia Lawrence.
Erin Vinoski Thomas

Hi, I'm Erin Vinoski Thomas, and you're listening to ADA live.

Barry Whaley

Hello 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 project director at the southeast ADA Center, listening audience. If you have questions about the Americans with Disabilities Act, you can use our online form anytime at Ada live.org, or you can call southeast ADA Center at 404-541-9001 remember, those calls are always free and they're confidential. One of the most important issues for people with disabilities is being able to access the health care they need in their local communities. According to the National Institute of Health, people with disabilities far too often experience a wide and varying range of health conditions that lead to poorer health and shorter lifespans, in addition discrimination, inequality and exclusionary structural practices, programs and policies that inhibit access to timely and comprehensive healthcare further results in poorer health outcomes. So on this episode, we're going to feature a new project launched by the Georgia affiliate of the southeast ADA Center that aims to educate nursing students about providing equitable, inclusive healthcare services for people with disabilities. Our guests for this episode are Erin Vinoski Thomas. Erin is a research associate professor and the director of the Center for Leadership and disability, a University Center for Excellence in Developmental Disabilities, or a UCEDD at Georgia State University School of Public Health. Joining us also is Sydney Smith, project manager in the Center for Leadership and disability at Georgia State University. And finally, Patricia Lawrence, a PhD prepared nurse practitioner, educator and researcher at Georgia State so I want to welcome all three of you to this episode, and thanks for being with us.

Sydnie Smith

Hi, Barry.
Patricia Lawrence

Thanks so much for having us,

Barry Whaley

Erin, if you could tell us a little bit more about the Center for Leadership and disability at Georgia State. And how does the center serve people with disabilities?

Erin Vinoski Thomas

Yeah, sure, the Center for Leadership and disability is a University Center for Excellence in Developmental Disabilities, or a UCEDD. There are 68 ucedds in the United States, at least one in every state and territory overall. UCEDD serve the disability community by engaging in four broad areas, or core functions, as we call them. We conduct research and program evaluation. We provide community services such as trainings for individuals, families and community members, and technical assistance for organizations. We engage in interdisciplinary training efforts geared toward university students and professionals in disability serving disciplines, and we disseminate information about a range of topics relevant to the disability community in ways that are accessible to the broadest populations. Right now, our center specifically has a heavy emphasis on work in areas of health equity for people with disabilities, training educators and school systems to use evidence based practices to better serve kids with disabilities, working with early childhood education and early intervention personnel to help support children with disabilities and who are at risk for mental health problems, and conducting leadership trainings for individuals, family members and the community.

Barry Whaley

Great. Thank you. And as an aside, if you want to learn more about the work of ucedds, listen to episode 114 supporting meaningful change in research education service the Association of University Centers on Disabilities that was recorded in
March of last year. So Erin, the Center for Leadership and disability, is our Georgia affiliate representing southeast ADA Center in Georgia. What work does your team do as the Georgia affiliate?

**Erin Vinoski Thomas**

We've been the Georgia affiliate for the southeast ADA Center since 2021 and generally, our work with the southeast ADA Center involves collaborating with the center and with the other state affiliate organizations to ensure that people and organizations receive the training and technical assistance they need to really understand the Americans with Disabilities Act and ensure that they're meeting the legal and civil rights of individuals with disabilities who are living in our region of the country. We absolutely love being part of this group. And the most exciting thing, from my perspective, is that each state affiliate organization also gets to design and carry out a separate project or set of activities in an area in which they have specific expertise. So for us, that area is training healthcare professionals, including students who are studying to be healthcare professionals to better meet the healthcare needs of people with disabilities. Our specific project for this funding period focuses on developing and implementing a training specifically designed for nursing students, and that's what we'll be talking about today.

**Barry Whaley**

So as you said, the focus of this training program is to train future nursing professionals on the needs and the rights of people with disabilities or patients with disabilities. Can you tell us a little bit more about these training modules and how they were developed?

**Erin Vinoski Thomas**

Yeah, of course, that's a great question. We began developing this training first by conducting a broad needs assessment of many different types of healthcare providers, and that was back in 2021 and 2022 we assessed training needs by sending out surveys and conducting interviews with healthcare professionals who represented a
range of health disciplines like medicine, occupational therapy, physical therapy, nursing and others. And the findings from those surveys and interviews confirmed unfortunately, a lot of what we already knew, that healthcare providers in most disciplines do not receive any or they received very little training about how to appropriately serve patients with disabilities. The Interview suggested that it might be challenging to develop a training that covers all health disciplines, and that focusing on providers that spend the most time with patients and families like nurses might be the most beneficial. So at that point, we began speaking to Patricia Lawrence, our esteemed nursing colleague who's with us today, and we decided that developing a training that addresses nursing students specifically, and one that could be embedded into nursing curricula would be a great place to start. So we decided to focus on students because, you know, they're still learning and engaging in our training while they're still in school. Could help them learn comprehensive strategies for caring for patients with disabilities before they begin working in patient care training professionals who have already been in the workforce often require sort of a different process, because it requires them to unlearn some of what they've been may have been doing for years. Following that needs assessment process, we developed our three training modules alongside nursing subject matter experts, and we invited nursing students to review those modules and provide their feedback. So the three modules that are included in our training are, the first is Disability Rights and the Americans with Disabilities Act. The second covers ADA titles two and three, understanding your patient care responsibilities. And the third is strategies for communicating effectively with patients with disabilities. We also developed pre post knowledge test that goes along with the training. We are currently finalizing the modules based on that student feedback, and we hope to voice record the training modules within the next month.

Barry Whaley

So I'm curious by your comment and having to unlearn things, because certainly, a medical model of disability is predicated on being able to fix somebody, right, as opposed to a social model of disability. This must be a steep learning curve for these students.
Erin Vinoski Thomas

Yeah, absolutely. You know, I think when we think about learning versus unlearning, there are existing trainings that are, you know, continuing education for healthcare professionals, and we work on some of those trainings and different projects as well, but we really wanted to sort of meet students where they're at and start from the very beginning with them, so that they never have that that experience of unlearning, not only unlearning the content and the knowledge, but actually unlearning behaviors that they may have been using in practice. So that's really, you know, one of the the main reasons why we chose to focus on this population specifically.

Barry Whaley

Yeah, exactly. Thank you. I want to turn to Sydnie. Hi, Sydnie. If you could tell us who's eligible for this training and how do they register for it?

Sydnie Smith

Yeah, of course, as Erin described, this training is specifically for nursing students, and these can be students enrolled in any type of nursing training program at an undergraduate or graduate level. Once we voice record these modules, they will be ready to upload to the southeast ADA Center's online training platform. After that, we'll do an additional round of pilot testing to ensure the modules are completely accessible in their uploaded format, and once that is complete, people who wish to take the training will register on the southeast ADA Center's training platform. That link will be shared with anyone listening.

Barry Whaley

Thanks, Sydnie, Patricia, would I want to turn to you? Get your perspective, because you come from a different perspective than perhaps others. Why do you believe this training is important for nursing students?

Patricia Lawrence
I’m very glad you asked this question. It’s a very important one. When I think, when we think about nurses, we know that nurses are often the primary point of contact for patients in most healthcare settings. And as the listening audience knows, nurses work in a variety of settings, including hospitals, clinics, schools and really even visiting patients at home. They interact with patients more frequently, really, than any other healthcare provider, according to the American Association of Colleges of Nursing, or the Aacn nurses, make up the nation’s largest segments of the healthcare profession, with approximately 4.7 million registered nurses nationwide. So nurses are at the bedside, routine assessment throughout the day, getting vital signs, giving medications, developing therapeutic relationships with their patients and accompanying patients to test procedures and when speaking to other members of the healthcare team, so they’re really involved in in continuous patient care, from admission to discharge. And through these ongoing relationships, nurses are really in a prime position to monitor interventions over time, which can lead to better health outcomes. We also know that nurses are committed to patient centered care and are trained to consider the whole person, including physical, emotional, social and environmental factors, and this really is what makes nurses well suited to address not only social determinants of health and provide comprehensive care to patients, but really are in a prime position to targeting these modules for the other thing is that that trained nurses educate and mentor other health care professionals and staff, and that really creates this ripple effect that enhances the overall quality of care seen within the Health care system. You know, people look up to nurses who serve as patient advocates and other members of the healthcare team. Look for nurses guidance on how to communicate therapeutically with patients, and unfortunately, I found that most nurses are not given the skills and training on caring for meeting those unique needs of patients with a variety of disabilities. I've had several students over the last few years tell me that they wish they had more specific training around caring for individuals with disabilities. For instance, in my leadership class that I teach at Georgia State, I've been told more than once by students that the topic of care around patients with disabilities just isn't discussed enough individuals with disabilities are a growing yet underserved population, and as researchers in the healthcare and public health space, we know
that further study is needed to completely understand the barriers to healthcare, their unmet needs, and the discriminatory and exclusionary practices of disabled individuals that lead to their poor health outcomes. So in my opinion, developing this training with nurses in mind at the very beginning really makes perfect sense.

Barry Whaley

Yeah, so it's interesting, and I hadn't thought about it Patricia, that patient interaction with nurses. There's just so much more than other healthcare professionals, right? So that the need for them to understand what the nuance of disability, how to, you know, basic disability etiquette seems so very important

Patricia Lawrence

here. Yeah, absolutely. And I think that is what's missing in our nursing education programs, that students are really engaged and really a captive audience for I mean, they're they're asking for it. They want it. And so it does make perfect sense when you think about the different points of contact that a patient comes in, in contact with throughout a hospital stay, they are constantly interacting with their nurses.

Barry Whaley

So Patricia, how is the training content engaging and accessible for these students? We've done a lot of research on various learning styles and abilities. How does the content approach that?

Patricia Lawrence

Well, Erin Sydney and I are professionals who very much embrace the concept of universal design for learning, and we believe that this that the way this content has been developed and how it will be rolled out will meet the needs of students with different learning styles and abilities. The content is offered in text, audio and video, and it's very interactive, so students that have different learning preferences will find that this format is really user friendly, and it ensures accessibility for students with all types of learning abilities. UDL designs learning experiences that cater to different
motivational engagement strategies, and this can include interactive simulations, case studies, group discussions and. Piecing learning, and so by offering these varied ways to engage with the material, students can choose the methods that best align with their needs, and that only helps to foster better engagement, and, more importantly, better attention of the material that we're hoping to inform them about.

**Barry Whaley**

I'm sure our listeners are very familiar with the seven principles of universal design. But are there principles for universal design, for learning that we should be aware of? I'm going to throw that at Erin.

**Erin Vinoski Thomas**

and the Learn and the learning is approachable then by operating these times. Yep, thank you. Erin, how were self advocates and people with disabilities included in the development of this curriculum?

**Erin Vinoski Thomas**

Thanks. So at the Center for Leadership and disability, nearly every project that we have in some way involves the input of people with disabilities and family members during the project's conceptualization, its design, its implementation, its evaluation and or its dissemination. And this project is certainly no exception. People with disabilities have been and will continue to be involved in several ways. So first, before we even really begin working on this project, our idea for developing this training was shared with our center's Community Advisory Council, or CAC, which is a group of people, including people with disabilities and family members, that help shape our center's activities and strengthen their relevance to the disability community. So once those modules are finalized and they're uploaded to the southeast ADA Centers training site, the Center for Leadership and disability, CAC members will then be invited to review and provide final feedback on the module content, as well as the accessibility of the training for diverse learners. Secondly, I mentioned that we're working with nursing subject matter experts when we developed the training content, and one of those
experts was also a parent or child with a disability, and that person brought that perspective into the module development as well. Third, we always want to ensure that there's adequate representation of people with disabilities in the images and the videos that are embedded in our trainings. So we partnered with the Human Development Institute at the University of Kentucky, which is another UCEDD, to embed healthcare videos that they had already created into this current training. They also included videos from the Disability Rights Education and Defense Fund or dread up that feature people with disabilities discussing their own healthcare experiences from their own perspectives. So to summarize, we first use our community advisory council or CAC. We work with subject matter experts who also have lived experience, and then we ensure representation through the use of videos from our partners.

Barry Whaley

Right? Thank you. I'm curious, were there any nursing professionals with disabilities included in that group?

Sydnie Smith

No, so not within the subject matter experts that we used there, I believe, when we did the initial needs assessment, I think there was one person who responded to the survey who had nursing expertise and also identified as having disabilities, if I remember correctly.

Barry Whaley

Thank you Sydnie. What resources and tools are included in the training that would support ongoing learning, especially the application of ADA guidelines and accessible healthcare practices.

Sydnie Smith

There's several resources throughout each module, as well as a broad resource list that is listed at the end of the conclusion of the third module, the first and foremost is the ADA foundations course developed by the southeast ADA Center is listed as a
strongly encouraged prerequisite to these nursing modules. By completing this training prior will allow students a more comprehensive knowledge of the ADA before learning in depth knowledge of titles two and three and their responsibilities as a nurse, additional resources such as the responsive practice training for health professionals, which covers disability competent care strategies, how to locate your local health department. Ada, frequently asked question guides and guides to developing. Resources and plain language are also provided, right?

Barry Whaley

And Patricia, you have something to add?

Patricia Lawrence

Want me to share some tips on how the training and resources might be able to be used in the nursing classes? Sure? Okay, well, I think this training can be introduced, really, in any part of of a nursing curriculum. Nursing students who are just starting their nursing education are very often very overwhelmed with just the basics, like learning how to take vital signs, how to perform a health history. But really, as students gain these skills and develop more confidence and confidence, this training can really then be incorporated into the classroom and even into the simulation lab. I'm hoping this fall to be teaching pediatric simulation in our simulation lab at Georgia State, and I'm really excited to incorporate some of these concepts that are important to caring for patients with disabilities. We know the Americans with Disabilities after the ADA was signed into law in July of 1990 to guarantee that disabled individuals have the same opportunities as non disabled persons. And despite the passage of the ADA more than 30 years ago, nursing education has only just begun to incorporate many of these concepts into nursing curricula. So although nursing training programs emphasize the importance of inclusivity and limiting and ideally eliminating personal biases when caring for individuals, there's still a lack of Disability Cultural Competence. Training in nursing education, research we know, has demonstrated that nursing student participation in clinical training with individuals with disabilities only enhances compassion and sensitivity toward the lived experience of disabled persons, and it
enhances disability related knowledge and skills when providing that hands on care for individuals with disabilities. You know, interestingly, there's been some debate on whether nursing programs should create a separate course focused on the care of people with disabilities, versus creating, you know, core care competencies for disabled individuals that are incorporated and weaved into a nursing curriculum over, you know, one or two years. And there really is a paucity of nursing education focusing on the care of disabled individuals. So in my opinion, integrating any disability training into nursing education and career onboarding is a very reasonable starting point. I know I, for 1am, very excited about the work that we're doing, because unlearning of those harmful beliefs and attitudes and biases that contribute to the health disparities that disabled people are known to experience is just so important.

Barry Whaley

Yeah, that's very important. Thank you. So what's the end goal? What do we hope to accomplish Sydney with this curriculum?

Sydnie Smith

Yeah, we're really hoping that this training will provide nursing students with the knowledge and understanding of what the ADA means to them as a nurse and their responsibilities under that as well as the appropriate skills and strategies to provide accessible care that hands on. What does it mean in practice or clinical settings? Content on disability, competent care is limited in health professional training programs, so these modules give nursing students the opportunities to gain this extremely important knowledge prior to entering their careers as nurses.

Barry Whaley

We're going to take a break for a moment. Thanks to Erin, Sydnie, and Patricia for being with us. ADA live listening audience. If you have questions on this topic or any other ADA live topic, you can submit your questions online at Ada live.org or you can call the southeast ADA Center at 404-541-9001 and now award from this episode sponsor the Center for Leadership and disability at Georgia State University.
Voice Over

The Center for Leadership and Disability, CLD, is a University Center for Excellence in Developmental Disabilities. CLD is housed within the School of Public Health at Georgia State University. The CLD is one of 67 programs in the country funded by the Administration on Intellectual and Developmental Disabilities US Department of Health and Human Services. Their mission is to translate research into sustainable community practices that contribute to independent, self determined, inclusive and productive lives for people with disabilities and their families. To learn more about CLD, visit their website at cld.gsu.edu

Barry Whaley

Hi everybody. Welcome back. I’m Barry Whaley at the southeast ADA Center. We’re talking with Aaron vinoski, Thomas, Sydney Smith and Patricia Lawrence. We’re with the Center for Leadership and disability. A UCEDD at Georgia State University, Patricia, before the break, we were talking about. Training you’re developing at the Georgia affiliate for the southeast ADA Center. We talked about the goals of the program, how the modules were developed to help future nursing professionals better understand the needs and rights of people with disabilities under the ADA Can you give us some feedback on how the students have responded so far to these modules?

Patricia Lawrence

Sure. Erin mentioned earlier that nursing students were asked to provide their feedback on earlier versions of the training modules, and those students were largely recruited from actually one of my courses that I taught a year ago, and feedback from the students at that time was really helpful in revising and reshaping the module content, as well as the pre post knowledge test that goes along with the modules, students indicated that the information was really important to them and was not really something that they learned about in their regular classes. Students indicated also that they wanted the training content to include more examples of real world approaches.
So I'm working on now to finalize case study examples that'll be included in each of those modules. So it's really exciting.

Barry Whaley

I would imagine for some students, it's pretty eye opening. Who have never experienced, or have had experiences with people with disabilities, open, opening them to a whole new range of experiences or understanding.

Patricia Lawrence

Yes, and you know, I've had, unfortunately, some students who are seniors. It's one of the courses that I teach are for senior students. And I've had one or two students say, how is it that I'm just now learning about this? And, you know, as nursing professionals and as nursing educators, we can't include every, every bit of content in their education. But I think this is such an important concept that that stems from birth to to the aged. And so I think it's, it's such a pivotal piece of content that we're focusing on and really important.

Barry Whaley

Sure and considering the 25% of the US population are people with disabilities, and as our population ages and we acquire disabilities, the importance of this curriculum and the importance for nursing students to be aware,

Patricia Lawrence

yeah, I couldn't agree with you more.

Barry Whaley

So Aaron, when the training is done and it's available and it's loaded on to our learning management system. How are you going to know that this is effective? This is successful?

Erin Vinoski Thomas
That's a great question as an evaluator. These are the types of questions I mentioned earlier that the training will be accompanied by a prepost Knowledge Test, which will be a required component of the training. So for us, comparing people's responses before they complete the training with their responses after they complete the training will help us understand if the training modules effectively help nursing students to increase their knowledge about their responsibilities as designated by the ADA, including topics that we covered, like how to provide reasonable accommodations and how to communicate effectively with patients with disabilities. We will also do some qualitative work, so we'll reach out to people who have completed the training within about six months to a year of when they completed it, so that we can also try to understand if that increased knowledge from the training also translates to improved clinical practices or other behaviors.

Barry Whaley

So these training modules are not just for people within Georgia. We're looking at improving healthcare disparities across the country, right? Sydnie,

Sydnie Smith

yeah, eventually this will be broadly available, because we're still in the development and testing phase. We are working within our state partners in Georgia, but once the training is live on the southeast ADA Center website, anyone from any state will be able to complete it. We're also engaging in targeted dissemination of the training, especially in the other seven states we work with through the southeast, ADA Center,

Barry Whaley

well, Erin, Sydnie, and Patricia, I want to thank you. This is great information you've shared with us today about the Center for Leadership and disability and its work as the Georgia affiliate, and especially these modules and how vital they are to nursing education. You know, this featured project aims to educate nursing students about the needs and the rights that people have under the Americans with Disabilities Act. If people wanted to learn more about this project or become involved, what can they do?
Erin Vinoski Thomas

Yeah, thanks. I'm always happy to talk with people about this work or any of the other work that's going on at our center. So if any listener wants to learn more about the training, please reach out to me via email or by phone, and I'll be happy to speak about it and really receive any feedback that folks are willing to share. Here, and if any listeners want to know more about the work we do at the Center for Leadership and disability at Georgia State as always, they're welcome to visit our website cld.gsu.edu, or email or call me to set up a time to chat.

Barry Whaley

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Music4 Wheel City
They watching. They don't want us be part of the city, man. They put all these steps, man. All these curbs we can't get over. All these inaccessible stores. 4 Wheel City. They don't want us here. We'll survive and we're going to make our own place. Our own world. The 4 Wheel City-

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