



## **ADA Live! Episode 103b: Meet the Director! Anjali Forber-Pratt of the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR)**

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**Guest:** Anjali Forber-Pratt, Ph.D. - Director of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at Administration for Community Living

**Host:** Peter Blanck - University Professor and Chairman, Burton Blatt Institute at Syracuse University

**Recording:** [adalive.org/episodes/episode-103b/](https://adalive.org/episodes/episode-103b/)

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**Dr. Anjali Forber-Pratt:** Hi, I'm Dr. Anjali Forber-Pratt and you're listening to ADA Live!.

**Intro:** Yo. Hi, let's roll (singing)

**Barry Whaley:**

Hi everybody. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network we want to welcome you to ADA Live!. My name is Barry Whaley, I'm the director of the Southeast ADA Center and as a reminder listening audience, if you have questions about the Americans with disabilities act, you can use our online form anytime at [adalive.org](https://adalive.org). We're so very pleased to welcome as our guest today, Dr. Anjali Forber-Pratt. She is the director of the National

Institute on Disability, Independent Living, and Rehabilitation Research also known as N I D I L R R or NIDILRR. Dr. Forber-Pratt assumed this important post in May of 2021 and I can't believe that its almost been a year on Anjali, but we are so excited to have this opportunity to talk with you today, to learn more about the important work of NIDILRR, as well as your thoughts on our challenges moving forward. I also want to welcome as our guest, Dr. Peter Blanck, a university professor and chairman of the Burton Blatt Institute at Syracuse University. So Peter, I'm going to turn the show over to you.

**Peter Blanck:**

Well, thank you, Barry and Dr. Forber-Pratt Anjali, it's fantastic to have you with us. I guess a few things have happened since you took over NIDILRR in the last year-

**Dr. Anjali Forber-Pratt:**

Just a few.

**Peter Blanck:**

... from an international crisis to an international crisis. Well, you are the person to be in the spot you're at. I'm a believer in many ways in destiny. I remember president Obama had you as a champion of change many years ago when we were all working under the Obama administration. And you certainly have been that, you have been a champion of change, you've been a leader, an advocate, an academic, a Paralympian medalist. I guess the first question I have to ask, did any of that prepare you for what you have to deal with today as the director of NIDILRR, the premier institute on disability issues? Which of course, as we all know, the elephant in the room is facing terrific challenges in the community that we both live in and work with.

**Dr. Anjali Forber-Pratt:**

Absolutely. I think that when I reflect on just my experience growing up for as long as I can remember with a disability and all of those experiences' kind of combined into one have really made me the disability advocate that I am today and have made me very well positioned as a researcher and as the director of NIDILRR. I think that each and every

single one of those experiences, both as a researcher, as a competitive athlete, as an individual with a disability have really shaped and provided me with a strong foundation.

**Peter Blanck:**

You know, Anjali of course, NIDILRR is not only a beacon in the United States, but it's a beacon of hope and inspiration around the world. NIDILRR most graciously and we are honored to for example work on the Southeast ADA, which is of course, one of NIDILRR's projects. And the amount of interest and concern we've had from all over the country just recent involved with the Ukraine crisis has really reflected the unity of people with disabilities, not only in the United States, but across the globe. I'm sure you have experienced that already and how would you convey that experience that really motivating advocacy that you're talking about as the leader of this premier institution?

**Dr. Anjali Forber-Pratt:**

I think that first and foremost leading NIDILRR to be on the forefront of disability research and rehabilitation research for our country is so very important, but it's also important for us to be a voice internationally and to help to cultivate the energy and the importance of disability research and these important conversations more broadly. The other piece is that advocacy runs long and deep throughout all of that. And I think that from my perspective, advocacy, whether that's disability advocacy, whether it's advocating for disability research, whether it's advocating for sharing of people with disabilities, their stories, all of those advocacy elements are critically important. We know that individuals really gravitate towards hearing people's stories, that's what makes the research come to life.

**Dr. Anjali Forber-Pratt:**

And from one of my earliest memories of outwardly being an advocate, I was in the first grade and I filmed a video called I can do different things. And then I went in person to the big old middle school to be my big brother, who was in the fifth grade at the time, to be my big brother's class project. And I still take credit for his A that he earned on that project. I mean, I think I might have earned him that A, but it was really fun to teach others about

disability and to explain the challenges and the solutions. And that just became such an integral part of who I am even at those early ages. And I see those pieces of advocacy in the work that I'm doing now as director of NIDILRR, both nationally and internationally.

**Peter Blanck:**

And that of course is so needed. Now, I had some questions about the history of NIDILRR and the mission and so forth, but frankly, I think we and our listeners will learn about that as we speak. What I was interested in is we've all had to reinvent ourselves basically in the last three years, things that were unimaginable really five years ago and the way we went about doing business, how do you bring that to your agency? What do we have to do to make that reinvention at NIDILRR and more broadly in the disability community in light of what's going on today?

**Dr. Anjali Forber-Pratt:**

And an interesting overlay on this, which is, I think important perspective is that coming into this role, I still to this day have not met all of my staff in person. And so that's just one example of an element of how the pandemic and how the world of work has really changed. When I think about that experience for myself, it also amplifies how I personally have really approached these changes that we all were thrust to, which is to really listen, to really listen to my incredible staff and to observe day to day operations, who at the time when I came in, were being led by Dr. Kristi Hill, who is my deputy, and also known as my right hand. I also continue to ask a lot of questions. I think that sometimes it's why has this been done this way? Or is there a reason we approach it this way?

**Dr. Anjali Forber-Pratt:**

And I think that, that natural curiosity is also something that just living in a pandemic has made us all question like, why were we traveling around to attend these conferences in person? When now, two years into this, we've been able to come up with workable hybrid ways that are also accessible for individuals with disabilities and in some cases, maybe more accessible than running the risk of traveling with a disability and having personal medical equipment damaged potentially by airlines or just having to deal with personal

care needs on the road. And so in some ways, some aspects of our world in this hybrid or virtual environment have become more accessible. It's not to say that there aren't also challenges that have come up from this virtual changes and change in terms of how we've approached work, but there have also been some significant wins.

**Peter Blanck:**

Part of this new era we're living in we must talk about efforts in terms of racial and gender justice and other areas as well. I know when I first started working as a person with family members with disabilities, disability was viewed as rather monolithic. And then we sort of expanded into mental in disability and different sorts of issues today are focus and I'm sure yours is really the total identities of the person from an intersectional perspective. So we no longer in our grant proposals to you speak of disability, but we speak of multiple identities, including disability race, LGBTQ+ status, gender of course and so forth. Is NIDILRR embracing with that move towards a conception of multiple identity in the context of environment and how is that reflected in what you're trying to do at NIDILRR?

**Dr. Anjali Forber-Pratt:**

Yes, it absolutely is reflected in so much of our day to day operation. So at the highest level, very early in president Biden's time in office, he signed two executive orders related to equity. And for the first time disability was listed as one of several identities. And certainly for a long time, long before that executive order existed NIDILRR and the Administration for Community Living has believed wholeheartedly in making sure that we were meeting the needs of all individuals with disabilities. However, this call out and this nod towards the importance of disability in relation to these other underrepresented identities is really, really important and it really signals the importance of these efforts. And for us within NIDILRR, this is something that I was able to really build upon within our own grant making and our own funding opportunity development.

**Dr. Anjali Forber-Pratt:**

For example, we have criteria that has always encouraged the involvement of people with disability in whatever the work is that's being proposed, like all the way through, from the

design of the project, to the conducting of the said project to the dissemination of the work. But we also require investigators who are proposing work to describe how are you going to reach the intersectional communities of individuals with disabilities who are also traditionally underrepresented? So how are you going to reach the black and brown disabled community? How are you going to reach individuals who are disabled and also identify as LGBTQ? And so by calling this out as a specific element within the grant applications that our applicants are expected to respond to, it also helps to elevate that importance. The other piece that I think is critically important is that we must include as much as we can in terms of all aspects of disability and types of multiple representation of disability across the entire research enterprise.

**Dr. Anjali Forber-Pratt:**

So what I mean by that is that we need to make sure that we have investigators who are black and brown and disabled, that we have investigators who are LGBTQ and disabled, and that we have peer reviewers who identify as people with disabilities, that we have project officers on NIDILRR staff that identify as people with disabilities. So all of those different groupings of identities adds to diversity of thought and allows for different perspectives of the research projects that we fund and that are carried out. And we really see that as fundamentally important so that we get a better understanding of the true needs of the entire disability community.

**Peter Blanck:**

Exactly. And so, for example, increasingly build the capacity of historically black colleges and universities or Hispanic university and so forth to build that next generation of multidimensional, multi identity researchers, which I think is needed very much as you say. The other big issue of course, is many people are expecting a continued mental health crisis, that word has been used as a result of the trauma that we've experienced collectively. Mental health issues are related to physical health and vice versa, is that an area which NIDILRR has focused on quite a bit, this cross disability integration? So it's not just a study on mental disability, but again, this more intersectional complete study.

**Dr. Anjali Forber-Pratt:**

Absolutely. First and foremost, when I think about the work that NIDILRR funds, we fund work across the entire spectrum of disabilities and that includes psychiatric disabilities, that includes mental health, that includes of course, physical disability, intellectual disability, and any potential combination there of. But it has also really highlighted the opportunity to strengthen relationships between NIDILRR and our other federal partners. So for example, for about 30 years NIDILRR has had a relationship with SAMHSA, which is the Substance Abuse and Mental Health Services area within the federal government. And we are actively having communications with our colleagues at SAMHSA, how can we better assess the intersection of mental health conditions, whether that's mental health challenges because of the pandemic or just mental health challenges in general, as well as with that intersection of disability. So we are very actively involved in these conversations and see this as being certainly an area of growth and expansion.

**Peter Blanck:**

That cross agency fertilization is so important and can lead to so many interesting ideas as well as cost efficiencies. So everybody's working towards the same general goal. I want to take a moment as I must to thank our audience, our listening audience, and tell them that if they have any questions about this topic or other ADA Live! topics, please submit your questions online at [www.adalive.org](http://www.adalive.org), or call the Southeast ADA Center at 1-404-541-9001. And now we'll take a word from this episodes sponsor.

**Voice Over Announcement:**

As part of the Association for Community Living, ACL, the mission of the National Institute on Disability, Independent Living, and Rehabilitation Research NIDILRR is to generate new knowledge and to promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community. NIDILRR's mission is also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. NIDILRR achieves this mission by funding research, promoting the transfer of, use and adoption of rehabilitation technology and ensuring the widespread

distribution and usable formats of practical, scientific, and technological information. For more information about the important work of NIDILRR visit [www.acl.gov](http://www.acl.gov).

**Peter Blanck:**

So welcome back at everybody. I'm here with Anjali, Dr. Anjali Forber-Pratt who is the director of NIDILRR. It's been a fantastic conversation. I have to ask you since you were involved in many sports' wheelchair racing track, I think you also were a skier too, how did that stimulate and affect your advocacy? You've touched upon it earlier, did you know at a young age that this was a path you were interested in?

**Dr. Anjali Forber-Pratt:**

I did. So here's how the story goes. So I grew up in Natick, Massachusetts, which is 20 minutes west of Boston and is also affectionately known as the eight mile marker of the Boston Marathon. It wasn't until I moved out of the Boston area out of state where I learned that Marathon Monday was not a national holiday because growing up everybody goes out to support the Boston Marathon and to cheer the crowd on. One of my earliest memories was I was about five years old and was woken up early to go cheer for the runners going by. And it was the first time that I saw people in racing wheelchairs going flying by and it was just the coolest thing. And it led to me seeing individuals like Jean Driscoll on the front page of the Boston paper, the newspapers and things like that.

**Dr. Anjali Forber-Pratt:**

And it was just this really pivotal moment as a young five year old, where I began to realize that I could live my life disability and all, and that I could grow up to be somebody despite having a disability and that I could have this experience athletically. So I started begging and pleading my parents to pretty please get one of those really cool looking racing wheelchairs. Eventually was able to get one and was involved with a Saturday sports clinic. So for once a week on a Saturday morning, about 45 minutes away from my parents' house, I got to try all different types of adaptive sports. I did fall in love with the sports with speed, wheelchair racing and downhill skiing in particular, but this was just a

really, really fantastic experience because it provided me with the opportunity to meet other kids like me.

**Dr. Anjali Forber-Pratt:**

So I was really... In my home community, I was one of the only ones with a disability, with a visible disability in my grade that I saw on a regular basis and in and around the community. And so this gave me these built in friends where I didn't have to explain why I used a wheelchair. I didn't have to explain the annoyances of going to hospital appointments or things like that. I could just be me and have really fun time doing all of these sports. And so for me, that early exposure to sport provided that strong sense of community. And as I encountered accessibility barriers as I went through schooling, it gave me a support system and individuals who understood that frustration when I encountered the inaccessibility of my high school, for example, or when I encountered other elements of just frustration living life with a disability.

**Dr. Anjali Forber-Pratt:**

So for me, that advocacy really came about and gave me a sense of community because of sport. And then of course, being able to go on to the world stage and compete and represent team USA at the Paralympics, it just amplified that platform in a different way. So as I had successes in wheelchair racing, I was a sprinter, so 100, 200 meter, 400 meter were my main events. But as I had success with wheelchair racing I also had the opportunity to help to develop disability sport programs in other countries and to help individuals at the grassroots level in other countries learn about their own disability advocacy. Sport is something that is cool and is neat to watch and can be very empowering to center the voice and the needs that people with disabilities may have in terms of barriers that they might be facing within the community. And it was just a really incredible platform to be able to be able to engage in that advocacy work.

**Peter Blanck:**

I should say, you probably know a friend of our community who I had the honor to meet Kent Waldrip. He was a football player in Texas who was paralyzed after a football injury,

before the ADA and he went on to be a key driver of the Americans with Disabilities Act from his athletic competitive point of view. And I believe he's one of the folks who envisioned the ADA as this unified big law. So Kent, wherever you are, we're still talking about you.

**Peter Blanck:**

You talk about accessibility, but of course, you're very focused on universal design as well. I'm a chair of a global nonprofit called the Global Universal Design Commission and we advised on building a new YMCA in Michigan and the idea was, no retrofitting, no "accessibility," everything was available to everybody. So a big iconic ramp, which is not just a wheelchair ramp, but a beautiful kind of entry ramp greets everybody. And we did surveys in focus groups, for example, people who played wheelchair basketball often brought two wheelchairs, their basketball wheelchair and their other and it was cumbersome to leave those around and why should they? So there was built an accessible universally design locker room where all individuals could leave things including wheelchairs, second wheelchairs. Is your sense that we are moving towards this concept of universal design or do we have a lot still to do? Is that an aspiration of NIDILRR to move in that thought way?

**Dr. Anjali Forber-Pratt:**

Absolutely. I think that there are so many aspects that are connected to the principle of universal design that I believe benefit not just those within the disability community. So, certainly in terms of the physical access, examples that you provided and I wish that more new construction would take advantage of those principles and have them be embodied throughout. But the other aspect is also around communication access. And so when I think of, for example, close captioning, that's something that, yes, it's greatly beneficial for individuals who may be deaf, but it's also highly beneficial for individuals where English may not be their first language or for any individual, regardless of hearing status, if you're just in a noisy environment, if you're out at a restaurant, for example, and back when we were able to do that pre pandemic. If you're out at a restaurant and there's something on

the television, but it's a noisy restaurant while having those close captions on that benefits everyone who's in that restaurant space.

**Dr. Anjali Forber-Pratt:**

And so my hope is that these technologies and affordances that are often thought of as being for the disability community, if they can be adopted more broadly from a universal design perspective and be able to show the value added for all, it will just help to make the world more accessible for all.

**Peter Blanck:**

And of course, one test of that will be as you mentioned earlier, whether a so called silver lining of the pandemic as my colleague, Doug Cruz has said will be that in the workplace, for example, more technology is generally accessible because it had to be, like you said, early on that you just haven't met in person, some of your colleagues.

**Dr. Anjali Forber-Pratt:**

Absolutely.

**Peter Blanck:**

I'd like to talk for a moment about the world of work, which of course is a big area of NIDILRR. What's your views on, do you think that we are in for a sea change as people return to work not only in the physical and technological structure, but more so, even in the attitudinal views about life and work and about family and work and about personhood and work? It seems like it's a very important time for NIDILRR in that regard to rethink what work means for all sorts of people who formally have been excluded from the workplace.

**Dr. Anjali Forber-Pratt:**

Absolutely. Unfortunately as you certainly know, individuals with disabilities face extremely high unemployment statistics and often are not afforded the same opportunities

to just get that work experience and to get that initial foot in the door. But some of the other challenges that we've heard for a long time from individuals with disabilities are reluctance on the parts of some employers when it comes to flexibility and accommodations. And one of the most commonly asked for accommodations for many within the disability community is a flexible work schedule in order to accommodate things like doctor's appointment, in order to accommodate things like chronic pain management, in order to accommodate procedures that you might need to do that might take a little bit longer related to your own activities of daily living. And so there's many, many reasons that individuals with disabilities might be looking for a flexible work schedule and the pandemic has really shown the value of that specific accommodation for so many individuals.

**Dr. Anjali Forber-Pratt:**

We've heard that there's been less resistance to granting of that type of accommodation again, through the regular reasonable accommodation process and so forth in terms of requesting that. My hope is that return to office, return to workplace movements are occurring, that we don't forget about the value added and the fact that many individuals were able to be more productive with those flexibilities, regardless of disability status. Being able to be present when your child is finishing up their classroom day, whether that's coming off the bus or coming off of the computer from virtual school, whatever those needs may be, that we are seeing the shift.

**Peter Blanck:**

That's really well said. I've always thought as you have and others that the ADA, which is a crucially important law, but it established a floor against which employer will say, "Okay, you can have an accommodation, you can't," For purposes of the law. It would seem that we might even as we move away from accessibility towards universal design, like you say, maybe we move away from accommodation towards what do you need to be a healthy and productive employee and we will make that happen for you, notice I didn't use the word accommodation, based on your individual needs. So what is going to make you feel well and healthy and productive? And maybe that means a mental health day,

maybe that means things that were not necessarily originally thought as accommodations to make it a level playing field, but as you say, an aspect of our lives that allows us to be more productive. Is there thinking going on about that maybe that's beyond, well, it's certainly beyond the purview of the law, but NIDILRR from an aspirational point of view, you certainly can think about those things.

**Dr. Anjali Forber-Pratt:**

You know, Peter, I think for myself, I'm certainly thinking of those things. I don't know in terms of where the direction of work and so forth will go, but I also think it's fundamentally important in particular for our ADA centers to also still continue to provide the technical support and the interpretation of what the laws and what those protections are, because we can be aspirational all day every day, but I also know that there are unfortunately going to be challenges and barriers that some individuals with disabilities face in terms of accessing accommodations, in terms of having the ability to enter the workforce. One very specific example with this current time in the world is that we're in such new territory with COVID 19 and particular long COVID. There are many individuals who do not realize protections that exist under the Americans with Disabilities Act for individuals with long COVID. The Department of Health and Human Services developed guidance about this explaining that long COVID can be a disability under the Americans with Disabilities Act and under section 504, if it substantially limits one or more major life activities.

**Dr. Anjali Forber-Pratt:**

But there are many individuals who may be experiencing long COVID or employers or loved ones who do not realize this. And so this is all new and I just applaud the work of the ADA centers as being really integral in helping us to spread the word and to help to educate the broader American public of the existing protections that do exist.

**Peter Blanck:**

Again, that's very well said. There was a case out of Alabama, I believe this week, which basically held that long COVID was a disability for purposes of the Americans with Disabilities Act, not only an actual disability, but a record of a disability and also perceived

disability. Your points also with regard to the ADA are very well taken. And I must say, not a week, maybe a day, that goes by where we don't get a troubling call at the ADA centers. So I guess your point is while we can be aspirational at the same time there's a lot of work to do on a day to day basis and the ADA centers thankful to your agency try to be at the forefront of that.

**Peter Blanck:**

Well, we've had a terrific conversation. This is the kind of conversation that could go on all day. I just wanted to give you the chance to make any closing remarks you would. I particularly think that your support of the ADA centers are crucial. And as you say, the ADA centers are kind of a backbone for many of the day to day activities that take place in our community. Do you have any final thoughts as to what we've talked about or your vision for going forward in the shorter term or longer term?

**Dr. Anjali Forber-Pratt:**

Just a huge thank you to you all, to all of the ADA centers, to all of the listeners who are taking an interest in these important topics. My commitment as a director of NIDILRR is to ensure that we remain as the federal go-to and leader for disability research and for the technical support related to the Americans with Disabilities Act. As we talked about, I certainly have goals to increase the representation of just disability in general, across the entire research process and the research enterprise. And I really look towards our entire disability community to make sure that all voices are being represented in the work that NIDILRR does. All means all and I want to really make sure that means that we're not forgetting any disabled voice in the work that we do.

**Peter Blanck:**

Well, thank you. And I must say for our team, this is truly a community effort, which is inspired by you all. We believe we are reflective of the community and work for the community, and it's been a terrific pleasure to speak with you today. I want to thank Barry and his team, none of this could happen without them and I want to thank our listeners as well. So, Barry, I turn it back to you to take over from this point and thank you all again.

**Barry Whaley:**

Thank you, Peter. Thank you Dr. Forber-Pratt for being our guest today, it was great episode. Listeners as a reminder, if you want to learn more about long COVID or post COVID symptoms, we urge you to tune into episode 104 of ADA Live! with our guest Sharon Reynard from the Equal Employment Opportunity Commission, the EEOC discussing long COVID and its implications for work. Listeners you can access all ADA Live! episodes with archived audio, accessible transcripts and resources at our website [adalive.org](http://adalive.org). We invite you to listen to the SoundCloud, ADA Live! channel at [soundcloud.com/adalive](https://soundcloud.com/adalive). As a reminder, you can download ADA Live! to your mobile device. Go to your podcast app and search for ADA Live!.

**Barry Whaley:**

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**Barry Whaley:**

ADA Live! is a program of the Southeast ADA Center, Burton Blatt Institute at Syracuse University and a collaboration with the disability, inclusive employment policy rehabilitation research and training center. Our producer is Celestia Ohrazda with Beth Miller Harrison, Mary Morder, Emily Rueber, Marsha Schwanke, and me, I'm Barry Whaley. Our music is from 4 Wheel City, The Movement 4 Improvement. See you next episode.

**4 Wheel City: (rapping)**

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