



ADA Live!

Episode 83b: Celebrate. Learn. Share. The ADA turns 30. The Future of Disability Rights with Lex Frieden

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Speaker: Lex Frieden

Host: Peter Blanck, Chairman Burton Blatt Institute at Syracuse University

Lex Frieden: Hi, this is Lex Frieden, and you're listening to ADA Live.

4 Wheel City: (rapping)

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 at the Southeast ADA Center. And as a reminder, audience, you can submit your questions about the ADA at any time to adalive.org.

I'm always pleased when I get to introduce my boss. Peter Blanck, will be our host for today's episode, as we celebrate the 30th anniversary of the Americans with Disabilities Act. It's my honor and privilege, Peter, to turn it over to you to interview Lex Frieden, an American educator, researcher, disability pioneer, policy expert, and the man regarded as the architect of the ADA. So Peter, it's all yours.

Peter Blanck: Well, thank you, Barry. And hi, Lex. And I would add to that introduction of Lex, a great American.

If I may, Lex, in my life I've met a lot of citizens as you have, and I have a category for great American citizens and you're just about at the top of that list. For me, that means somebody who inspires, somebody who's focused on positive and real change, somebody who does it so naturally and so humbly that others follow, and they don't even think they're following sometimes. They're just swept along in the magic of Lex Frieden. And it's quite an honor and delight, Lex, to speak with you today.

Lex Frieden: Peter, I'm glad to be here, glad to speak with you anytime. And I appreciate all the work that you've done to promote equal opportunity and advancement of rights of people with disabilities, all types of disabilities.

And I think history is only that which we make of it. And we have a short time during our lives to make a contribution to society. And I think we all do that as well as we can.

Peter Blanck: Well, as you know, Lex, and coming up on the 30th anniversary of the Americans with Disabilities Act, the ADA, we are honored to recognize that anniversary. As we are honored to recognize you, somebody who has lived prior to an ADA, and now living through the ADA, and all the permutations it's gone through. As everybody knows, it's quite a broad law, covers most aspects, certainly maybe every aspect of American life from education equality, to physical equality, to employment issues. The list goes on. And Lex, you've been interviewed many times and you've written so many things. You've written the forward to my recent book, which is an extraordinary forward about these issues. What do you think, is there something that you would like to convey just to start, that you really haven't conveyed before? Or something that most of our readers would not normally be aware of, in regard to the evolution of this law that came to be known as the ADA, and how it has really shaped your life and shaped the lives of so many others?

Lex Frieden: Well, I think that's an open ended question Peter, and books have been written about the ADA and others need to be written. No matter how much you talk about it, there are aspects of it that have not yet been exposed or discussed. And I would say, for everybody engaged in the ADA process, all the people who worked on ADA, all the people with disabilities who marched, wrote letters, attended meetings, expressed themselves, everybody has a story and everybody's story is important. And the ADA

would not be complete without those stories, some of which will probably never be told. But I got to tell you, people made great sacrifices to participate in the ADA process. Some of them use themselves as examples. And the examples that they gave were from a life that differs from a life they would experience today.

Lex Frieden: Many of those who've gone before us had to suffer unnecessarily, simply because they happened to have a physical or mental impairment that prevented them from doing that which they would like to do, that which they might've done had there been no barriers. And today I think we have to reflect on that, remember that, and know that each one of those people, each one of their lives made a contribution to ADA. We have to honor that by continuing to work on the ADA, by ensuring full implementation, and by making the occasional updates to the ADA that are necessary to accommodate changes in society.

So the question that you ask would be a difficult one to answer in a short period of time. Personally, my experience started when I broke my neck in a car wreck and less than six months later, I was told by a university that because I was disabled would not be attending as a student there now. What happened during the six months when they wanted to give me a scholarship and were recruiting me to attend their school, and the time that they wrote and told me I would not be admitted because I had a disability. The only thing that happened in my life was I was in a car wreck and that's it, period. End of story. And yet, that episode, that 30 seconds, with one car filled with students filing into another car load of a downtown street in Stillwater, Oklahoma, affected my life dramatically. And to the extent that it helped me, introduced me, to the life of advocacy that I've lived. It was a significant moment in time. And I think we've all experienced those kinds of epiphanies.

Peter Blanck: We have talked about this before. You've written about that car wreck. The first part of this question maybe is more factual, and the second part is a little more speculative, but interesting. Who was Lex Frieden before that car hit that other car? And did that Lex Frieden ever think twice about civil rights, or inequalities, and life at that time?

I recognize you were very young at the time. And what do you think that pre car wreck Lex Frieden would be today, if it hadn't been for that car wreck?

Lex Frieden: That's a good question. I grew up in a small rural community in northwestern Oklahoma, and it was a homogeneous community. As far as I know, no black people lived in our community. There were some Hispanics with people who lived there, but we considered them to be part of the family, part of the community. They had lived there for generations. So we didn't think of them as being minorities. There were people with disabilities in the community. I had in my class, all the way through high school, a young woman who was short stature. In fact, two of them. One of them I don't even think of today because she had a different kind of dwarfism, but Andrea Markum did all the things everybody else did. And we wouldn't think about having an event that Andrea couldn't participate in. And in other schools, maybe her short stature would have prevented her from doing things.

But we simply as a class, as a community, as a group, refused to do things... It didn't even seem natural for us to do something that she could not be involved in. But that frankly, is the extent of my experience with disabilities when I was young. Except for having old grandparents who lived in a nursing home and had help getting up and going to bed. And as I reflect here, there was a young man who grew up with us down the street when we were kids and played in the yard, who was intellectually challenged. He was a friend and we played with him, and he participated in all our neighborhood activities, until we started the school. And all of a sudden Roger disappeared. And nobody asked where Roger went. But later on, when I was thinking about it, I asked my mother and my mother was a little shy about describing Roger's disappearance, and I continued to press.

And finally, my mother explained to me that Roger had learning challenges and that he was not able to attend the school with the rest of us, therefore had been sent to a special school somewhere far away. And we never knew what happened to Roger. We didn't miss him long because there were obviously other kids and other things to do. Until I think about it now, and I have thought about it a few times in the past, people with disabilities were treated. They were treated the way they were treated. People thought they were

doing the right thing when they gave treatment and those solutions occurred. But they were not really supportive of the individuals with disabilities. There was a visually impaired man that lived in my community, and he sat down on the sidewalk outside the TG&Y store with a cup. And I observed, when I was down there one summer day, that nobody put any money in the cup.

And I thought, what's Jim's purpose here with his cup on the sidewalk? I also observed, that people would stop and chat with Jim. And it occurred to me that Jim's objective here was not to collect money, but instead have a conversation with somebody to be social. And so one day I went and spoke to Jim. And he was a conversive gentleman. And I asked him about his cup and he sat it down and he said, "Oh, man that's just a conversation starter." And so I had some experience with disability. I didn't think about it much. I didn't consider myself to be an advocate, despite the fact that I spent time with other people who had disabilities. When I was told by the university, I couldn't go to school there. The first thing I tried to think of is, why not?

Is there a precedent for that? And it occurred to me that the President probably lay in the treatment of people who were black in the South. And I had grown up during a time that in the 1960s, when there were protesters. People still protesting segregation, and people who were protesting the war in Vietnam, and people who were protesting the treatment of women. And so that was the background when many of us, who were disability advocates, grew up. That framework of speaking out. And I adopted that perspective growing up and I think naturally applied it to my own experience with disability discrimination.

Peter Blanck: My favorite movie is, It's a Wonderful Life, which of course many of us know has a theme about... We really don't know how many lives we touch in small ways. Whether it's Roger, in your hometown. Or the person who was blind with the cup. And we often think, as George Bailey did in It's a Wonderful Life, what would I have been, Lex Frieden, had I not been in that car on that day? Do you ever think about that, from that perspective?

Lex Frieden: Yeah. I mean, I think everybody who experiences a traumatic disability like mine, probably thinks about that. I don't spend a lot of time. I mean, I haven't thought about it in years. I used to, when I was feeling depressed, think about what life might have been otherwise. And it's hard to imagine, frankly. I was interested in radio and television. I was interested in law. My mother named me, Lex, which as you know, is Latin for law. I thought I was destined to become an orator. And I was interested in electronics and engineering. And I had many, many interests. When I started college, I had no idea what I wanted to do. When they told me I needed to have a degree plan, I told them my plan was to go to college until I found something I liked to do and something I could get paid for.

But I really wasn't even concerned about that because growing up, I had done many, many jobs and been paid for all of them in my little town. I changed tires for cars, I worked at the radio station, I flipped eggs in the diner. I did yards, cleaned cemeteries, lifeguard at the pool. One advantage of growing up in a little town like that, is that if you want to try something, you usually can find an opportunity to do that. And I like trying everything. So I have no idea what I would have been or done had I not met my destiny in advocacy. And I suppose there wasn't another [inaudible 00:15:28] me. I did what I was supposed to do. I did what nature led me to do. And that's kind of why I'm here today.

Peter Blanck: I actually thought of that also from a selfish point of view, on what a wonderful life you have and you created. And what our world would be like without that incident you experienced. It would be potentially a Pottersville, in which if you know the movie, is a much darker society than what they would have experienced had he lived. What do you think of today, Lex, at this very moment, the young college student who's going to get in that car, exited, and break his or her neck? And what is that person going to face today? Which is obvious to you and me, and on many dimensions because we work in that area, but what do you think a listener who is in that car accident at this moment, what do they have to look forward to?

Lex Frieden: Regardless of the care somebody gets, they still have to make an adjustment to disability. People have to make an adjustment. And frankly, I don't think

everyone makes the same kind of adjustment. And even given ADA, I don't think people are able to compare. So when somebody gets hurt, regardless of zaniness of the society is, they have to make an adjustment. They have to find themselves in a new life and they have to make themselves comfortable and productive in that life.

Now, I believe when you discover that you have a disability, that you weren't different in material ways from other people, you must put that into your personal set, personal view of yourself. And you have to define yourself in those terms, in the context of the larger society. And I don't think that's any easier to do today than it was. Now, the adjustment eventually, may be easier because we have the ADA and because there are provisions for non-discrimination. But I think the adjustment is still a challenge to anyone who discovers they have a disability and they try to adopt that persona into their view of self, and their view of the larger world.

Peter Blanck: What's the work that has to be done by this new generation of advocates and leaders? Are young folks picking up that leadership and what do they really need to do to move this forward?

Lex Frieden: Setting the example. We're living the example right now in the aftermath of the George Floyd killing. People around the world are becoming familiar with the reality of discrimination on the basis of skin color. They're responding to that, and the society is learning from that. And some people are changing their attitudes and we're doing the necessary things that are fundamentally important to changing the framework of the way we treat people. And people with disabilities, have to lead the same kind of movement. Maybe not, hopefully not over the death of a member of our community, but maybe it will be over the unnecessary death of a person with a disability. That occurs frequently. And it occurs by suicide and in people who are with disabilities, living at home, trying to manage their own lives, and they are killed by their caregivers. And it only happens because the society allows it.

So we have to fundamentally change and continue to change the views of people about those of us with disabilities. People with disabilities, I think are still not considered part of the mainstream, the normal mainstream. There are too many episodes where somebody

plans a meeting, and then doesn't consider people with disabilities in the planning. They don't plan to include interpreters. They don't think about an interpreter for a deaf person, unless a deaf person says, "Hey, wait a minute. I want to come to your meeting, please accommodate me." They shouldn't have to do that. That should be normal. That should be the way things are anyway. We have a lot of things that can be done for advocates today. And they need to understand and take control of that. That's the way we move forward. We just keep helping society to adjust to the reality of disability.

Peter Blanck: Now, we of course, would be naive not to consider the elephant in the room. And that is the present global health and economic emergency from the pandemic, COVID-19. That's an overlay on top of all this. How are we going to come out of this from a disability community perspective? Or how is this impacting the progress you were just talking about?

Lex Frieden: Well, more than anything, I think it magnifies some of the differences that still exist, and some of the challenges that we have. But I do believe that there will be opportunity here. In other words, we've been using telemedicine now more than ever before. Telemedicine, for a long time, has been the solution to improve healthcare for people with disabilities. And yet, rules at the state and federal level, have prevented effective utilization of telemedicine. Now, because we have the examples that have been provided through COVID, and we because of COVID, I believe telemedicine can be effectively extended to populations that before have not had good access to health care. I think people with mental illness, who have difficulty seeing physicians, I think people in rural areas, who have difficulties seeing physicians, I think people with mobility impairments, who have difficulty getting healthcare, I think all of those people will benefit from the tele medical changes that have been made during the COVID.

But we've also seen rationing. Rationing of supplies, rationing of ventilators, rationing of medicine. And some of that rationing has been focused on value making decisions about the nature of the people who receive limited supplies. And that I think, again, points to our kind of societal de-emphasis, or even devaluing people with disabilities.

Peter Blanck: Your points are very well taken. Literally, a month or so before the pandemic, I was arguing, working on a case involving tele work as an accommodation for a woman with a disability. And the employer was pushing back on remote work. And now, as you say, the new norm is tele work and a big questioning of commercial real estate, which might be another area you've thought about as well as telehealth, of course.

Lex Frieden: Telework is only part of the solution there. I think we can still see the prospects of discrimination until we have tele interviews without video, tele interviews with artificial speech. People will still discriminate based on their values of appearance, whether that person's going to be working at home or not. I mean, I'm a little skeptical of the decisions that some employers make about whom to hire. And I've seen too many examples of discrimination based on disability that may not even be acknowledged, or understood by the person who's making the evaluating decision of whom to hire. We have too many examples of the disparities of employment, Peter, where an employer can get down to three final candidates. Two of the three will not be disabled, one will be. And the odds are greater than two and three, that one of the non-disabled people will be selected for the job.

And statistically, it should come out one in three, if you were basing it strictly on a statistical framework, but it's not. It's less than one of in three who wind up in the finals getting employed. So there's still something subconsciously at work when it comes to employment of people with disabilities. And I think we have to figure that out and stop doing it.

Peter Blanck: Of course, as you are aware, we had a monumental Supreme Court decision this week under Title VII, of the Civil Rights Act of 1964, which now bans job discrimination on the basis of sexual orientation and gender identity. It's quite a long decision, but if you read that decision, one of the rationales that the majority used in upholding that and making that decision was an analogy to the Americans with Disabilities Act. In that, when the act was passed, it really wasn't contemplated that prisons would be covered under the law. And yet there was a 9-0 decision, called *Yeskey*, which you're familiar with, which interpreted the law reasonably that way. And it was very interesting to

me that the majority would particularly use that example of the ADA in support of that decision, which was very encouraging to me. I don't know if you've had a chance to think about that or look at that decision at all?

Lex Frieden: I had not seen that, Peter. That's interesting. And I think it's important that the ADA is used that way, as a reference, and a precedent. Let me just add, that the new generation needs to be far more integrated than the generation we have working on it, now. People of color, people with other disabilities, people who have gender differences, we need to stretch. We need to find ways of promoting integration. We need to do that effectively and not just talk about it. And we need to be met. We need to be met by people who want to adopt the disability movement. And those people be of every persuasion. And until that happens, we're not going to make a great deal of additional progress, I don't think. So it's incumbent on us to be awake and to reach out, and to provide every opportunity for people to be embraced by the movement. And that is our current challenge. If we don't meet that challenge, the disability movement is apt to die.

Peter Blanck: That last point is very important. I know from my colleagues and myself, we are working hard on this concept of intersectionality, or multiple minority identities that people experience. Whether it's disability and race, or gender, or sexual orientation. And it does seem that this non monochromatic view of disability, may be the wave of the future. Particularly, in light of what you talked about earlier in terms of the Black Lives Matter. And the #metoo movements, as well. I never think I could learn anything more from you, but every time we talk or meet, I do. It's really inspirational to talk with you. We have had a full, and really appropriate, and timely talk. Is there something about what you'd like to do next in your life? Or what challenges you'd like to devote your time to, that you would like to leave us with? Or the sort of things that you're working on now that are particularly important?

Lex Frieden: I'm currently interested in healthcare reform, as it relates to people with disabilities. I'm very sorry that some of the provisions in the Affordable Care Act have been set aside and I think they need to be reinstated, those that affect people with disabilities and ensure good health care. I think that we need to continue to work on

integrating our movement. I think we need to look at making the regulation stronger as it relates to the virtual world. I'm interested in learning more about the disparities that we face in terms of getting people out of institutions and into the community. And I think it's very important for us, as a society, to establish a perspective of older adults and people with disabilities that place them in the community. Aging in place, that enable them to live in their own homes and be as independent as they can be, giving them the supports and services they need in the home, so that they can be active throughout their lives.

Peter Blanck: As we're closing today and celebrating the ADA anniversary, the ADA National Network, Lex, is asking everyone, people like yourself, to share a hashtag thanks to the ADA moment of what the ADA means to you. A moment in your life when you were thankful for the ADA. Lex, may I ask you, what is your thanks to the ADA moment?

Lex Frieden: My thanks for the ADA moment is the first breath I took when I woke up this morning. Every day in my life, as a result of the ADA, it is better. It gives me the opportunity to go outside my home, use the public transit like everybody else in my neighborhood and my community. Gives me the opportunity to go to my favorite restaurant, to find my way from the restaurant into the bathroom, use the accessible toilet facilities. Gives me an opportunity to go to my work and to be there with my colleagues in my office, to be able to use the building, the facilities and to be able to communicate with all my colleagues. Some of whom are deaf, some of whom are visually impaired, some of whom have intellectual impairments, and others who have different types of disabilities. The ADA gives me an opportunity to be me. Thank you, Peter.

Peter Blanck: Thank you, Lex. And I'm getting hungry because my wish is that someday soon, we're going to break bread at your favorite restaurant in Houston and share a meal face to face. So be well dear friend and I hope we'll see you soon.

Lex Frieden: All right. Thanks, Peter. Bye. Bye.

Peter Blanck: Bye. Bye.

Barry Whaley: ADA live listeners, thank you for joining us for today's episode. We are so very grateful to have as guests today, Lex Frieden and Dr. Peter Blanck, sharing about the ADA as we celebrate the 30th anniversary of the signing of the law. As a reminder, Dr. Blanck has a new book titled *Disability, Law, and Policy* with a forward by Lex Frieden. The book was released in honor of the 30th anniversary of the Americans with Disabilities Act. *Disability, Law and Policy* is a compelling compendium of stories about how our legal system has responded to the needs of people whose lives are impacted by disability. *Disability, Law and Policy* is published by Foundation Press and is available for pre-order from West Academic, that's westacademic.com. And as a reminder, if you have questions or comments about this podcast, you can submit them at adalive.org.

You can access all ADA Live episodes on our website, adalive.org. Every episode is archived with streamed audio, accessible transcript, and resources. Listen to the SoundCloud ADA Live channel at soundcloud.com/ADALive. You can download ADA Live on your mobile device. Just go to podcast icon, and search for ADA Live. We encourage you to celebrate, learn, and share about the 30th anniversary of the ADA on July 26, 2020, and throughout the year. Check out the ADA anniversary tool kit at adaanniversary.org. The tool kit is a product of the Southeast ADA Center and the ADA National Network. And it features logos, social media posts, monthly themes, and other resources to keep the celebration going. Also, on a social media platform of your choosing, please use [#thankstotheADA](https://twitter.com/ADA), to share what the ADA means to you, that moment in your life when you were thankful for the ADA. So you could share by using the hashtag [#thankstotheadada](https://twitter.com/ADA).

ADA Live is a program of the Southeast ADA Center. Our producer is Celestia Ohrazda, with Beth Harrison, Mary Morder, Emily Ruber, Marsha Schwanke, and me, I'm Barry Whaley. Our music is from Four Wheel City, the movement for improvement. We look forward to seeing you on the next episode, and wish you well.

4 Wheel City: (rapping)

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