



ADALIVE!

Episode 70: Celebration of the ADA Anniversary - a conversation with Senator Tom Harkin

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

SENATOR HARKIN: Hello, I'm Senator Tom Harkin, retired, and I'm delighted to be on this podcast of ADA Live!

Music: [Car starting] Yo. [Car starting, helicopter whirling] [Music] [Car starting] All right, let's roll. Let's go. Wel-come to / Here we come [Music fades out].

PETER BLANCK: Good afternoon! On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network, welcome to episode 70 of ADA Live! I'm Peter Blanck, a University Professor, and Chairman of the Burton Blatt Institute, at Syracuse University. Before we move on listening audience, you can submit your questions about the ADA at any time at ADALive.org.

Well, I'm sitting in beautiful Washington, D.C. in a reflective mood, because I'm about to address several self advocates who have grown up not knowing a world without the Americans with Disabilities Act in Washington, D.C. They have new and high expectations about being included in our country and our world. Since 1990, when President bush signed the Americans with Disabilities Act, the ADA has given protections

to people with disabilities all across the country. Today we have an honored guest, the author of that Americans with Disabilities Act, Senator Tom Harkin, former congressman, veteran, attorney, proud Hawkeye, as I am, and chief sponsor of the ADA in the Senate. Senator Harkin, I've had the pleasure of knowing you and you had you represented me and my family in the senate. And my kids grew up in a world not knowing life without the Americans with Disabilities Act because of you. It's truly a great honor to have you on the show.

SENATOR HARKIN: Peter, it's an honor to be with you again. I thank you for your efforts over so many years to make the ADA actually live. I've often said you can pass a law but it really doesn't do anything until people make it work. And so I thank you and for all the work you've done to actually make it live.

PETER BLANCK: Senator, I hope to ask you a few questions you haven't been asked before. As a fellow Hawkeye, I raised a family in Iowa and understand the midwestern ideals and soil and its value. Many of you know of your loving relationship with your brother, your late brother. But I wanted to ask you maybe even going back to your parents or their parents, what is it about that Iowa soil, Senator, and your history there that really gave you this spirit, this sense of equality, this sense of dignity for all?

SENATOR HARKIN: Well, Peter, I don't know that I have a concise answer for that. I just think there has been in the state of Iowa for a long time a sort of spirit of social consciousness, even going back to Civil War days. We had one of the most active underground railroads for getting African Americans out of bleeding Kansas and Missouri into northern states. So even at that time we were socially conscious. And I think that's sort of come down through the years. I think because of rural Iowa, small towns, people tend to know one another. They tend to help neighbors out. It's just been a kind of a wealth ring of what would I say Neighborliness? The old story of the independence of Iowans. Basically, when the early settlers came into Iowa and they got their land from the government, by the way, and they would build their barns and their homes. And all the neighbors around would come help build the barns and the homes. You heard of all the phrase "barn raising" but after that you were sort of on your own. You had to pull your

own weight. You had to be independent. But you always knew that your neighbors were nearby to lend a hand in case something went wrong. Acts of God, flood, fires, tornadoes, whatever. Out of that comes a duality. One, we should do what we can to make life better for our neighbors, and neighbors being a broad concept. But that we also want to ensure that people can live as independently as possible without intrusions of the state or the government or big business or repressive laws, that kind of thing. I hope that kind of sums it up.

PETER BLANCK: Yes, that's excellent. And you were raised, your late brother Frank, and growing up in Iowa, what was your parents' attitude toward having a disability, having a brother who was deaf. Which probably wasn't that common in Iowa at the time.

SENATOR HARKIN: No, it wasn't common at all at that time. When my brother got spinal meningitis at the age of around 5 and 6 and became totally deaf, it was quite a shock and of course my parents, my mother mainly, being adamant about education, there was no place for him to go to school. And so the state came in and took him away from our home and our small town and sent him halfway across the state to the Iowa School for The Deaf, which at that time people referred to as the School for Deaf and Dumb. So it was very traumatic for the family. For my brother, we lived in a small town. All of a sudden he can't hear. He could hear before and now he can't hear anything. And he's take away and our family didn't have money. We couldn't travel halfway across the state to see him in school and things like that. So he was basically on his own. That's very traumatic on a family and on a person. So that's what it was like in those days.

PETER BLANCK: And how did your relationship with Frank evolve over the years?

SENATOR HARKIN: As we grew up, and he would come home from school, I started learning sign language. That was one thing. Then when he graduated and became a baker, there's another story there, by the way, he lived at home. And then he lived away from home, but he always brought his dirty clothes home to be laundered by my mom. He was just a nice big brother to me. A very kind person. But he just had that independent streak of his. I told you about Iowans. You help one another, but you got to make sure people are independent and people like to be on their own and independent.

So that sort of struck a deep cord with me at that time and that's sort of part of the whole ADA is independent living, making sure that there are supports and services, but that people can live independently. That's sort of what impressed me as we were growing up.

PETER BLANCK: We're going to talk about the ADA, but can you recall when it first struck you when you were a congressman or a veteran or whatever that there was something that needed to be done in society to allow folks like Frank have a better experience of inclusion?

SENATOR HARKIN: Well, Peter, I think my story is appropriate for a lot of reasons. I started out with a very narrow view. Two things my brother said to me I'll never forget. One time he said to me I may be deaf, but I'm not dumb. And the other thing later on when he changed jobs and got a really good job, he said to me once, he said there's only one thing I know I can't do. I can't hear. He said there may be other things I can't do, but I don't know that until I try them. That struck me with me, too. The idea that people shouldn't be categorized because of their disability. That people should be allowed to try whatever they want. And so that. And then I say I started out narrowly. When I went to congress in 1975, I was really interested in deafness. And I started working at that time. I had read a lot and I knew there was a new technology. A new technology that would allow a deaf person to watch television and to read closed captions along what was called line 21 at the bottom of the screen. Well, I saw a demonstration of this oh gosh it must have been around 1976, something like that. '76, '77? Something in that range. And there was a big box that was made and this sort of predated me. But Sears Roebuck was selling this is and it would decode that line 21 on television programs. There was a senator from West Virginia and I was then a congressman and we delivered the first decoding box to Jimmy Carter in the White House. This was around 1978. I think. Big demonstration of it. Then I got involved in working with a lot of others to establish the National Captioning Institute in Alexandria, Virginia. And they would take prerecorded television programs and caption them and then send them out so that when they were played on television, if you had one of those big boxes, you could read the closed captions. But they could only do that with prerecorded. And I remember one of the early ones was always the Ed Sullivan show. It was on Sunday night. And it was an hour

show. But it was always prerecorded. And so the National Captioning Institute would get it and then, so I got one of the first boxes for my brother. Carter got the first one. I may have gotten the third or fourth or fifth. Anyway, I got one really early. Took it out and put it on his TV set, plugged it in, and for the first time he got to watch a television show. With closed captions. Well, this was amazing. He just, of course then he had to just know every program that he could watch, even if he didn't like them. He would watch them just to get the closed captions. Well, this was in the early '80s.

About the same time, in the late '70s, again, late '70s, about the time I was doing this, my nephew, my sister's boy, Kelly, was in the Navy. We was on an aircraft carrier, and he inadvertently got sucked down a jet engine of a jet aircraft carrier. Broke his neck. 19 year old kid, big strapping boy, and became severely paraplegic. Actually, initially it was almost quadriplegic, but he got the use of his arms back. I had not known anyone who had known wheelchairs. I went out to Colorado where they lived and all of a sudden it hit me about how there were all these mobility problems. He wanted to go to college. He hadn't been in college yet. But at Colorado State, he wanted to take a course but it was on the second floor. There was no elevator. So, he couldn't take the course, which I thought was crazy. I had never thought about this before. And then he lived at home. His father, my brother in law, was quite a carpenter and a doting type person. So he widened all the doorways and put in a ramp. I never thought about this before. We wanted to go out to dinner one night and we couldn't go to a restaurant to eat.

All of a sudden my vision starts to broaden. It's more than just deafness. It's mobility problems. Then in the early '80s, again I got to backtrack. I had been involved in education with the education of all handicap children's act. That predated me, but I was in the House when it was being implemented, so I kind of tracked that. And getting kids into schools. I was familiar with the Pennsylvania circuit court case, and this had to do with learning disabilities, being the Pennsylvania Association of Retarded Citizens to get kids equal and appropriate education. So I started learning about that. I hadn't really thought about that.

So then in the early '80s, I became aware of this movement that had sprung up to get a Civil Rights bill for persons with disabilities. And then my vision became even broader when I met Danny Piper, the son of a family in Iowa, a young man with Down Syndrome. His folks fought hard to get him mainstreamed under that Part B case. He became part of the football team, and took care of all the uniforms and that stuff. He was a great actor.

All of a sudden I'm thinking wait a minute. It's not just deafness. Or blindness. Or mobility. It's how about intellectual impairment? I hadn't thought about that before either as part of a disability community. So as I'm broadening my views, I get in contact with this movement. That's going across America, mainly through ADAPT and others.

So then I go to the Senate. I get in the Senate. First thing I did in the Senate when I got there was to establish the National Institute on Deafness and Communication Disorders at the National Institute of Health. Again, I'm still focused on that. But then I become aware of this movement for a broad civil rights bill and I'm on the right committee in the Senate. On the Health and Education Committee and on the Appropriations Committee. And I'm on the Appropriations Committee with a guy by the name of Lowell from Connecticut. He had a son with Down Syndrome. And he had also been involved in disability law. And he was the first person to actually write or introduce an Americans with Disabilities Act, a broad based civil rights bill. I was his chief co sponsor. He was Republican. I was a Democrat. Republicans were in charge at that time. Then he got defeated for reelection and then the democrats took over, so I took over the ADA bill and reintroduced it. We had to make changes. And that's how I sort of became the lead author of the ADA. I've always said I was not the first. Lowell was the first and in the House was Tony, who led the charge for the House bill. Now that's a long-winded answer. I even forget what your question was now, Peter.

PETER BLANCK: It's a great answer. And I've always been struck particularly in this day and age by great Americans like yourself, in the particular my dear friends The former attorney General Dick Thornburgh, how partisan politics weren't a part of this. What was your sense.

SENATOR HARKIN: I get asked that a lot. Could you pass the ADA today? The answer is no. If we brought up the Americans with Disabilities Act, it would never get through the Senate. Maybe, I'm thinking it wouldn't get through the House either. Just a different time. Everything sort of came together. We had a decade at least of demonstrations and leaders like Lex and Justin Dart, Ed Roberts, Judy Heumann. I can go down the whole list of them now. ADAPT. I know they get hit a lot. But I call ADAPT our marines. They took the most hits and were always get arresting. But they were the ones that laid under the bus tires of the Greyhound buses and got people thinking what is this all about. Sometimes you got to shake people up a little bit.

And they did that. During the eighties. And then we also keep in mind that we had the president of the United States strongly behind it. George H.W. Bush made this a cause he supported it strongly. I have stories about that that I can relate. It was wonderful to have that support. And Dick Thornburgh, Attorney General of the United States, former governor of Pennsylvania, wonderful human being and supportive of this. It sort of all came together then. And as I said, we had republican Bob Dole who led his weight to it first as majority leader and then minority leader when we finally passed it. And, you know, Bob Dole, his first senate speech on the floor of the Senate was about disability inclusion. That was 1989, if I'm not mistaken. So a different time, perhaps. But no, it could not pass today.

PETER BLANCK: On that beautiful day on the White House lawn when President Bush was signing the ADA into law, what were you thinking? What was going through your mind?

SENATOR HARKIN: I remember it vividly as yesterday. Beautiful sunshine, gorgeous day. I saw all of these people out there. I thought, you know, this is one of the unique moments in American history. Now I wasn't there for the signing of the Civil Rights Bill. I was in the military at that time. But again, a unique bend point in terms of our own country, what we stand for as a nation. The whole broadening of the concept of inclusion and equality. I just thought that day was one of the bend points in our nation's history

going towards toward what Martin Luther King, Jr. once said. The art of justice. I'm sorry. The art of history is long and it bends toward justice, but it doesn't bend by itself. And I thought about that saying at that time. The arc of history is bending and all of these people help bend it towards more justice.

PETER BLANCK: We have not much time today. I feel I could speak with you today. And I'm sure you have done that many times in your archives, which perhaps we can cite to at Drake University, so people could hear more of your interviews. But the past 30 years have kind of gone by in a flash. A lot has happened. What stands out in your mind over the past 30 years as some of the highlights in your life as how this law has really changed society?

SENATOR HARKIN: Well, a number of points along the way. There have been some bad hits to the trilogy of the Supreme Court in 1999 that set us back for nearly 10 years in terms of employment of persons with disabilities. But we got over it. And we passed the ADA Amendments Act in 2008 and

PETER BLANCK: 2008.

SENATOR HARKIN: Thank you. That got us back up again to where I thought we were before the Supreme Court decisions. That was a good bipartisan effort, also. The four goals of the ADA are independence, full participation, equal opportunity, and economic self-sufficiency. Full participation, we've come quite a way. Equal opportunity, we've made great inroads. Independent living, much more independent living centers and people living independently today than ever before, although we still have the Medicaid bias, which we're still working on. I introduced the first bill on that back in 1994, I think it was. Anyway, that's kind of getting into the weeds a little bit.

But the one thing that we haven't made any progress on and that's economic self-sufficiency: Jobs, to be short. So when I retired from the Senate and we started the Harkin Institute at Drake University, as you mentioned, we have an offshoot of that called the Harkin Summit. Harkinsummit.org. So every year we sponsor an international conference with the private sector on only one thing. And that is expanding opportunities

for jobs. And when I say jobs, I mean employment, competitive integrated employment. In other words, real jobs. Not make believe jobs, not dead end jobs, or sub minimum wage jobs, real employment. We've had four of those. Three in Washington. We just had our fourth one in Paris, France. I hope next summer to be in Tokyo. So the idea, and we're getting more and more businesses on board to really focus on employment. That's the one place where we just haven't made much progress and that's where I spend the majority of my time right now on that issue.

PETER BLANCK: Well, Senator, I could spend a lot of time talking with you and listen and listen. I think you're a prophet. Nobody is a prophet, really. But Frank's grand nieces and nephews, Kelly's grand nieces and nephews, your kids, your grand kids, what do you hope for them over the coming years in this area? And what is the responsibility of the next generation perhaps to continue this drive forward?

SENATOR HARKIN: I hope what we'll see is more full inclusion in all aspects of society, especially for young people. But you said when you opened this up, you talked about the ADA generation. A lot different than the generation before. Kids who have grown up with the ADA are not going to take a backseat. They're going to be more proactive. And I think their children and their nieces and nephews and brothers and sisters, they're going to be more active.

So as we broaden this out, I see a future where a young person with a disability, either an acquired disability or born with a disability, whether it's physical or intellectual, mental, or a combination of both, will really have all kinds of Vistas opened up where they can really dream about what they want to do and they won't be told like my brother was you can be a baker, a shoe cobbler, or a printer's assistant. That's all you can do. We've gone beyond that. But now opening up Vistas and new horizons. I just saw the actress who just got the Tony award. First person using a wheelchair to get a Tony award for a stage performance. Now again, role models. So now how many young people with disabilities can say if she can do that, I can do that too. Or engineers. One other example. We're building a new building for Drake University at the Harkin Institute. I insisted it had to be state of the art accessible. Not just the minimum standards, but state of the art. And not

just for mobility impairment, but for sight impairment, hearing impairment, intellectual disabilities, everything. Well, it turns out the first round they found an architecture firm and the architect is actually a person with a disability. That's fantastic. Think about that? An architect! That's what I see in the future. Young people thinking I can be an architect, I can be a senator, president, a hedge fund operator. I can do anything. That to me is really where we're headed, I hope, and more people in competitive, integrated employment, real jobs. Again, I can go on that.

With my last bill in the senate before I left was to change some of the voc rehab so that young people with IEPs aren't shunted into dead end, sub minimum wage jobs anymore. That's what I see. More inclusion. Young people can dream and hope and try to do different things and don't be afraid of failure. Failure is a part of life. I always say to young people try something. If you fail, that's okay. I failed at things in my lifetime, too. Until I found out maybe what I was good at or something. But don't worry about it. Try something. If you don't fit, if it doesn't fit you, try something else. That's life's experience. So to me, that's what I see. That's my vision for the future.

PETER BLANCK: Senator, I can say I know firsthand Midwestern, lowan modesty. But I can tell you in my book and by many others, you are a great American. Your legacy and the people you work with will transcend you as an individual and will make the world better for all of us. You have done that senator, and I can't thank you enough for taking the time to speak with us today. I hope it's the beginning of a conversation. And I would strongly suggest to our thousands of listeners that they tune in or look up the Harkin Center at Drake University. Thank you very much, Senator.

SENATOR HARKIN: Peter, thank you. It's overly kind and generous of you to say that. Whenever someone says that to me, what comes to mind is all of those who laid under those greyhound bus wheels who got arrested. The Justin Darts and the Ed Roberts and the Tony Quails, all of the people who did all of this. It wasn't one person. It was thousands of different people all kind of coming together to make this happen.

PETER BLANCK: Thank you very much, Senator. And I do hope this is the beginning of a conversation that will continue. Thank you and have a fantastic day.

SENATOR HARKIN: Thank you. I appreciate it.

BARRY WHALEY: As always, we want to thank you for joining us for this episode of ADA Live! as a reminder, this web episode and all previous episodes are available on our website at adalive.org as well as on Sound Cloud. All episodes are archived in a variety of formats including streamed audio and accessible transcripts and download as a podcast. It's as easy as going to the podcast icon on your mobile device and searching for ADA Live!. Listening audience, check out the ADA celebration tool kit from the Southeast ADA Center and the ADA National Network. Celebrate the ADA in July and year-round with the tool kit or the media kit, publications, and other resources to keep the celebration going. That address is www.ADAanniversary.org. As a reminder, if you have questions about the Americans with Disabilities Act, you can submit your questions any time online at adalive.org or you can contact your regional ADA center at 1 800 949 4232. And as a reminder, all calls are free and they're confidential. ADA Live! is a program of the Southeast ADA Center. Our producer is Celestia Ohrazda, with Beth Harrison, Mary Morder, Emily Rueber, Marsha Schwanke, and Barry Whaley. Our music is from 4 Wheel City, the Movement for Improvement. So please join us on the next episode.

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