



Interviewee: **Joyce Bender**

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Voices of Our Region
Joyce Bender
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Do you want to talk about an individual with a disability, or do you want to talk about the greater picture, or do you want to talk about both?

How about if I talk about all parts of it?

Okay.

So where do you want me to start?

Well, the first thing we always do for the transcription is to give your name, where you're from, and everybody talks a little bit about their family and what they do.

Okay. And when you say where I'm from, do you mean originally where I was born?

People have told us both. "I was born in St. Louis, but I moved to Pittsburgh when I was ten."

(1, 0:44)

No. Sorry. Okay, uh...are you ready? Okay. My name is Joyce Bender, and I was born in New Castle, Pennsylvania, but have lived in Pittsburgh, Pennsylvania since I moved here in 1979, my husband and I. My husband Bill and I have been married for over thirty-two years, so really we are Pittsburghers. This is where we've always lived, and I'm very happy to be here.

I am the CEO of Bender Consulting Services and Bender Consulting Services of Canada, and the host of the internet talk radio show Disability Matters with Joyce Bender. And I can't begin to emphasize before I say anything else how happy I am that Liza worked with Judy Barricella and the rest of the group to include people with disabilities for the 250th celebration of Pittsburgh, because the question is, "Why would you not?" Why would you not? There are fifty-four million Americans with disabilities. Ten percent of the population are people with disabilities. Of course this should be included. So I'm very happy to see that that did occur.

I started Bender Consulting Services really as a result of my own disabilities, because when I grew up I occasionally had fainting spells, but I did not know what my disability was, nor did my family. First fainting spells were not that significant when I was a teenager. But after I got married, in my early twenties, I started having really horrific fainting spells. Now during this time I was working here in Pittsburgh, Pennsylvania, I owned an executive search firm. That's what I did as a living when I first moved to Pittsburgh in 1979.

I did executive search in information technology. But why that is so important to the rest of my life is that gave me two things. Number one an understanding of the private sector, the business world and employment. Obviously I built up a business network because corporations would come to me, pay me a fee to find them people, frequently on a retain basis, higher level search and recruitment.

Well, along the way my fainting spells started to get worse. You know, one night my husband found me unconscious at three o'clock in the morning. Off we go to the doctor. We described that something is happening that I would faint, and when I described the faint, the doctor said, "Oh, you know what? That is a female hormonal problem. You're fine," and did not test me. And of course the question is, "Why the heck would I believe something like that?" and the answer is, I was in my early twenties. I'm fifty-four years old now. And in my early twenties I believed the doctor knows. They know everything. I know, of course, now, that isn't true.

But I did believe him and I probably was happy to hear that I was fine. But one evening in 1985 in Pittsburgh, Pennsylvania, at South Hills Village Theatre, which is no longer here, but was here at that time, my husband and I went to see the movie *Amadeus*, the Mozart film; and at the intermission of the film my husband went to the men's room. I went to get a Diet Coke, and this is the last thing I remember saying, "May I have a Diet Coke, please," and I had a tonic seizure and I hit the floor so hard that I fractured my skull, had an intracranial brain hemorrhage, broke all the bones in my right ear, which is why I wear a hearing aid. I have a sixty percent hearing loss, rushed to the hospital in a coma, and this is when they tell my husband they don't know if I will live, but even if I do, I will have many other issues. That he, in fact, would have to consent to immediate brain surgery or I would not live. So that is what happened. I had brain surgery that evening at Mercy Hospital, and it wasn't until a few days later, in Intensive Care, that the doctor walks over to me and says, "Oh, by the way, you have epilepsy."

By this time, I'm intravenous on Dilantin, which I still take 450mg every day, and for those of you that aren't familiar with epilepsy, there are three million Americans with epilepsy. It is a very, very misunderstood, but common disability, but due to the stigma attached, many people will not disclose they have epilepsy.

My life changed so much from that day forward that I'm very proud to tell you that in the year 2009 I will be the Chair of National Board of the Epilepsy Foundation. And I'm so excited about this, and of course, I'm on the local board of the Epilepsy Foundation of Western and Central Pennsylvania, but I will be the Chair of the National Board, so as you can see, a seizure really did change my life and defined my life now.

Medication has pretty much controlled my seizures, although I have still had three seizures over the past several years. And I still occasionally have an aura, which really is the beginning of a seizure, although people don't understand that.

So I was out of work for two and a half months. I was in rehabilitation in the Head Trauma Unit at Mercy Hospital, and when I finally did get back to work, in executive

search, in employment, in Information Technology, I was contacted by a woman. here in Pittsburgh. She's no longer here in Pittsburgh, her name is Jane Johnston. She was a partner with Deloitte and Touche. She was doing work with Jim Sarny, who at that time was the CEO at PPG Industries. He was the Chairman of the Board of a school that sadly is no longer here, the Institute of Advanced Technology, and Jane called me and said, "Listen, there's this school. They train people with disabilities to be computer programmers. Would you go meet with them?"

And I'm thinking, "Wow, is this me?" I have a disability and what do I do, find employment for people in the computer field. So of course, I'm so excited.

I go over to the school. I meet all the students. I had no idea at this time that the attitudinal barrier toward the employment of people with disabilities was so significant. Because I meet all these qualified people and, guess what, no one would hire them. So what I did was I started doing volunteer work.

For the next eight years I did volunteer work for this school. I would use my own business network, and I would go to customers, such as at that time Blue Cross of Western Pennsylvania, which is now Highmark today. And I would say, "Listen, would you consider hiring one of these students?"

And the biggest problem for people with disabilities is, remember, they're usually entry-level in experience. If we have a huge unemployment rate, which today the unemployment rate is still over sixty percent. Now think about that. During World War II and the Great Depression, the unemployment rate was twenty-five percent. That's so horrifying to us, yet as an American with a disability, you are supposed to be accepting and happy that it's sixty-five percent. Which is just absolutely sinful, shameful, outrageous and unacceptable.

Well, after years of doing volunteer work, I found out that there were only a few companies would hire anyone, even though I'm referring people for free. Blue Cross was the company that hired the most people. PPG hired, I think, one or two people. So I came up with this idea. You know what I'm going to do. I'm going to start my own company. I'm going to start a company, Bender Consulting Services, a for-profit company that employs Americans with significant disabilities.

And I want to tell you the reason that I wanted it to be for-profit. A few years after I started the company I received the President's Award at the White House from President Clinton, which was just an overwhelming experience. You get to walk in with the President of the United States while the Marine Corps Band is playing "Hail to the Chief." It is just hard to imagine it, so honored, so happy that this happened. But because of that I immediately started getting in the news everywhere. You know, I had been in Reader's Digest, and since then many things. And I have my radio show now, but back then I'd be interviewed on all these radio shows, one in New York City.

The first thing the gentleman said to me was, “I have a question to ask you. At Bender Consulting Services, you employ people with disabilities. Correct?”

I said, “Yes.”

My question to you is, “Why are you for-profit?”

And I said, “And my answer to you is would you have asked me that question if they were not disabled?”

He said, “No.”

I said, “That’s why I am for-profit. My number one reason for being a for-profit company – no pity. I do not want people to think of me as a charity. I want people to understand that we want to work, we want employment, and we want paid equally. My second reason is that still to this day, thirteen years later, I’m very proud to tell you that still to this day, not just my employee, but the employee and family, I provide one hundred percent health payment to the premium. In other words, my employees do not contribute from their paycheck to the premium, and probably, as anyone listening to this right now knows, I am in a big minority in the United States.”

But the reason I still do that, even though many people question why I do that, is because of what I went through myself when I had that brain surgery. And the fact that whether or not the person would have a disability, it is so important that you believe in your employees and to let them know how important they are to you. So, I’m very big on health care. We still do that, but again, I would not be able to do that as a non-profit company.

So that’s how we started, and then I had to have an anchor company. How would I do this? I’m going to go across Pittsburgh and I’m going to ask companies, “Hire one of my employees. By the way, they’re probably entry-level in experience.” Once again, if there’s a sixty-five percent unemployment rate, I need people that will have a master’s degree, maybe two master’s degrees, you know, a bachelor’s degree, but they don’t have work experience because no one will give them a chance.

So now here you are. A person with a disability and no work experience. Everyone wants you to be the volunteer – the intern. Everyone wants you to do that.

But people want a paycheck, so I want to tell you while I’m talking about that, for just one minute, that when I first came up with this idea, that everyone I knew said it would never happen, except for one person -- Linda Dickerson. Linda Dickerson is the only one, of course other than my own colleagues right here at my company, but I mean outside people, but when I would tell them my idea, they would say, “Joyce, you will never be able to do this. Do you really think people are going to pay you money to hire people with disabilities and... because they’ll take them only if they’re for free. And at the same time, they don’t have experience?”

Linda Dickerson, on the other hand, said to me “You know what? You will be so successful, my prediction is you won’t be able to find enough people.”

And guess who was right? Linda Dickerson.

So I thought, “Well you know what then?” So many people I talked to about this think this is not going to happen. I need an anchor company. I need someone that would help me get started, so what I did was I went to Bill Lowry, who at that time was the CEO of Blue Cross of Western Pennsylvania, and I said, “Bill, I have an idea. I’m going to start this company where I’m going to hire people with disabilities. They will be consultants at companies and after they’ve worked there for a period of time, they then will be hired by the partner company. In other words, I’ll hire them. I’ll take the risk. I’ll take that risk. I’ll put them on a six-month contract, and at the end of that time, if they perform well, they get to move to the partner company. But first, I would need a company that would take on at least six people for at least three years on contract and pay me money all that time, because I need one company that would believe in me, you know. So I’d have revenues coming in, so I’d have time to go to other companies.

I want to tell you, it only took Bill Lowry and Keith Catmeyer one day. They called me right back and they said, “We will do it,” and that is why, to this day, when I speak nationally, I always tell people, “If it were not for Highmark, there would not be a Bender. That’s a fact because, guess what, when Bill Lowry and Keith Catmeyer retired, they took me to lunch to meet the new CEO John Brouse and the new COO, Jim Klingensmith. And so “We’re having this lunch just to introduce you to Joyce, and to let you know we want to keep this going.”

They passed the baton. When John Brouse retired, he took me to breakfast with the current CEO, Dr. Kenneth Milani, but I already knew Ken very well. And Ken has taken it to an even higher level, but think about that. In thirteen years, three CEOs and they have stood behind me. I have to add to that the reason we have a Pennsylvania Leadership Business network is that I went to John Brouse and said, “Will you, Highmark, be the lead company?” and they said yes.

The Pittsburgh Disability Employment Project for Freedom was started as a result of OFCCP calling me and saying, “Why can’t we get business to drive employment here?”

And I went to Highmark and Bayer, and Bender Consulting Services, Highmark and Bayer formed the Pittsburgh Disability Employment Project for Freedom, to train people on Help Desk.

I’m only giving two examples because we wouldn’t have enough time for me to list everything Highmark has agreed to do, but I want to add just one last thing. When Jonathan Young was at the White House during the Clinton administration, he called me and said, “Joyce, I have an idea. We want to have a Disability History Month.” Well, he

tried, but he couldn't get enough support. So they said, "How about... What do we need the most?"

Employment. What if we have a Disability Mentoring Day, where on that one day, the third Wednesday of every October, high school students and college students, and now elementary students, with disabilities could go to a company for a day of job shadowing.

When he called me do you know Pittsburgh was the first city to participate. During that first year, the only other people to participate were all the Federal agencies. But Highmark had a Disability Mentoring Day, and of course Bender did, and Bayer did, and only one other city did, Newark, Delaware did because that was my other customer, and I got them to. But really, it was mainly Pittsburgh. And now, this coming year, we may have the first national launch of Disability Mentoring Day right here in Pittsburgh, which will bring the national media, but my point is that Highmark really has done more than people could ever imagine.

But you know what the most important thing is that they've done? Hire people. See, it's so easy to talk about this. We don't need people to talk about it. That's why when I speak nationally, I always say, "Don't tell me I'm doing a good thing. Don't tell me how nice I am. Don't tell me this is inspiring. Hire a person with a disability. Put your money where your mouth is. That's the only thing that's going to make a difference." And Highmark has hired people for years.

In competitive employment! That's the other thing I want to mention. When I came up with the idea to start Bender, my job motto was going to be "Jobs Mean Freedom." And I showed that to Linda Dickerson and she said, "That's not what you mean."

And I said, "What do you mean?"

She said, "That's not what you're about. You're about competitive jobs mean freedom," so I changed the logo. The logo is Competitive Jobs Mean Freedom, meaning we don't want to just be in an inferior job where you do not have health care, where you are part-time or where you can't have a career. Therefore, Bender focuses on information technology, finance, accounting and human resources. So it all started thirteen years ago, and now, guess what, today? We are in eighteen states and two provinces of Canada, because we now have a Bender Consulting Services of Canada and have hired over 360 people, and when I tell people that, they always say, "Wow, that's so amazing," and it is, except with my contacts and the people that support me, CEO's across the country, Tony Coelho, the author of the Americans With Disabilities Act, is my mentor and best friend, and Chair of the Bender Advisory Board, which we have a meeting once a year.

He recruited President Bush's sister, Doro Cook, because he wanted to make sure we were bipartisan, and he also thought highly of Doro. And then we recruited CEO's across the United States that I work with, that are on our advisory board. With all these people, I should have hired ten thousand employees by now.

So my point is the employment is the issue for people with disabilities. It is employment. Commissioner of the United States EEOC, Commissioner Christine Griffin, is right now leading the charge in Washington, DC, because the employment of Americans with disabilities has gone backwards by over twenty percent in the Federal government, and presently, less than one percent, less than one are employees with disabilities. Do you know, it's the lowest it has been since, like, 1990. It is the lowest it has been, which is so sad when you think about that the Federal government we look to, you know, as the role model for other companies. And so she herself, Commissioner Griffin is in a wheelchair, and she frequently tells the story, "We're not going to change the world by just seeing a person with a disability out at the movies or out at a restaurant or out at some event. You're only going to change everything when they're at work. That's not happening enough. That's what the problem is."

Seeing people with significant disabilities gainfully employed. That is the issue we're dealing with. When I started here in Pittsburgh, when I first became involved with the American Association of People with Disabilities, with Andy Imparato, who is the CEO, and I also worked with Ted Kennedy, Jr. and Cheryl Sensenbrenner. As I mentioned, I am also involved with the National Epilepsy Foundation and many other organizations, but I don't think a lot of people realize how much has been done right here in Pittsburgh, like Variety, the Children's Charity, like the work that Achieva did in the area of special education.

So many things started right here in Pittsburgh for people with disabilities. Nationally, how many people still don't know about that.

So I am on a crusade, 24 by 7 I think about this. It's only by the grace of God I'm talking to everyone right now, and I am on a crusade, a civil rights crusade for equal employment for people with disabilities. In thirteen years, we have had ninety percent success rate of our employees transitioning to partner companies, great companies. Companies like Highmark, Bayer, companies like the MGM Mirage in Las Vegas, Well Point, Computer Sciences Corporation, and I'm so proud we work with the National Security Agency. As a matter of fact, former United States Attorney General, Dick Thornburg, Governor Thornburg to everyone in Pennsylvania, when he spoke at the New York Law School at the Tony Coelho Lecture Series, he said, "There's a company in Pittsburgh that is known nationally, Bender Consulting Services, which I'm so proud of. I have something to say. They work with the National Security Agency. If they can work with the National Security Agency, what's your excuse for not working with them?"

What he meant, of course, to be hired by the NSA, you must go through a lifestyle polygraph test, a big security clearance that takes months, and they hire only the crème de la crème. Think about that. They are hiring Americans with disabilities to protect our country. Think about that. So his point, come on, if you can work for them, surely you can be an accountant at a bank. You know, or in some other position of that nature. So if I had to stress one thing, I would say, "I hope the next time in the future, ten years from now, when we're talking about this, we have made so much progress, because what

bothers me the most is that in the year 2010, it is the Twentieth Anniversary of the Americans with Disabilities Act, and yet we still have a very long way to go. It is an attitudinal barrier. There are many factors, but yet still companies today, when I talk to them, the idea of a person with a disability, are they going to be inferior? Can they do the job? Can they get the job done? Coupled with a system that has put people in a position where even with a ticket to work, still they fear leaving Social Security for employment because of health care.

So, you know, our biggest issue is employment. Remember you will never ever be free in this country ever, until you have employment. You can't buy a house, can't go on vacation, can't live the American dream that everyone else, you know, lives. They watch TV, they see all of this, they can't live it.

And I want to also add one thing I've been doing for the past several years, is I've been working with young people in high schools with people with disabilities. I've started a Bender Leadership Academy, trying to teach them about the world of work, because I see that our high school students with disabilities, the bar has been lowered. They have been labeled. They have not been given the same opportunities, and I do this with Bayer and Fedex Ground, and Computer Sciences Corporation.

I actually designed a program. I do this totally on a volunteer basis, where I go to a company and over a course of four months, they come, different schools come, and I do a training program. It's called Student Business Leaders and the Bender Leadership Academy. I sadly have found out how high school students with disabilities, and elementary school students with disabilities, are the target of bullying to an enormous degree. As a matter of fact, over forty percent of the children who are bullied are children with disabilities. And even sadder, there's a new phenomenon called Bullycide, where teenagers commit suicide as a result of bullying.

So now when I speak, I say to employers, "You know what happens? Kids will raise their hand and say, 'I'm not invited. I'm not asked to go to a slumber party. I'm not included. I'm left out.' Well, well, if they're left out of employment, who's the bully?"

Now we have grownup bullies.

So that I want to stress. We need several things to happen, but the main thing is employment. There is no ifs, ands, or buts about it. You can't worry about buying a house if you don't have employment. You can't worry about getting to work if you don't have a job to go to. Employment. It's all about employment.

Ok, I ask this not because I necessarily believe that you should do this, but, does it ever happen where you would put somebody in a company and then keep them as your employee? I'm thinking about—I don't work for Allegheny County. Technically, I work for Great Lakes Behavioral Research Institute. They hire people to work, then they contract them out to DHS. So we get our paychecks from Great Lakes. We don't get them from the county. We don't get any county benefits

or anything like that. And...that's what you do, except you expect that company to hire them.

Yes.

You know, the county would never hire us. Did you ever think that you would do that? You would keep people on?

You mean as my full... on with me forever? Oh, yeah, I do. I have a group of about ten to twelve managers. That's the other thing that I did when I formed...

In reference to the question do I have any employees that are full-time Bender employees that stay with Bender. I do because when I started Bender, I made the decision we were going to have a management training program for the small... At that time there were only about ten people or eight people who wanted to stay with me to build this company. Because obviously I, as I'm getting larger, I, too, employ people that stay here, and I made up my mind, well they would be people with disabilities. So at that time I went to the young people that were working for me and I said, "Listen, are you interested in going through a management training program, it's called Bender Leadership Program, BCS Leadership? Are you interested in that? You will have to make a commitment of time. You'll have to come in on Saturdays. I'll do all the training. You will have to do community work." There were all these rules I had of what they would have to do, and a group of people said yes, and that same group of people, still with me today, are the frontline managers.

So in other words, at some companies I have an account manager who is there, but who is a Bender fulltime, staying with Bender fulltime. I mean everyone's a fulltime employee, but these are people that do not leave Bender. So I have a group of managers, because what is more powerful when you're talking to someone in Washington, DC, or Pittsburgh, no matter where it is -- if they say, "Gee, I don't know, will I be able to do it?" and you say, "I'm able to do it, and by the way I have cerebral palsy or I'm blind, or whatever."

So I was not going to hire nondisabled, all nondisabled people. Now I do have some nondisabled people, but the majority of all of the managers that deal with the customers and our employees, and by the way, when our employees leave and join the other companies, they're called Bender Ambassadors because they are now the -- one was just interviewed by the New York Times and a few weeks ago I was on Fox TV in Washington, DC with another employee. So we try to get the news out everywhere of "Look at the great ability of all these people." See that's it. You have to look at the ability, not the disability.

I do have employees, I'm glad you asked that question, because they're phenomenal leaders. I have not made this company successful on my own. It is my employees. I have the greatest employees you could ever ask for. My team of leaders, they are awesome in all ways. I'm just the one, I'm lucky that I have them, so yes, that is true.

The Federal government hires. What about our local government? Do they hire a lot of people? I don't see a lot of people with disabilities?

I do not see a lot of people with disabilities hired in any local government anywhere. And what I want to do as my next thing is, I want to try to meet with more people and say, "Why don't we try to make Pittsburgh an example? Why don't we try to make Pittsburgh an example?" A good example would be if you saw people with disabilities in prominent roles in our own government.

Once again, people with disabilities, they don't want to just go to some rally and hear some legislator telling them whatever. They want jobs. They want to be employed. How many people say that to me? They'll say, "I don't want anymore volunteer work. I don't any more speeches. I don't want to just go to Disability Mentoring Day. I don't want to go to a National Disability Employee Awareness Month. I want a paycheck."

Actually, my new company coming out is going to be doing web-based training for high school students with disabilities. It's called, "Paychecks, Not Pity." We don't need pity. We need paychecks.

Access was started in Pittsburgh. It just seems that Pittsburgh has that tradition.

We have excelled in having in Pittsburgh great leaders, thinkers in some of these areas. They came up through the sixties. Where we're not raising the bar is employment. So remember, I am saying we have done so many great things in Pittsburgh, and we have. But what would mean the most is if we could say, "We are the employable city. Period."

Joyce, what about people with disabilities who, for whatever reason, may not get that accounting degree, or that computer science degree? What's employment look like for them in this city?

Now I want to tell you that the question of "What happens if you don't have a degree, in reference to your future with employment?" I do have people that I hire and find employment for, who only have an Associate's Degree or only have a Technical Degree, and I have been successful finding them employment. But I want to mention that several years ago I was in Washington, DC, and heard Alan Greenspan speak. And I'll never forget what he said. "Some day there will be the haves and the have-nots. The haves will be computer literate." He was so right, because today, even positions that you don't think of as like a computer job, being a mechanic, or working as an administrative assistant, or working in retail. What do you have to know? You have to be computer literate. So I want to tell you, education is the key. Education is the key. Judy Uman stressed years and years ago that you know what? We need to really emphasize to more of our young people when they are in elementary school the power of education in the areas of math and in the area science and engineering, because here we are right now in the year 2008 and over the next decade there will be thirteen million Americans who are going to be retiring. Right now, the Federal Government, I heard someone speak at this event about how they're going to be losing forty percent in some of the agencies of their employees.

At the same time, there's a lack of skill sets in math, physics, engineering and IT. That is why this is really the time that I hope we see the biggest change. Because there will be a job shortage here. That's why we have to educate our young people and educate all of the people in the community.

Again, I have found employment for many people right here in Pittsburgh at Bayer Corporation, who are now supervisors today, that do not have a four-year degree. When I hired them person actually had a technical degree, but of course, can now go on to continue their education through tuition reimbursement, but education is the key to success in employment.

You know what the other key thing is? We've got to change the whole way we think, because too many people talk to everyone about, "Let's go to these employers and let's tell them they have to start hiring us, and we have to change the way they think." And they sort of talk to people with disabilities like they're in an audience and they're just sitting back there waiting. And unfortunately, that has created a system where that's the way it is. A lot of people are just waiting. They're waiting.

And that's why now when I speak to people with disabilities, I tell them, "Remember when Ghandi said you're the change"? You have to change. You can no longer wait. No one is going to knock on that door and say, "Here I am. I want to hire you, I want to help you. Come on. We want to give you employment." You have to start networking. You have to build social capital. You have to do volunteer work with United Way, or Epilepsy Foundation or Variety Children's Foundation or Achieva or The Hill House, or whomever it is, you have to get out there and go to events where you meet people. You have to be the change. No more sitting back. No more sitting back.

I always tell people when I speak, Dr. Martin Luther King, Jr., when he was in Birmingham jail. He said, "There is a word ringing in the ear of every Negro in America, and that word is 'wait. Wait. Wait. Wait.' But 'wait' almost always means 'never'." That's the same thing with people with disabilities. Wait. Wait. We're going to change this. Wait. We're going to put together an agenda, so that we can get more people with disabilities hired. Wait. We're going to do all these things. Wait. And then people just sit back and wait.

No more waiting. No more waiting. We have to be the change. That's the other big thing. The mindset, the paradigm shift of too many people waiting. No more waiting.

That's absolutely true. You mentioned a lot of things that you're proud of. What are you most proud of.

Absolutely, I can tell you, I know that the proudest thing of my life is being able to found a company that provides competitive employment for people with disabilities. That is what it is. Because there isn't anything ever that is more rewarding than seeing a person with a disability go from poverty to competitive employment, to see that person have that

one thing that everyone wants. Do you know what that is? Dignity. Respect. The first question you're asked is "What is your name?" The second question you're asked is "Where do you work?"

Rico Brusco is a manager of my company. One of the first people who I hired. He spoke at an event when we brought Tony Coelho here to Pittsburgh. He spoke at an event, and Rico uses a wheelchair. He said, "You know? My greatest day is when I went to the Social Security Department and said, 'I don't need your checks.'" And they said, "Sorry, the way our system is put together, you have to accept them over the next nine months."

Think about that, though. Why? Why? Because of the assumption you won't make it. How shocked were they when nine months later Rico went back and gave them all of those checks. He had saved all of those checks for nine months and said, "Here's your money." That's because the power of dignity and self-esteem is overwhelming.

Great stories in Pittsburgh? Jamie Protho. Oh, what a great story is Jamie Protho. First of all I want to mention, because he's African-American, that the minority community the unemployment rate is like eighty percent. So you know, it's even worse for a person of color. Jamie, cerebral palsy, very significant disability, uses augmented communication to speak when he goes to conferences and to speak to others. Jamie, no one would hire Jamie. So I meet Jamie and he gives me his resume, and at the bottom of the resume it says, "I will accept thirteen thousand dollars a year because of my significant disability."

And I looked at him and I said, "Who told you to put that on there? Because whoever did, take it off now."

Guess what Jamie's education is. Master's Degree in Rehabilitative Engineering from the University of Pittsburgh. To think that anyone who has given him this idea is just unbelievable. Well, anyway -- Jamie also uses a personal attendant. And I hired Jamie and I put him onsite at Highmark to do what? Software development. IT Developer. The first shock they had at Highmark is when he out-programmed the non-disabled people, by the way using a stick in his mouth attached for when he programs. That was the first shock.

Well, he was hired and he was promoted, and he's been promoted since then. But a couple of years ago, one day he went to the... Now, he's a Bender Ambassador and he works for Highmark now. And one day he went to the doctor and while he was there, what happened? His wheelchair broke. During the day, during a work day. Do you know what he did? He called the Pittsburgh Police to get an ambulance and went back to Highmark on a stretcher because he did not want to miss work. Now fortunately, when they got him there, they somehow were able to fix the wheelchair, so they didn't have to take him up to his floor, you know, on a stretcher, but to this day the CEO, Ken Melani says, "Okay, I get it. I've seen people leave on a stretcher, but I've never seen them come to work on a stretcher."

Once again, that's because if you've been oppressed or left out, give that person a chance to work. What a mistake employers are making that don't hire people with disabilities. They could just say, "I'm going to stay home and try to be on system."

And by the way, what I hate is when people say, "Oh, well, they can stay home and be on disability." Oh, yeah, they can live on that whopping six hundred sixty-some dollars a month. That can barely even pay your gas, let alone pay gas and your rent. I'm sure everyone's just dying to be in poverty like this.

So if a person with a disability is seeking employment, remember, they could say, "I want to stay home." They're saying, "I want to work."

Did I ever tell you my story about the bank? I don't know if I was working for the county then or where I was working. One of the people at the desk said to me, "Why don't you use direct deposit? Do you have direct deposit?"

I said, "No, I don't have direct deposit." I was working.

They said, "We can set you up with that."

And I'm thinking to myself "How can they set this up with Great Lakes?" And I said, "Hey, if you can do it, great." So, I go over to the lady's desk, and she pulls out these papers and I said to her, "How can you do this?" And she said, "Well, we can send the paperwork to Social Security."

Ohhh, my. Ugh.

And my mouth just dropped. (5, 5:14) The assumption was, "Well, you're on—you have to be on Social Security."

Another voice: Yes, because clearly you can't function at all.

May I ask, how many years ago was that?

Well, I've been working for the county for eight years, so that would be maybe seven or eight years.

That's terrible. They would still say that today, though. There are people that would still say that. That's the sad part.

Oh yes, definitely. So, what has been the hardest thing for you in this journey?

The hardest thing is when you have a candidate with great ability and you go talk with someone, and they look you in the eyes and say the absolutely unbelievable thing, such as -- the first time I ever started doing this, I talked to the CEO of a smaller company, who told me he would never hire a blind person. I could not believe anyone would say this,

first of all. Things that people have said to me have shown me that people with disabilities sometimes even on the radar screen. It's like they never heard of the Americans With Disabilities Act, as if we don't matter or don't count. And to me, really, the hardest obstacle has been ignorance. That is the hardest thing, is when you have a qualified person that you know can do that job and you cannot get the person in because of that person's own bias. Because people want to hire people that look like them. People want to hire people that talk like them. People want to hire people that act like them. But this is when I remind people, "Remember, you are the temporarily able-bodied, you can join my group at any time in your life, and I hope that it won't take that for you to suddenly realize, you know, that you are looking through lenses that are, really, bigotry. You're discriminating. Period."

I would say that my biggest obstacle is when I talk to people who are ignorant and say just unbelievable things. And I'll tell you what, I don't give up. Because I believe in education. You know, I've done this for so long that I know it's going to be hard, but my other big obstacle is that when you place someone with a disability, it's as if they're to be this Spiderman, superhero, compared to any other people in the group. That's why another thing I hate is when people say to me, "Let me tell you something. Twelve years ago we hired a blind person and they didn't work out, so you're probably going to have a problem."

And my answer to that is, "Did you ever hire a white man that you fired? In all these years, have you ever fired a white man? Because I yet, to this day, have never heard anyone say to me, 'That's it. No more white men. We're not hiring them, because twelve years ago we fired one. They didn't work out, so we're not going to hire them.'"

So it would be, you know, when I first started, there were a lot of places such resisted. It really was amazing. I will say Gregg Babe at Bayer Corporation; they have been phenomenal leaders also, like Highmark. They have really just been phenomenal.

Who has been the biggest influence on you?

Tony Coelho. No doubt about it, it's Tony Coelho, because what happened to me was I went to Washington, DC, when I first started the company, John Bernard was the Director of Tech Link. I was the Chair of the Board. I go to one meeting, I leave I'm the Chair. See, now, you have to be careful at these meetings. But then John told me, MEAF Foundation is going to have an event in Washington because Mitsubishi Electric America Foundation gives out all this money specifically to groups working with disabilities. And Rania Alward is the Executive Director. I didn't know her then, I know her now.

So then I asked John, "Do you think I could go also? I want to tell her about Bender, because there will be all these people there who will be interested in disabilities and he said, "Oh, I don't know." He wanted me to go, but you know, they had all these rules.

Well, finally, I can go, but I'm only allowed to talk for two minutes. And I can't go to the luncheon, and I can't do this and I can't do that.

"That's okay, I'll still go."

So I go and I gave my two minute speech, and when I was done, this man came over to me and said, "Oh, I wish you could have met my boss. He would have loved you." And that man was Dick Shepherd, who sadly has passed away since then, but was on the President's Committee. He worked for the President's Committee, on employment for people with disabilities.

So, I'm leaving and all these cameras are going off. Some famous person's there. And I start to leave and someone taps me on the shoulder and says, "I want you to meet my boss, Tony Coelho. He's the Chairman of the President's Committee and reports to President Clinton," and of course, that's who they were taking the pictures of.

So I only talked for Tony for five minutes and told him what I did. And he said, "You need to hear my speech. We have something in common."

And all of a sudden I go from I'm not allowed to go in to this luncheon to I'm now at the head table. So I went in to this luncheon, and that's when I first heard Tony tell his riveting story of how he was rejected because of his epilepsy, and how, in fact, he ended up being the author of the Americans With Disabilities Act. He then told me, "I'm going to put you on the President's Committee," and when I told somebody that, they said, "Oh, yeah, you'll never really be on."

Well, the next thing you know, an official letter came with the Presidential Emblem, and I went on the President's Committee, and then Tony got me involved with the Epilepsy Foundation, but he is a great man, great civil rights leader, and it is he who has had the biggest influence on me realizing one person can make a difference. One person. And to never give up, to never give up, no matter what. He has done so much for me that I really can't speak highly enough of him.

You know, we're having a premier event, and this is.... We're having it on November 10th, and we're having it at Carnegie Music Hall. And we're expecting maybe seven hundred people, and we're still talking about what that's going to look like. We're so busy doing interviews now. We don't have the nuts and bolts of that-

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(tape cuts)

There's pictures of him everywhere, when you go through here.

I'll ask him if you send me an e-mail. The way you may have a chance there of getting him is that's National Epilepsy Month.

Again, as I said, so many people were talking about the discrimination, the attitude toward employment, and why they, the barriers that have been set up.

Does anyone have any other questions?

Another voice: I do. Could you talk a little bit more about epilepsy, and what it does, like, personally and why you said it was oftentimes misdiagnosed. Just talk more about that. Because I don't know much, no one we've interviewed had it. So I would just like to hear more about it.

Epilepsy is a neurological disorder where too many neurons firing off in the brain. That's why I always tell people, it fits my personality. Too much fire power, that's what that is. But the worst part about epilepsy, and Tony always talks about this, is the stigma that is attached. There is a terrible stigma. In other words, you could go to a company, there could be a million people there that have epilepsy, and you'd be lucky if two of them would want you to know or would want their employer to know, for many reasons.

First of all, there's just a feeling that that's like ugh, that's like voodoo, that's bad, that's evil, that's demonic, that's, you know. I know that it's hard to believe that people still feel this way, but there is a stigma attached. People... I just spoke in Washington, DC, to like five hundred people, parents and children with epilepsy, and when I said, "Raise your hand if you've been bullied, and you'd be willing to talk about it," and about fifty hands went up. And these young people are saying, "Oh, yeah, I'm being called Seizure Dog, Seizure Freak, or I'm spit on, I'm made fun of," but the worst part is the exclusion. "I'm not invited to slumber parties, I'm not invited to events." People who work have lost their jobs because they have a seizure. You know, with the changes to the Americans with Disabilities Act, as you all well know, the Supreme Court rulings that occurred, you can be in a situation where well you don't really have a disability because you're not having a seizure at that moment. The fact that epilepsy, of all things, would be defined this way, when the author of the ADA himself has epilepsy is the reason Tony Coelho is right now, the spearhead behind the ADA Restoration Act. Which if passed, and it's moving right along, and if signed by the President, will restore the ADA to the way it was originally...

(static)

Oops, sorry.

But the main thing I would say about epilepsy is that, you know, when you have a seizure at school and you fall down to the ground, and people see you have a convulsion or lose bodily control, whatever it is, you know there are a lot of people that just are terrible with people when this happens. Plus there are people at work, they don't want anyone to know. They would never tell anyone that they have epilepsy. So it is that stigma, that stigma, it's different with epilepsy. You know, there is a real stigma. As a matter of fact, I always tell people, here is a good way, even with some of my relatives, where I can clear the room, all I have to do is start talking about my epilepsy. People feel very

uncomfortable. A lot of people think it's because of the seizure itself that makes people feel like this, but you know, that is something that we're really working on nationally, is trying to educate people to change the stigma. Even I, myself, spoke somewhere, and this employer knew I had epilepsy, and he said, "Well, I have a guy that works for me, he has epilepsy, but I can't let him work on Saturdays."

I said, "Okay, this is a good one. You have to tell me, why if you have epilepsy that you cannot work on Saturdays, because I didn't know that."

He said, "Well, because he'd be alone."

I said, "And?"

"Well he could swallow his tongue."

I said, "Okay, urban myth number one, it is impossible to swallow your tongue. That is an urban legend."

But you know, there are all these strange things people think. I was in one part of Pennsylvania, in a rural area, at a hospital where they still had tongue depressors. I couldn't believe it. But I hope that answers your question. But, you know, epilepsy is just part of who I am. It is not me, defining me, it's just part of who I am, but through medication today, fifty percent of people with epilepsy can control their seizures, and there are many types of seizures. There are absence seizures, complex partial seizures. Here's some trivia most people don't know: complex partial seizures are much more frequent than a tonic-clonic seizure, which is the correct name for a grand mal seizure. Tonic-clonic seizure. Everyone thinks that's it, that's all you have, but many people have absence seizures where it looks as if they're staring, or complex partial seizures, where they may be walking around, looking as if they're in a stupor or that they're drunk, or they don't know what's wrong. And the other thing that a lot of people don't know is one population that is really getting epilepsy is the elderly. That is one of the largest populations. See people don't think that you just have this when you're little or -- no, you can acquire this at any time. And many people who are right now in a nursing home and maybe being told that they have dementia, you know, I see them staring off, they actually have epilepsy. And if you go to epilepsyfoundation.org, we have a lot of information on epilepsy with the elderly.

Is the stigma more related to the fear of not understanding it, or where does that...?

Tony Coelho, when someday you hear him speak, you will hear the story about how Tony, he had been in a car accident, actually a truck accident. He was driving his father's truck when he was about fourteen, around the farm, which he shouldn't have been. And a few days later he's having these, which we now know are seizures. They took him to doctor after doctor. Every doctor, the mother, would say, "There's nothing, they don't know what's wrong. They don't know what's wrong." Until Tony wanted to be a priest,

and had to have a physical and that priest, who was also a doctor, told him, “Hey, do you have like these unusual events happen, that are sort of like fainting?”

“Oh, yeah, I have those all the time.”

“Yeah, well, you know what? You have epilepsy.”

And he said, “That can’t be. I’ve been checked all this time.” Remember his mother took him to all these doctors? But see, his mother knew what he had, but his mother did not accept what he had, because their background is Portuguese, and they have all these weird beliefs about a person having epilepsy.

So the next thing that happened is they had to tell Tony he could not be a priest in the Catholic Church because he had epilepsy. Demonic possession. This was in canon law. If you have epilepsy you cannot be a priest. I mean, to me that is so hard to believe. Now Tony did get that changed, but you know you still have to have a special dispensation?

So, answering your question, part of it based on the whole religious belief, you know, of demonic, part of it based on just fear, part of it based on – to be honest with you – there’s a stigma of, “Ooh, that’s weird, that’s not cool. That’s strange.” Because people don’t understand it. We’ve done surveys with young people, where they’ve said they would not date someone that has epilepsy.

Have you seen the news report on this one doctor I heard about was, um...kids who were diagnosed with autism They, um...he did brain scans, or MRI, or whatever he did, found that they were having seizures, and when they went on seizure medicine, they started learning, they started talking. This has been over the last couple of years, and these kids are at where they should be, developmentally now. On seizure medicine.

Isn’t that amazing.

Yeah, and you do because...why didn’t anyone ever think of that because...I mean, you know, I’ve worked in preschools with kids with different disabilities, and you would see them just be staring, and you *knew* they were having a seizure. And that’s what these kids with autism were doing, a lot of times.

And they’re saying that’s just autism. They’re just staring off because they’re autistic, and that’s just so amazing.

Well, listen, I really enjoyed it. I hope I answered all of your questions.

Right. You did. Thank you.