

## CHAPTER 2

### Keynote Address

#### **Marca Bristo, MS, President and CEO<sup>1</sup> Access Living, Chicago**

I am very proud to be here as a nurse. This meeting is so long overdue. My role today is to help set the tone, to help add some context to the dialogue that we are about to have, to help answer why we're here in the first place and how we got here. To do this, I will step outside the practice of nursing and talk about what it is like to be disabled in America. Statistically, 70 percent of people with disabilities are not working. There are 54 million people with disabilities in the United States. That number is increased from the 37 million we started out with when we started to pass the American with Disabilities Act (ADA) in the late 80's and it is a population that is rapidly growing. We are here to stay.

The disabilities group is the largest minority group in the United States and the only minority group that every single person in this room can and probably will join sometime in their lives. So if you came here thinking this is someone else's issue, it is not—it is every single person's issue in the U.S. and in the world. The statistics—whether it's the unemployment rate, or whether it's the disproportionate number of young people with disabilities who graduate to no future, who are less well educated than their non-disabled counterparts because schools have failed them—only tell a little bit of the story. You can only get inside the disability experience if you start to learn more of the personal dimension. To help you understand what it means to be a disabled person, I will tell you about a few of my friends and colleagues: Ed, Judy, Tony and Pat.

**ED.** As a young boy, Ed contracted polio. He chose to live in spite of, at a very early age, wanting to give up. He spent every night on a

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ventilator and nearly did give up in the 1950's, but made a decision to go on. He decided to go on to college and did not want to go to the only college in America that would accept kids like him, the University of Illinois, Champaign/Urbana; he wanted to go to the University of California at Berkeley. So Ed applied to Berkeley, was accepted and he made arrangements to show up on the first day of school only to discover that the campus was not accessible and was told he would have to live in the infirmary. Ed, if you ever knew him, said, "But I'm not infirm, I'm not sick. This campus has to change a little to let me in."

**JUDY.** Judy was born with a disability. Her mother took her to school on the first day when she was a little girl in New York City. And the school said, "Sorry, you cannot come here because you use a wheelchair. You're a fire hazard, our insurance will not cover you." The school sent her home. The school could send her home because there was no law then to say it was discriminatory. Up until 1975, nine million children with disabilities were kept out of schools. Later, Judy graduated from school and college, the same college, Berkeley, where Ed had broken down the barriers. Judy wanted to be a teacher in that same New York City elementary school system. When she showed up and applied for the job, guess what? They told her the same damn thing! "You cannot teach here because you are a fire hazard."

**TONY.** Tony wanted to be a priest. He was told, "We're sorry, you can't be a priest here because you have epilepsy." The reason is that particular religion believed that people with epilepsy were possessed by the devil. So Tony left. He and his family were not permitted to speak the word "epilepsy" because his family believed that, too. Tony did not speak to his family for twenty years because they believed he was possessed by the devil because he had epilepsy; their church had taught them that.

**PAT.** Pat is a nurse, a director of nursing at a major state-run medical education center in Alabama. Pat was diagnosed with breast cancer after an illustrious nursing career directing a nursing center. She was undergoing chemotherapy and felt pretty good. Then was told by the institution she needed to take a medical leave, so "she would feel better." The institution paternalized her into taking a leave she did not want to take. Then when she said, "I'm ready to come back," she was told, "Sorry, we gave your job to someone else; we'll give you

another job, which, by the way, pays half as much as the job you were hired to do (and had done for several years)."

This is what it means to be a person with a disability in the United States. I wish I could tell you that all this happened before the ADA was passed, but it did not. Pat's experience is quite recent. Now I will give you the other side to these stories.

**ED.** Ed went on after graduating from Berkeley and wanted to go to work. The state of California's vocational rehabilitation system told Ed he was too severely disabled to work. They rejected him. They closed him out as "too severely disable to work," and told him he could not get state-supported services to become employed. Many years later, after Ed created the first center for independent living (like Access Living) and really created the worldwide movement of people with disabilities which is now all over the world, Ed was hired by the former governor of California to be the director of the same state agency that told him he was too severely disabled to work. That's justice.

**JUDY.** Judy, the person who could not go to school and then when she wanted to be a teacher, could not be a teacher. I am so proud that President Bill Clinton appointed Judy to be the assistant secretary at the Department of Education heading up all the education for children with disabilities in the United States. That's justice. Judy is now the advisor to the President of the World Bank working on disability policy for the whole world to make it more inclusive of people with disabilities.

**TONY.** Tony is former Congressman, Tony Coelho, who led the charge to pass the historic Americans with Disabilities Act. He did so by encouraging the rest of us to "bare the scar tissue," put it before the light of public scrutiny. When Tony told his story before a packed hearing, Senator Bob Dole and Senator Orrin Hatch wept. They wept because we live in America and this should be wrong.

**PAT.** I wish I had a good news story about Pat. Pat's case, and therefore indirectly the nursing profession, gave us the single worst Supreme Court decision that we've had under the ADA. Her case went all the way to the Supreme Court where she never received her day in court because the justices determined that Congress, and Tony

Coelho, had overstepped national authority when the ADA was passed and brought state governments and employers under the purview of federal law. So, in an indirect way, the nursing field or at least the nurses at the University of Alabama brought us a terrible decision.

I hope you all feel this — feel an incredible opportunity to do justice here in a different way. Though you cannot reverse the Supreme Court decision, you can reverse the prejudice and the stereotype that underplayed that decision in the first place.

Now I want to briefly tell my own story. I'm a nurse. I broke my neck in a diving accident. I was on my way to becoming a nurse midwife. My story is a little different. I decided I wanted to get my graduate degree because I knew my career would flourish if I could either be an educator, a researcher or a nurse administrator. All my colleagues in the profession told me I would need a master's degree. I went to the Illinois vocational rehabilitation system, told them I wanted a master's degree and needed support for my master's education. My vocational rehabilitation counselor told me that I had unrealistic career goals. In spite of the fact that I was practicing as a nurse from my wheelchair, they rejected my request and said no.

Well, I had enough of a fighting spirit in me by then, even before I was in the disability movement, so I went to my boss and to the woman who taught me about midwifery and said I needed their help. And unannounced, I took the director of nursing and my instructor into my Illinois vocational rehabilitation appeal hearing and said, "I'm not going to say a thing. Listen to them." They told the appeal board that not only were they wrong, but they had hired me as a nurse. They told the board that I was practicing as a nurse and that my long-term career potential was in jeopardy unless they enabled me to go on to graduate school. We won.

We won because of the enlightened perspective of two nurses who chose to look at me differently. These nurses did not really know me, I had only worked for one of them for four weeks when I broke my neck. I originally lost my job. I did not have the ADA then. But shortly after my accident, out of the blue they called me on the phone and said, "Would you like to come back to work?" I was just stunned. I had begun to accept my new life as an unemployed person, trying to figure out how I was going to live with no money, with no healthcare at the

time, and no transportation. And I was going through the process of trying to put the “happy face” on my fate and figure out something else to do.

When the phone call came I went to talk with my former boss and asked how could I be a nurse using a wheelchair? At the time, I did not believe I could do this. My nurse supervisors, Judy and Angela, took apart three jobs and put them back together and made all three nurses happier by giving me a job. They did what we now call job sharing. They did this before the ADA was passed.

Why they did this I'll never really know. I think it's because they were just decent human beings and they just wanted to reach out and give me a chance. That's the opportunity that you can choose to do. So that the Ed Roberts', the Judy Heumann's the Tony Coehlo's and the Pat Garrett's lives are not played over and over again.

People with disabilities have begun to reclaim disability. For most of history society has defined us. Those days are over, we are defining ourselves now. We're doing it because we have created a movement that is helping each one of us to reject the outdated notions about disabled people and replace them with the notions we carry in our hearts and know to be true. This is an enormous revolution in thinking; a paradigm shift that this country has almost never seen before. Because we are asking you — no, we're demanding that you join us in this paradigm shift and throw out the medical model of disability which sees us as “patients” first —sick, to be cured or treated or fixed. At a certain point we cannot be fixed anymore. We're asking that you accept us where we are. This is very important because the medical model puts all the power in your hands — there is something wrong with us and you are there to help fix us. And it takes all the power out of our hands.

The disability rights model, also called the sociopolitical model or the independent living model, changes all that. It throws the medical model on its head and says, “There's nothing wrong with us.” Yes, there are things we cannot do, but we have a responsibility to adjust and learn what we can do to be functional in our community. However, the world has met us halfway. The barriers that have kept most of us out are man-made barriers either in people's minds or in the world about us. As Mayor Daley, Mayor of Chicago, showed us last week

when he ripped up Meigs airfield in the middle of the night, all it takes is a jackhammer to get rid of some of those barriers.

Something has to change at a deeper level inside people to do the real hard work. For example, today while we are meeting here, the City of Chicago zoning commissioners are evaluating a recommendation to allow a height exception to the zoning ordinance so we can build multi-family units three feet taller. This three feet will make the first floor accessible and get rid of the up and down of Chicago architecture. We are being told that it can't be done because it does not fit into the character of the Chicago architectural landscape, "because we won't have the Chicago stoop, the porch." Take a look at the 10,000 people a day after the year 2012 who will be at the age where they are going to be likely candidates for nursing homes. Soon the world will wake up and realize the missed opportunity we had in 2003 as we're redesigning housing in Chicago, and understand that you too will need housing that was zoned to be accessible. Remember you were told that it didn't fit with the character of Chicago architecture.

So what is really going on here? Prejudice. People come up with all sorts of great excuses as to why they can't do things. Those of us in this room with disabilities hear this all the time. We hear all the lame excuses that are given about why we can't do something or go someplace or be part of something. This is an absolutely critical juncture. The ADA created a legal tool for us, and that tool is extraordinarily important. We could never have our day in court before the ADA. I don't want to undervalue how important the legal victory was. But those of us who wrote it —and the main author, Bobby Silverstein, is in the room and you will hear from him tomorrow — knew that we were doing something more important than writing a law, we were changing the world.

It was a symbolic victory to disabled people, almost of greater proportion than the legal victory. For the first time in the United States, we said that disability is a normal part of the human condition and that the world has to change a little to let us in. Bobby Silverstein put it in simple terms: The ADA means replacing exclusion with inclusion, dependence with independence and paternalism with empowerment. And that's what we are asking you to do.

Martin Luther King understood so much better than many of us that to get there requires much more than a law, when he said: Desegregation will break down the legal barriers and bring men together physically, but what is needed is to touch the hearts and souls of men so they will come together spiritually, because it is natural and right.

And that is what we are here to ask you to do today. We can argue all the legal terms, and we will, but we want you to understand that even if there isn't a legal reason for you to do this, and there might not be 100 percent of the time, do it because it is right. We have it within our power to do this.

Up to this point I have spoken to some extent about the legal and moral arguments. Now I want to talk a little bit about the more mundane and practical issues. First, look at the state of affairs in health care. We cannot get health care to people who need it. There is a shortage of nurses not only in our big institutions like Rush, but think of rural America where nobody's giving health care at all. How dare we not let people into a field that is crying out to heal our nation's ills. People with disabilities can and are doing those nursing jobs right now.

No nurse does everything. We're trained to be able to do everything, but once we've had that training, we do what everybody in the world does, we follow our hearts and we pick the path that we want to do and that we're best at. What makes you think that disabled people are any different? Most of us are not going to choose a part of the profession that we will not be successful in. It defies logic. We want to get raises, we want to get promotions. So if a disabled person cannot do a particular type of nursing, it is more than likely you are not going to see too many of us there trying to do it.

In some respects, nursing lends itself to accommodations in the simplest way possible because there are a hundred jobs in nursing and they are all different. Therefore, the essential qualifications of those jobs are what we should be looking at, not the field of nursing because it is too diverse.

Finally, and this is something you might miss, people with disabilities add value to health care. Who has been through the health care system more than us? Who knows how to navigate it better? Who

knows how to get through the bureaucratic morasses better? Who knows where the public resources are? Who knows how to refer you to all those important but little-known networks? Who knows how to get peer support, which is most often the missing link in the whole healthcare system? We do, because we've had to do it for ourselves. Not only do we add value, but over time, we may save you some money. We will contribute and enrich the practice of nursing because we bring something to the table that many other people simply do not have — the experience of living with a disability.

This will require the nursing profession to do something that in some respects is going to be harder for nursing to do than other professions, and that is to throw out the medical model. Nurses have been taught in the medical model that disabled persons are your patients. We are the people you have committed your lives, in some respects, to serve. Asking you to let go of that is a hard thing to do because it requires you to see us not as patients but as people.

This is a challenge I believe you are up to. This is not rocket science. What we're asking is common sense; it does not require vast researchers from the Massachusetts Institute of Technology. It takes commitment, common sense and an understanding of how our world has changed. My friend Justin Dart, who recently passed away and is considered the Martin Luther King of the disability rights movement, taught us that science and technology created a new human. Infants did not live when they were born severely premature, and now they do because of technology. There are many more senior-aged people because of new ways of looking at things, because of research, science and technology.

And yet that same technology and that same science can sometimes trap us out, but it does not have to. If you choose to join in this paradigm shift, there are many wonderful people here today who are going to teach us how to do that. These are nurses with disabilities who are enjoying tremendous careers, and you're going to hear about how they are able to do that.

You are also going to hear from another group of people who have not been allowed to continue their dreams in the field of nursing because of outdated attitudes. This week Karen McCulloh, a member of this symposium planning committee, has been in touch with a nurse

from Alabama who has a visual impairment acquired after she became a nurse. This nurse requested a job reassignment to a position she could do because she was concerned that her new visual impairment might interfere with her ability to safely administer medicine. This nurse was not looking for a handout, she was caring for her patients. She went to her boss and said, "Work with me on this." The institution said no, so the nurse filed an EEOC complaint. The complaint is pending. Finally, they relented a little bit and they said okay, we will give you another job. They gave her another job doing the same kind of work including administering medications on the nightshift. This week she quit. Nobody should have to quit anymore.

To my colleagues in the field of —we have a lot of work to do. I'm so glad there are people like you who are there to give this person support, direction and hope; to help her fight the valleys of self-esteem as they dip because it is so easy to give up. It's so easy to blame yourself in the face of these odds. Those in the disability community have an incredibly important challenge before us to continue to get the word out that times are changing. It does not have to be this way and people do not have to give up. Those of us in the field of nursing have an incredibly important opportunity here.

I'm going to close with something —I want to read a long quote. I don't do this often, but this one is so pertinent to today. This quote is from Deval Patrick, the former assistant attorney general at the Department of Justice under Janet Reno, who said these words as he was sworn into that post:

"This nation as I see it has a creed. That creed is deeply rooted in the concepts of equality, opportunity and fair play. Our faith in that creed has made us a prideful nation and enabled us to accomplish feats of extraordinary achievement and uplift. And yet, in that same instant we see unfairness all around us. We see acts of unspeakable cruelty and violence because of race or ethnicity or gender orientation. They present a legal problem to be sure. But they also pose a moral dilemma. How can a nation founded on such principles, dedicated to such a creed, sometimes fall so short? And let me assure you, that is a question asked not just by intellectuals and pundits but by simple, everyday people, every day. To understand civil rights you must understand how it feels to be hounded by uncertainty and fear about

whether you will be fairly treated. How it feels to be trapped in someone else's stereotype; to have people look right through you. And what will be our answer? Will we sit back and claim that we have no answer? Or that it is not our business to devise one? Will we shrink from the moral dimension of our work? We will not shrink. I know because I can look around this room and see every kind of woman and man joined here in one brief but illustrative moment of harmony, common in our humanity and in our resolve. We have but so many moments, I think, where the confluence of opportunity and resolve is in this wondrous balance. And so it is right now."

And so it is right now. Thank you.