

Effective Strategies for Social Change

Ed Roberts Speaks to Partners in Policymaking Session 1

One of the things I'm sure that a lot of you know about already is how this society treats people with disabilities, and how the attitudes around treat us. Well, I've discovered over the years that I don't really need to sit down and tell you, or anybody else, about weakness. I want to talk to you about strength. And I want to talk to you about what people can really do when they're motivated and when they're clear about who they are.

I got polio when I was 14, in 1953. That's a while ago. It was before the vaccine. So, I don't know how many of you can remember those days, but polio was a scourge, you know. It was a terrifier. People were just terrified that children might get it. Or their family or somebody might get it.

It was a virus that spread like the flu or cold. And not too many people got it around me... one of my friends died, then I got it. And when I got it, everybody got it. My whole family got the polio. But, their polio was non-paralytic. All they had was, basically, they were quarantined.

People were so afraid of polio, though, when someone would get polio in your household, they'd put these big red signs on the front of your house and warn everybody away. People had to stay in. When I got polio, the whole school emptied. There was such a negative attitude about what might happen.

At first, I was the March of Dimes poster child, but then they discovered that I was too disabled, right? And the March of Dimes was a classic charity. In that they knew how to make people feel horrifically guilty. Yes, they knew how to pull all kinds of money out of people.

But, in the process of doing that they created a lot of fear and a lot of problems for all of us, as most charities have, because they have this dual role. They're supposed to be helping you, or your family, but at the same time they've got to get money, so they portray you as weak, and sick, and unable and actually, or probably, created a lot of the old attitudinal problems that we fight day to day now.

So when I talk to people, I talk about the fact that we are a group of people created by charity, and all they did was keep us from the Civil Rights Laws, because they still are—as intact as they are—our basic rights. And we did have a right that, if we are discriminated against, to help them, to fight back. Discrimination comes in a lot of forms.

So what I do for my talks... I talk a lot about my experiences. I talk a lot about the fact that I've become a very strong person over the years. Not only because of life in general, but because I have a disability.

It's forced me to do things and learn things that many young people never have to. I've come to terms with death. I'm not afraid of that. I had to when I was 14 or 15. The first

thing I had to decide was whether I wanted to live or die, which is a very difficult decision.

I wanted to die. You know, you're 14 and you're paralyzed from the neck down and you're in an iron lung—you have to be terrifically creative to commit suicide. I had all these people around me, doctors and nurses and their job is to save your life and you're just totally depressed and not knowing what the hell your life is going to be all about.

And I had totally accepted the whole idea that being crippled was terrible, the worst thing. We don't really understand how we inculcate all these attitudes in people.

But back to before I became disabled, how I thought it was really going to be a terrible thing, a tragedy, and how awful would it be to be disabled.

I remember being on my father's shoulders. I was at, like, the State Fair or something. And I saw this woman in a wheelchair, who also had cerebral palsy. And she was just moving about in her chair, and I was fascinated by this person. I'd never seen anybody like that. And I was really looking, and all of a sudden my father reached up and yanked me back and said, "Don't stare!" without any explanation. And I thought, well, my God, if you can't even look at it, what must that be? Something really to be afraid of! It's terrible!

And you know in so many ways we perpetuate, with our young people, these stereotypes. Often by not explaining what might not be polite. She was fascinating! She was different! And I celebrate difference. I think difference is wonderful! And it would be pretty awful if we were all the same.

And I've worried about my difference, but when people stare at me, when they look at me, and look at me as so different that, in a way, they want to feel pity, or feel sorry for me, I have a couple of reactions: One is, that I can probably get anything I want out of them, because I can manipulate the hell out of them. While they see me as weak and unable, I'm not, and I come on strong and capable while they're staring at my wheelchair and my respirator and feeling entirely sorry for me—I can use that.

It's a very powerful tool and it's something we should teach people to use practically. The other feeling I have is that it's totally their problem, and I'm not going to internalize that and feel bad about who I am. There's nothing wrong with that.

I don't particularly like it, but I also do—and I learned this, interestingly enough, from the women's movement—I learned how to manipulate the stereotype. I was in a couple of self-support groups when I was living in Berkeley. I was watching these women teaching each other how to manipulate the stereotypes of weakness in women. And I thought—wow. That would work real well for disabilities and I began to use it tactically.

Now, you see a lot of people who do that as part of their whole life, it's a different thing I think; and that's all they know how to do—use some sign of weakness to manipulate. I

understand most of you are parents. You may see that a lot in your own children as they manipulate you to try to get something. You need to be aware of that.

They may not be very aware of how they're doing it, but there's a very natural tendency to use that and play on the guilt feelings. You may have some guilt feelings—you may have a lot of other kind of feelings—but hopefully you can recognize it when it happens and encourage them when it needs to be used, but also be clear with them that that's happening. And that they can come from that angle, but they can come from other points of view, too.

My mother was probably the most important person in my life because she would believe in me. She was told, I mean, she went to the doctor, after I'd been ill for about two days—and polio's a voracious fever, you're running a 106 fever—so you're really going through a lot of dreams and a lot of hallucinations, so you're terribly sick—and they don't know whether you'll live or die. Antibiotics didn't really work to stop the fever. She went up to the doctor and asked if I would live or die? And the doctor said, “Well, maybe you should hope he dies, because if he lives, he'll be nothing more than a vegetable for the rest of his life.”

Now, I don't know how many of you have had this happen to you, but I'm proud as ___ to be known as an artichoke. And I use that really a lot because, first of all, that's such a dead serious thing—to be saying to a doctor, is my child going to live or die? And have the doctor say it's better that he should die than live as a cripple and be nothing more than a vegetable—well, he doesn't know! And I'm not sure why medical people and others around like to predict the most dire circumstances about who you are. But, almost everything that I was told was _____. You need to be clear about that.

I mean, somehow, people relish—or something—in telling you the worst! You know, “your child or this person will never be able to do this, will never have a family.” When I brought up the issue of sexuality, oh my God! I mean, what I recognize now is that they must have been real screwed up themselves about their own sexuality, because obviously they couldn't talk about it to me. And I think that's true, I mean, it's the only explanation I have.

And as I got older, I wanted to know—shoot!—am I going to be able to have a normal sex life or if I'd have children? All those questions... and every answer was negative. Every time I asked, or even when I didn't ask, about what my future would be like, there was a negative reply.

Maybe some people who choose to go into professions are so wound up in trying to help, and, in a sense, take over for you. And in a sense, are trying to prepare you for the worst. I don't understand that. I don't understand the psychology behind that. But it's pretty awful when you're a parent, or a person with a disability, to hear only the most negative aspects. The doctor will say to you, “this person that you're helping to raise...”

A lot of things that happen, in terms of whether they are positive or negative, will depend on whether or not you are positive or negative. And whether you can help the person learn to advocate for themselves—but first you have to do it.

When I went to graduate from high school, I went to high school by radio/telephone. I didn't want to go out. I was terrified that people would stare at me; I didn't like myself very much. As I said, I accepted all those old stereotypes about me.

I did very well in school, I didn't have a lot of distractions, either, I mean, I didn't have all that teenage social rating and dating and all that stuff, and so I could concentrate on my studies. I was something—I mean I didn't know I had a brain hardly, but when I was in grammar school—and I hated school—for me it was torture. I liked going outside and playing sports. I was a young athlete, and I was an aspiring athlete—a good athlete. I wanted to be a professional baseball player.

But polio changed that real fast. It made me begin to think of another profession, at least. And I began to discover that I had a brain, and that not only did I have a brain, but that I was smart...and that, when I applied myself, I was one of the top students in the high school.

So, what changed? From being viewed as a kid who was an average, kind of ordinary kid—not the brightest—to one of the top students in the class? I began to realize the advantages to being considered “smart.” You know, the way people label you in school and the way you label yourself is so much similar to the way you are labeled when you become disabled. Whether you're labeled “severely disabled,” or whatever your label is, “CP” or “MS” or, oh man, there are so many labels I can't believe. But, almost all of them are negative.

And then we move into other labels—somebody called me an “invalid” the other day. Invalid: I love that word. It's just one of my favorites. And you know, for a while I was a “shut-in.” I have some “deaf and dumb” friends. And you think of the words—do you use “cripple?” The word “cripple?” All the words that are used to describe us in any way are the worst! They epitomize how we are viewed by society. How we are not valued in any sense of the word.

We need, all of us together, need to be sure that we're not using “value,” or “valued” lightly. When I talk, I am a person with a disability. I am a person first, and then I have a disability. And when I talk, I talk about that people have needs. That's not our whole life—my disability does not define my whole life.

Because I just have normal needs, like anyone else. And wishes, and desires. And to pull people apart, segregate them, put them in separate schools, and keep themselves separately is a real crime, I feel. It perpetuates the presence of a lot of things.

To me, what we have to be together is to be very political. I mean, that's what you're here for, obviously. You're so lucky! This is a remarkable thing that's happening here! I

don't know too many states that would do this—who have some leaders who have the imagination and the ability to bring people for today, myself and others, in to talk to you and to give you some of our experience. And maybe to teach you that some what you've heard, and some of the expectations you maybe have for yourself or your children are not true and don't have to be true. And that a few people can make a big difference in this state, or the next, and make fundamental change. And we need to change this place.

I began to discover how little—while everybody else is concentrating on disability—how sometimes disability was irrelevant almost. It didn't even matter. It's funny, I went to the University of California at Berkeley—and it was a bitch to get in—I mean, they said, “well, we tried cripples, and it failed.” I love it! And then when I got in, there was a headline in the local newspaper that said “Helpless Cripple Attends CAL.” I still have that. I save those. They're priceless—they've gotta be worth a lot now. People have to be able to laugh at these things because they come from a massive ignorance. And you don't see it quite as much, anymore, but people do still make those kinds of faux pas.

While I was at Berkeley, I fell in love. People have been known to do that once in a while, and it was wonderful, what a great feeling! And I was told that I could never drive a power wheelchair. I was just too disabled to drive a power wheelchair. And it's ridiculously inconvenient to have an attendant with you, pushing you around in a wheelchair everywhere. Real difficult to be intimate and to be alone. And I learned how to drive a power chair in two days. Two days, we're on my lap and we were heading off into the sunset—I tell you, that's motivation!

If you're highly motivated to do something—I got portable, we figured how to do this thing out so fast, and yet, for 15 years, I was pushed around. It changed my life again. I mean, it was like leaving home for the first time, going to university, or going and hiring my own attendant, and then firing one for the first time, learning that I could control my own life.

Talk about being reborn, revitalized. The power chair was almost the exactly same kind of experience. For those of you who have children, or people, that are not mobile, find a way to make them mobile because it fundamentally changes their personality. I've watched little babies, children who are a year old, or two years, who have never been mobile because they're paralyzed, get an electric scooter or something and within ten minutes, their personality has changed from being totally passive to being so aggressive you wonder where they're going to go next.

How they're going to challenge... we took a young student at Berkeley who came in and all he'd done for 15 years was sit in his room. And this guy was a genius! He was bright with electronics and computers. He'd done all this assembly work, and built all these things. When we brought him to Berkeley we could hardly hear him. He wouldn't even talk. You had to get real close because he wasn't used to talking with people at all.

And we gave him a power chair the first day he got there. And we lost him! We couldn't find him! Finally, the campus police brought him back. And they'd fished him out of the

creek. Because what he was doing—and Berkeley has a lot of hills—he was going to the top of the highest hills and he was putting his wheelchair on full speed. He was just going fast as he could, and he couldn't stop and he ran into the creek. And that day, he came in and I heard him talk, and he was so totally exhilarated by the ability to be able to move and to do things.

And I think that's where people take engineering and the use of new technology comes in. I'm just learning how to use a computer, for example. Wow, what a big change that's going to be in my life. I've always dictated. I went through thousands of books at the university because I worked through a Ph. D. in political science—of course, politics, right?—and we had thousands of books, boy, if I'd had a computer, I could have written so much faster, so much easier with word processing. And it's hard for me to write, but if I had a computer I think I could be able to. Finally I talk a lot, but now I'll be able to write it. Now, it's like I'd better because everybody else is writing what I've been talking about.

Now, my mother, we had to learn to fight together because there were so many people around with their little narrow rule books who were always willing to say “No!” It was so amazing to me. I know those of you with a disability or are a parent must run into that a lot. Whether you want your son or daughter to go to regular school, or have this kind of problem... people find a way to say no. And sometimes when they're in a large bureaucracy it seems so cold and it seems so difficult to be able to fight them.

And one of my first struggles was I went to graduate from high school and I was immediately told that I couldn't graduate because I didn't have driver training and P.E. And well, to say the least, it ____ you off. I was the number two student in school, and I'd done all my academic requirements. My mother, she said something like, “well, we'll prop you up behind the wheel and I'll run the wheel.” You know, she got very sarcastic with this guy.

And he looked right at me and basically patronized me, he said: “You wouldn't want a cheap diploma, would you?” He said some really cold stuff, and aside from feeling so humiliated, working so hard and feeling like I'd earned it, at the same time feeling like I wanted to kill the guy—both my mom and I.

And so what we did, first we threw the guy out of the house because he had to come to me—which is a very interesting phenomenon, I think more of us should do that. And secondly, we said, “hey, how can we change this decision?” And we went to the school board. It was no problem at the school board. All we had to do was say, “Hey look, this is an injustice.” In every way I'd earned my degree. And I got the first diploma of all students with disabilities at that school.

But it was a very important thing for me and my mother, fighting together. It was like a landmark for me, first of all. I don't think I could have done that alone, at all. And both of

us were terrified. Oh boy, were we afraid—not that we'd lose, but its scary going up against authority. It is! It takes a lot to be able to do that.

And there was no question once they heard. I was given my diploma. You know, what that did for me, that and the other small fights that we learned how to fight together, it gave me the confidence to fight for myself. And I think that's why I'm here right now, in a lot of ways, because I learned how to fight.

I learned that if I was to be free, if I was going to be independent, if I was going to lead my own life, then I had to fight for it. And the other thing I learned is that when you start fighting, it encourages a lot of others to do it, too. It's like role modeling. When we set up the Center for Independent Living, the first center that brought together a lot of people with severe disabilities, not to live together, but to fight and advocate together, we found how powerful peer relationship and peer counseling can be.

I'll tell you one more thing—I was so terrified when I was young, I stayed in for 5 years. No one should say this will happen overnight. It's a process everyone goes through that's awful: feeling basically weak, and unable, and not very powerful; basically learning how to love your self again. And when you begin to love how to yourself, you find out that others love you as well and you begin to get into some interesting relationships and friendships and all kinds of things.

I stayed in 5 years. I was terrified that if I went out, people would stare at me. And so my mother and a couple of others said, "You know what, you're going to be here your whole life." And my biggest fear was, "what would happen when my parents died?" And of course their biggest fear was, "will we be taking care of him, our son, our whole lives?"

And so, with a swift kick in the butt, and I believe in that, sometimes... I think sometimes we're too gentle. We don't teach people to take risks. People have to learn how to take risks. Whether we're young or old, that's the only we can learn together, by learning how to take that next step, that risk.

I decided I'd physically attend the high school one day. And they got me in the car, and drove me to this courtyard where about 200 students were. I went, "Oh, No!" That feeling... and as they started getting me out, everyone turned to stare at me. Here I was. My worst fear! And I was sitting in the middle of it.

And all of a sudden, something happened in me. I looked around, and I wasn't hurting. It didn't hurt! And I said, "Whoa, it's kind of like being a star! Oh, hey, that's not so bad." Then I also thought, not only does this not hurt and maybe it's not so bad to be stared at, and then I said to myself, "Hmmm, you know? I have a choice here. I can decide it's because I'm ugly, because of all the bad feelings I had about myself, or I can decide, I'm a star! I'm different."

That was very important to me because I began to make choices about how I accepted it. And I realized, "Hey, I'm going to separate here what's my problem from what's

somebody else's problem." The fact that they're all staring at me doesn't have to be my problem. It can be theirs! I think those things are very important to me. I try to teach those—that you make choices about how you feel, whether people stare at you, or not. And that can be taught.

I think there are a lot of lessons I've learned being a person with a disability. I've been disabled now for 34 years. And I think it's been essentially a positive experience, and a strengthening experience. And I think it can be for most people.

A lot depends on your attitude, a positive attitude, whether you're impaired or a disabled person, and that you move through life making your own choices. You take risks—you learn to take risks and you're encouraged to take risks in your life. So that when you come up against new situations you're willing to try it.

I had to learn to say "I love you," because I was afraid that when I said it, I'd get hurt too bad. We all feel that. But when I did, the rewards were very great, as they often are.

And life's great. I have a little bit different perspective, you know? I relate to children real well because I'm at their level. That's interesting—it really is. You see, most children are very direct and honest with you. "What happened?" "Why?" You tell them, "That's why." And I think my nine year old—he's nine now and he's wonderful—he probably taught me as much as anybody has taught me because when you're "daddy" or "mama," it doesn't matter whether you're in a wheelchair or what you are, it doesn't matter. I wish more people could come from that perspective.

Whatever it is that makes you different is pretty irrelevant. It's who you are as a person that's the most relevant thing of all.