

Ed Roberts, and the World Institute on Disabilities

by Raymond Lemay

There was one event that created a great deal of anticipation and high expectation at the Reykjavik conference. Everybody was waiting to hear Ed Roberts of the World Institute on Disabilities (WID), but we were all disappointed when he didn't show up because of illness. In his place, one of his associates presented a 15-minute video on him that had been produced for the American television program *60 Minutes*. It was quite compelling. I came to see why so many people wanted to meet and especially hear Ed Roberts.

He is first and foremost a very engaging fellow. There is great strength and dynamism about the man, a *joie de vivre*, and of course a great deal of courage. Ed Roberts was afflicted with polio when he was very young and has lived on a respirator all his life since. He cannot breathe on his own and therefore spends much of his time in an iron lung, but because of his great will and energy, he's forced the medical establishment to create for him the kind of equipment that will allow him to get around without being in an iron lung.

Ed Roberts has many accomplishments to his credit. He has served as a high public functionary, and he is now the executive director of WID. A world traveler, he has met princes and presidents. He is part of the jet set of human services. He seems like a man who has that great power to engage others; clearly a leader who, I'm sure, many would gladly follow.

Ed Roberts is certainly the personification that handicapped persons have an important role to play not only in the debate on the place of handicapped persons in society, but in the running of society in general. There are too few great leaders today for us to forego the presence of those who happen to be handicapped.

Ed Roberts could be a great spokesperson for social integration and even for SRV. What a stroke of good fortune it would be to have a person of his quality to speak to all of us on the very complex issues that surround social devaluation. He is a remarkable role model who has played many roles that have made a difference, and have made people, in a sense, not care about his great handicaps. Today, he is a very talented and powerful spokesperson for many persons that society devalues. This is a role that he carved out for himself. He's been a policy advisor, he is a father, was a husband, and is now an employer and an executive director. He is the acquaintance, friend, and counselor/advisor of the powerful. These roles have grown out of each other and have multiplied.

But the message conveyed by WID, and its spokespersons that were present at the conference was that they refused to listen to, and would disrupt the presentations of, anybody who was non-handicapped. "The able-bodied just don't know what they are talking about." The WID representatives did not want to discuss "a society for all" but wanted everyone else to listen while they listed their demands. They have rights, and the rest of the people are told to live up to them, which is fine as far as it goes. They have put all their eggs in the basket of legal rights, despite the reality that legal rights are usually best utilized by those who have power, privilege and money.

The limits of this approach were compellingly brought forward in the video that hagiographed Ed Roberts. Throughout the video we saw many able-bodied persons who assisted him. There were persons who pushed his wheelchair about and who got it unstuck when it became stuck. There were persons who designed for him some very advanced technological equipment. There were persons who cared for Mr. Roberts most intimate bodily needs. There were able-bodied persons who flew the planes, drove the cars, cooked the food, and cleaned the house, and so on that allow Mr. Roberts to do the important work he has to do. And there are many, many people, most of them able-bodied, who pay

taxes to allow all of these things to happen.

To say that all these things should be done for the simple reason that Mr. Roberts has legal rights or that he demands them seems unsatisfactory. There is more to it than that. And to say that all these people don't have certain insights into what it is to be Mr. Roberts seems patently absurd. Thus to say that the able-bodied should not participate in the debate is as ridiculous and unjust as what has previously occurred: refusing to hear and acknowledge the voices of handicapped persons. And there are important questions that the majority of any society has to grapple with. In the case of Ed Roberts these include: What does it take and why should anybody be involved with Mr. Ed Roberts? And why would anybody chose to assist and become involved with a person who is maybe less charismatic and has less evident gifts and talents than Mr. Roberts?

Soon after Mr. Roberts became stricken with polio, the experts clearly said to his family that Ed was better off dead than alive because he just wouldn't be able to live on his own. "Who would want to live such a life"? But Ed was his mother's son; she defended him and did everything to keep him alive. Ed, at first, would have nothing to do with life and did everything in his power, which was very little, to see it end. He even attempted to starve himself to death, going down to 50 pounds. But there was a moment of conversion when he realized that despite his serious limitations there was still much he could do and enjoy; and enjoy he does.

In a sense, when he contracted polio, Ed Roberts became the son that only his mother could love. Everybody else, including Ed, wanted him dead. But she kept him alive, against his will. When polio struck him down, the only valued role that was left was that of "son" and it was this bond to his mother that made her his first advocate. Ed Roberts would have ended it all. It was his able-bodied mother who ensured that he would be around to make a difference.

(Note: We have just learned that Ed Roberts died of a heart attack in March 1995. His death was reported on many national news programs in the U.S.A. and his obituary appeared in *Time* magazine.)

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