

**ACT Self-Advocacy Resource Network**  
[www.selfadvocacy.com](http://www.selfadvocacy.com)

**Volume 1, Number 12**

As you requested, this is your ACT Self-Advocacy Resource Network memo facilitating a national dialogue among self-advocates and supporters and a clearinghouse for materials and training that support self-advocacy.

**TOPIC: Happy Father's Day, Ed Roberts!**

Ed Roberts is often called the "father of the independent living movement," so it's fitting that we honor him this Father's Day. Ed was paralyzed from the neck down at age 14. He faced a life of segregation and exclusion, but was not about to accept it. He spent his life breaking down barriers. His legacy -- the independent living movement -- is a true national treasure.

**1. About Ed Roberts**

In 1953, at the age of 14, Ed Roberts got polio. For the rest of his life, he could not move his arms or legs -- he was paralyzed from the neck down. In those days, persons like Ed would spend the rest of their lives in segregation -- not out in the community, but alone in a room. Even more limiting, they needed a machine called an "iron lung" to breathe for them. They needed all sorts of help from others just to stay alive.

Ed wanted to change all this. He went on to spend his life doing things: breaking down barriers for himself and others. He graduated from high school (California, late 1950s). Then he graduated from college. He lived on his own and worked out in the community. Along the way, he changed America, working for and winning civil rights for people with disabilities. Below he tells some of his story in his own words:

**2. In His Own Words**

**A. Getting polio (Ed tells his story)**

I got sick with polio when I was fourteen. I had a high fever. Within 24 hours, I was paralyzed and in an iron lung. I heard my mother ask the doctor whether I would live or die. "You should hope he dies," the doctor said. "Because if he lives he'll be no more than a vegetable for the rest of his life. How would you like to live in an iron lung 24 hours a day?" Those first few days were hard.

I was so young. I was fourteen years old. I had nurses doing things for me around the clock. I didn't have to make any decisions for myself. Other people did everything. I had to deal with some hard things at a young age. I decided that I wanted to die. Now, it's very hard to die in a hospital. Everything there is set up to save your life. But the mind is a powerful thing. I stopped eating. They started to force feed me. It felt awful, like they were in charge of my body instead of me. I lost a lot of weight. I dropped to 54 pounds.

Finally, the nurses quit trying to help me. The next day I decided I wanted to live. You see, that was a big turning point. When they all finally left, that's when I realized that I could have a life. I could make choices for myself. That is freedom. I started to eat again.

(From Ed's speeches as remembered by Jon Oda, ed. Bret Hesla)

## **B. Going to High School (in Ed's own words)**

Before I had polio, I was an athlete. I didn't like school. I wanted to be a professional baseball player. But after getting polio, school became my thing. I used to go to high school by telephone. After about a year in the hospital, I moved back home to Burlingame. We had a phone that was connected to the classroom. That's how I went to school for three years.

During my senior year, my social worker and my mother got together and kicked me in the butt. They told me that if I didn't get out of the house now, I would never get out. So I went to the high school for the first time. By this time, I had learned to breathe by swallowing air. That skill let me get out into the world, away from the iron lung. But I was scared to go out and be seen by people.

I remember that first day very clearly. I arrived at the high school during lunchtime. My brother lowered me out the back of the station wagon. It was like people watching a tennis match. Everyone turned their heads at the same time -- to look at me. I looked back at someone, right in the eyes. They turned and looked away. That was when I knew it wasn't my problem. It was their problem. I also learned two other things. First, their looking at me didn't hurt physically. Secondly I realized, hey, this is kind of like being a star. I've been a star ever since.

After my senior year, they told me that I couldn't graduate because I hadn't taken Physical Education and driver training. My mother was so ticked off. "He can sit on my lap. I'll hold the wheel, for heaven's sake," she told them. The vice principal came over to my house. He told me, "Now Eddie, you wouldn't want a cheap diploma, would you?" We kicked him out of our house. My mother took it to the school board. This was my first real fight. My mother was the one who showed me the ropes. When we told the board, they thought it was absurd. They told the school to give me my diploma.

(From Ed's speeches as remembered by Jon Oda, ed. Bret Hesla)

### **3. Following Ed's Example**

Ed Roberts was a person who wouldn't accept limitations imposed by society. By fighting for his rights and by organizing with those around him, he made a path of opportunity for others to follow. Each of us has the same potential. It's good to know that, as we work for our rights both as individuals and as groups, we are not only helping ourselves. We are making things better for others as well, both today and in the future.

#### **EXERCISE:**

#### **Honour a Father (or Mother) in Your Community**

Is there a "Father of the Self-Advocacy Movement" in your local area? Today's the day to honour him. Try having a short moment of recognition at your next regularly scheduled meeting. Thank him publicly and give him a little time to tell about the early days of the self-advocacy movement. Don't forget to do the same for local "Mothers of Self-Advocacy."