Ed Roberts, at Home and At Large

by Lydia Gans

Interviewing Ed at home is like finding yourself on stage during an improvisational theater production. There's the major dialogue going on in this case, Ed giving the interview interspersed with subordinate dialogues, phone calls dealing with Ed's multifarious activities. Meanwhile the several supporting actors are doing Ed's personal care and managing secretarial duties, all freely interjecting their own views on any of the subjects under discussion.

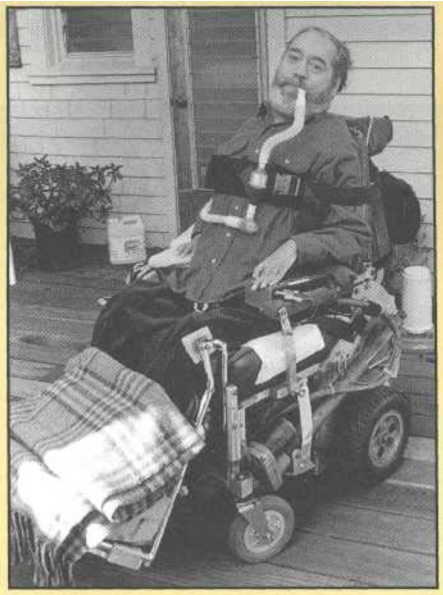
Ed is an eloquent speaker, in public and in private, and is very clear on what his life is all about. He thrives on challenges, on making dreams come true. Let the world say it can't be done, and he will do it.

In 1962, the dream was to live independently. He was among the first to do it as a student at the University of California at Berkeley, and then went on to make it a reality for others. Independent living is his passion. As he talks, John is washing and dressing him and from time to time Ed asks him to move his hand or raise his head or make some other adjustment in the position of his body.

He has another passion and great challenge-being a father. At first he wondered if he would be able to discipline his child, teach him good values, give him a sense of confidence in himself and his world. As he talks about his son Lee, now 15 years old, it is clear that he has been successful. Lee spends vacations with Ed and those are wonderful times for them both. His love for Lee is the most important thing in Ed's life.

The phone rings again, and Mike, who has been organizing some papers, answers and turns on the speaker. It's a local activist and friend wanting to thank Ed for his help in a successful election campaign. This calls for congratulations, advice and a bit of kidding with everybody getting in on the conversation.

Talking is a big part of what Ed does: He talks with politicians, representatives of organizations, members of the media and the public, as well as with disabled people or their families who need help or encouragement. This is Ed at work, Ed the role model, mentor, example to others. He likes being in that position, he says; it's a part of being proud of who he is and what he has achieved.



Ed provides his own job description: "My job is to inspire people, to get them thinking about what really could happen if they were empowered." This mission requires an enormous amount of travel. John begins to leaf through last year's engagement book, reading off trips they made to Daytona Beach, Orlando, Minnesota, Virginia, South Dakota, Dallas, Vancouver, many trips to Washington, D.C., and the list goes on. He loves being out in the world, relishes the diversity of people and places.

For Ed, smooth travel requires having a good attendant, a great attendant. Requisite skills: being assertive with airline personnel, tracking essential items-battery charger, spare batteries and respirators-and protecting the wheelchair against all the terrible things that can happen to it in transit. When he sleeps in hotels, Ed uses a positive pressure face mask for breathing which is different from his tank, the negative pressure iron lung he sleeps in at home. He sleeps well on the road, he says, which no doubt can be attributed to the pleasure he gets out of traveling and meeting people and making things happen around him.

Ed has been doing some coalition building with environmentalists, and has a plan to bring more disabled people into the environmental movement. This connection led to a recent peak experience in Florida, where he swam with dolphins. Ed explains how a special floating chair for him and his respirator was set up so he could check them out. To his great delight, the dolphins checked him out too. They nuzzled and kissed him on the cheek, made eye contact and gave him a distinct sense of communication and understanding. He felt they understood he was disabled and must be treated especially gently. It was a unique and wonderful happening and Ed's face glows as he talks about it.

Mike, ever helpful, suggests organizing Dolphins with Disabilities. "Right," says Ed, "DD's."

Then we move on to other encounters, friends and acquaintances, and somehow Ed drifts into recollections of embarrassing moments. As Mike and John tease him, Ed laughs now about the time he was out with someone he wanted very much to impress. She was wearing a beautiful white dress and was feeding him tomato soup when he dropped the respirator hose out of his mouth into the soup. And then it breathed. It blew the soup everywhere; over him, over her, over the beautiful white dress. " She was so cool about it," he recalls.

Ed has given much thought to the issues of our time, and he possesses the power of words to express his ideas and philosophy clearly. He reflects on the long road that he has come from wanting to die to actively asserting life. His negative feelings about his disability are past, he says, and he has learned to take the anger and use it as energy, because there are still many things to be angry about and that need to be changed. Now he relishes every day.

Much of his satisfaction comes from being involved in what has become a truly world wide movement of people with disabilities. And for himself? It is energizing to have a cause, and aside from Lee, the cause is the most important, energizing and fascinating thing he does. His experience, he says, has taught him to revere life, has made him strong. That sense of affirmation and celebration of humanity and the earth we share touches everybody who knows him.

Lydia Gans is the author of To Live With Grace and Dignity, *a book of photographs and essays exploring the relationships between people with disabilities and their personal care attendants. To order, call 1-800-341-7874, ext. 353.*