

and always have the option of refusing a job they do not want. The arrangement is clearly reciprocal, whether as an exchange of funds or services, and Peter is able to use the system with no residual guilt or obligation. This is not true when his mother is meeting most of his needs. When Peter is home, therefore, he spends a great deal of time in bed reading and sleeping. "It's fine for two or three weeks. I usually need a vacation after Berkeley, but I could never live like that again."

Peter's life since coming to Berkeley has been constantly changing and evolving. "I've had four roommates and I'm now moving into a house with some able-bodied people for the first time. I've had more than sixty attendants and I'll be living in my third place. I've gradually become involved in several disabled rights groups, both locally and statewide. I've become a vegetarian and my hair has gotten longer. I'm well on my way to a doctorate. What I expect is a future of continuing change and growth."

Mary Ann Hiserman

Mary Ann Hiserman is thirty years old. She was born in Salinas, California. Until five years ago, when she came to Berkeley as an undergraduate student, she had lived with her parents. Mary Ann is confined to a wheelchair. At four years of age she contracted arthritis, and at six years of age she contracted polio. In many ways her disability stems from having had these illnesses in childhood. Their effects marked her physical development. She has partial use of her arms and hands and can walk with braces, but with great difficulty. She prefers to use her power wheelchair both in and outside the home. With some assistance she can transfer between her chair and a full-sized automobile. This gives her a certain mobility that more-severely disabled people do not have.

Mary Ann is entering her second year of the three-year professional degree program in architecture. She lives off campus with a female friend, who is also disabled. Mary Ann has a part-time volunteer job with the Berkeley Housing Office. She also does volunteer work in the disabled community and works on the university campus in disabled affairs. She has no difficulty in fulfilling these many commitments, moving freely with the aid of a power chair to school, job, and meetings around city and campus.

Mary Ann has been in Berkeley for almost five years. During this period her self-awareness and the

development of her potential for an independent life have been most remarkable. Until Mary Ann was twenty-two, she had not left the company of her parents, especially that of her mother, who served as her only attendant every day of Mary Ann's life. The overprotectiveness of her home environment led Mary Ann to see herself as severely disabled because she could not develop the ability to look after herself. Today she speaks somewhat resentfully of that period. "Parents have a lot to do with encouraging or discouraging independence in their disabled child. I was not allowed to be independent. My mother went with me wherever I went, even to school and back. And so I grew to need her for everything: to take me places, buy things for me, wash my face."

At twenty-two Mary Ann felt strongly that she wanted to live under other circumstances, even though she was fully aware of her need for the kind of security that home and parents provided. She spent three months at Rancho Los Amigos in Downey, California, a well-known rehabilitation center 350 miles (563 kilometers) from her home. The purpose of being there was to train for a more independent life. Nevertheless she reported, "When I returned home none of my training was of any use. Nothing at home was as accessible as it was at Rancho." She found herself in the same situation she had left. A year later, Mary Ann made a second trip to the center, this time ostensibly to find out about corrective surgery on her elbows. Actually, she was more interested in finding a way to leave home. She remained only two weeks; it was determined that surgery was not practical. Again, she returned to Salinas.

Looking back, Mary Ann feels that two important things occurred while at Rancho Los Amigos. It was the first time she met other disabled people her own age and "had a good time" with them. This was helpful in modifying her fear and disdain of other disabled individuals. Also on the second trip, she learned of the program at the University of California at Berkeley that brought disabled students to the campus. She resolved to join it herself. With the help of interested neighbors at home, she persuaded her parents that she should go. In the spring of 1972, Mary Ann entered the Cowell program. She was then twenty-five years old.

The first few weeks were emotionally difficult for Mary Ann, and though she was soon to adjust, the process of adjusting told her much about herself. At that time "my mental outlook toward independence was pure fright. When I lived at home with my

parents, my mother instilled in me a fear of being alone. When my parents went out or my father was at work and my mother had just gone to the corner store, I had to have someone babysit me. Even when I was twenty-four years old! She would leave me with a neighbor child, four or five years old. I would have to fight her sometimes to let me stay alone for five minutes."

When Mary Ann entered the program, she was the only woman of eleven students living in the program's residence, which was situated on the fourth floor of the student health services building. The setting was reassuring for her. "I probably never would have left home if I'd thought that the Cowell program was anything but a medical program. I wouldn't have felt secure." However, her fear of being alone remained. "I didn't even want to go to classes by myself. I didn't know why I was afraid to be alone, but I was!"

The first week she didn't go out on campus. But within a short time, she made friends with others in the program; friends introduced her to their friends, and as her circle of acquaintances expanded, so did her social and spatial mobility. "Once in Berkeley I had my first truly ongoing contact with other disabled people my own age. I had my first relationships with men. I learned from others and was encouraged to help myself do things."

It was through role models and not through counseling that she and others she knows were eventually able to use their own potential for development of independent lifestyles. "If someone, at that point, had tried to offer me any kind of counseling, I would have freaked out and refused. There are those who want counseling for the attention it gets them, but it never really helps them. You can't talk a disabled child or adult into moving away from home or out of his rest home or hospital before he is ready. Some will succeed in leaving, but they have to be ready themselves. It took me twenty-five years and my friends Gwinn, twenty-seven years, and Alice, twenty-five years, to get up the courage to get out."

After a year and a half in the Cowell residence facility, Mary Ann and a disabled male friend, Lennis Jones (another key informant; see pages 37-40), whom she had met there, took an apartment off campus. Two weeks before she and Lennis were to leave, Mary Ann says she suddenly became aware of how little she could actually do for herself, such as using the toilet during the night, which required

getting herself out of bed, turning her bedlight on and off, or getting a drink of water for herself.

"When I lived at home I had no adaptive aids to help me do things for myself. When I went down to the rehabilitation center I was trained in the use of a raised toilet seat, a bathtub bench, and sticks with hooks on them to help me reach things and pick things up. But when I went home, I was not encouraged to use them. Most of them sat around until I moved to Berkeley."

There were people in the community who had similar needs and who were acquainted with Mary Ann and Lennis. Mary Ann went to them for advice and prepared to move. She and Lennis moved six blocks from the campus into a ground-floor apartment. They took with them the attendants they had engaged while living in the Cowell residence. A memorable experience was waking during the night to find the apartment being burglarized. It was Mary Ann's initiation into one of the meaner realities of independent life. She and Lennis quickly investigated how this had taken place and then took precautions so that it would not happen again.

A year and a half later, marking three years in Berkeley, Mary Ann moved again, this time into an apartment with a woman roommate, also physically disabled. Now, three years later, she is still there. "My apartment is now adapted, though not totally. As I think of how to do things, a new adaptation is added. I can use my stereo, get into my front door, close my door, use the telephone, get water at night, answer the phone at night, turn lights off and on, and so on. These things can all be done with the aid of adaptations. But I also want my apartment to look nice, and not necessarily be in the same building with other disabled people. I like to associate with other people besides the disabled."

Mary Ann's apartment is frequented by others every day. Together, she and her roommate Linda have nine to ten different attendants who come in to help weekly. Linda has a close friend, Ann, who lives part time in the apartment. Both Mary Ann and Linda have friends who come to meals, to spend the night, or to crash for several weeks running. To one familiar with student life, this apartment hardly seems different from any other on the periphery of the campus; but there are important differences. It is a setting in which two disabled women with limited mobility can meet others whose apartments are likely to be inaccessible. Here, a range of social interactions from which they would otherwise be excluded are available to them. Mary Ann's daily routine must be geared to the

Mary Ann Hiserman.

scheduled comings and goings of at least three different attendants. This places her at home with a certain regularity of which friends and acquaintances can take advantage. They come to visit Mary Ann or to avail themselves of her hospitality even when she is not at home. The same is true of the social activity that centers around Linda. Their apartment is, in a sense, a crossroads with both women at its center.

Of importance is the role played by their attendants, each of whom enters the apartment for a period of an hour or two, three to five times a week. Then each fans out into the community, entering into a second or even a third household in the same day. Their contacts with other disabled people and other attendants make them an invaluable source of information and contact beyond what would be possible for either one of the women. Mary Ann, for example, finds she solves many of her small problems by consulting with her own or Linda's attendants, who very likely have seen a similar problem elsewhere in the community.

Mary Ann's relationship with her attendants seems typical of the disabled person who has lived in Berkeley for several years and who "knows the ropes." She, like the others, has come to have definite opinions about what makes a good attendant. She is outspoken about not wanting attendants with formal medical training who typically appear dressed in white hospital clothes and call her a patient. "No one wants them. They make you feel like you're sick, really disabled. They remind you of hospitals and institutions." According to Mary Ann, those with a medical background enter into their work with a certain set of assumptions of what should and should not be done and of what they will and will not do as professionals. Mary Ann feels that this attitude objectifies the disabled person as a medical problem and limits the kind of social interaction with the attendant that might be desired by the disabled person. She likes to regard her attendants as possible friends. They spend time together inside and outside the apartment. Mary Ann feels that she can call on them in an emergency.

Currently, Mary Ann is very much involved as an architecture student. She is the first with her physical limitations to enter the program. After one year she has demonstrated that, though she might have to be assisted with some of the manual tasks, she reaches the same goal as everyone. She hopes, one day, to become self-supporting and to be able to give up her state and county financial benefits. At this time, like other disabled individuals in Califor-

nia, she is caught in the bind of losing benefits if outside income exceeds an amount permitted by the state and county. She feels this seriously jeopardizes her chances for on-the-job training while a student because employers "don't take me seriously when I offer to work for free." Besides, holding a regular job often requires additional expenses, because of her disability, that cannot be met without a salary.

Mary Ann is not sure what her future will offer when she finishes. It may include living in Berkeley, but not until after she has seen other places. She, like others who have benefited by living in Berkeley, speaks of its limitations and her own need to move on now that she feels she has accomplished something.

John McLaughlin

John McLaughlin, twenty-four years old, has hemophilia (factor nine deficiency). In childhood he had bleeding problems which, from time to time, caused temporary disability. Since his illness was not yet identified as hemophilia, he was urged to remain active, to "outgrow the problem." His intermittent experience with disability made him determined to be active and to overcome his "weakness." At age fifteen, 6 feet tall, and an avid tennis player, he had a severe hemorrhage that leaked blood into his spinal canal, leaving him paraplegic and confined to a wheelchair.

At the time of this life crisis, John lived in Glendale, California, with his parents, three brothers—now seventeen, eighteen, and twenty-one years old—and two sisters—now twelve and twenty-eight. His father, an air force officer, was frequently transferred, and the family went along. The experience of having to adjust over and over again to new environments and people is a factor of early life that John cites as important in his development of strong self-confidence. After his injury, which occurred while playing tennis, he left school but then returned to finish. He went on to the University of California at Los Angeles on a Merit Scholarship. He remained there for one year, but found it difficult to manage the multiplicity of problems that confronted him every day.

Leaving college, he remained in Los Angeles, moved in with a married couple, and went to work for the Salvation Army. When neither arrangement worked out, he reluctantly moved into a convales-

John McLaughlin.