

Gary Peterson is both confined to a wheelchair and blind. He has developed ways to cope with both disabilities and work toward a career goal that is uniquely suited to his interests.

Lennis Jones is a traumatic quadriplegic with very limited functions. By skillful management of his environment and his attendants, Lennis attends school and leads an active life. He is extremely dependent upon his surroundings and approaches them innovatively.

Carmen Anderson is the disabled mother of three children. Since the accident that left her a quadriplegic, she has both managed a household and launched a career as a "disabled capitalist."

Tom Dempsey, also a quadriplegic as the result of an accident, is a novelist-journalist who has created an environment in which he can manage without the help of attendants. For him, independence implies not relying on others.

The seven individuals profiled here will be followed throughout the text. Their environments will be examined and their feelings presented. They are, however, only a very small percentage of the more than one hundred disabled individuals and their attendants who were interviewed and observed. The concepts presented and the experiences described were taken from this much larger group and discussed with other disabled people to assure that a wide variety of experiences and outlooks were considered.

Peter Trier

Peter Trier, twenty-six, has been disabled since birth with hereditary muscular atrophy. Although this disease is not progressive, the effects have become more pronounced with age because his weakened muscles have had to support an increasing load. At twenty-six, Peter does not expect to grow, and there is no further potential for muscular development, so his condition is stable. Peter has limited use of his arms. He can use a push chair in a very limited indoor area, but requires an electric chair for all other activity. He requires help in transferring (for example, from chair to toilet), getting in or out of bed, or changing position. Peter also requires a strap to remain erect in his chair while traveling. One of his early fears of living independently was that his head would fall to the side and he would be helpless. The strap does not entirely prevent this occurrence, but his fear of its likelihood has vanished.

Peter is a member of a traveling family. His father was in the navy and moved regularly throughout his early life. The effects of frequent moves on small children—changes of school, lack of parental knowledge and power in the school situation, no stable social group, no predictable future activities or associations—were even more pronounced on Peter, who was not in a position to overcome these disadvantages independently. He feels that he was overprotected by his parents, who were hesitant to let him leave a sheltered environment—a fear he grew to share.

During childhood, his home environment was very limited in order to unobtrusively regulate freedom and to offer greater security. Peter's parents tried to minimize the risks and frustrations in his immediate (controllable) surroundings; the effect was to enable him to lead a relatively normal existence within this shell. Parental expectations clustered around academic achievement, where Peter experienced no limitations. His success reinforced the apparent normalcy achieved in his limited surroundings. He was able to use the telephone, move about indoors in a hand-powered chair, converse, eat, and otherwise participate in family activities.

The freedom within the home also implied security. The carefully controlled environment tended to increase anxiety in noncontrolled settings outside the home. Peter feels now that both he and his parents overemphasized the risks. His approach to new or challenging situations was passive. Barriers were accepted as the natural state of things in the world outside, and because of his reluctance to impose on anyone, he was unlikely to seek help. As a result he lacked the knowledge or willingness with which to approach new situations; an excess of caution kept him at home or on familiar routes when unaided.

The absence of either accessible public transportation or an available source of attendants as he grew up led to continued dependence on his parents to meet his needs for outside activity and contact. Consequently, he either gave up the things he wanted to do or did them less often than he would have liked.

In his early years Peter was never part of a regular social group. The first two schools he attended were specifically for disabled children; when they no longer offered him a satisfactory education, he attended a regular school. His first school in St. Louis was "all right." While limited to disabled students, it did offer some learning opportunities. The next school, however, just gave up. The physically disabled children were grouped with students who

were retarded or had learning disabilities. The role of the teacher was simply to babysit. It took a personal appeal by his father to the school board to enroll Peter in a public school where he could learn at a normal pace. Environmental barriers and inadequate staffing for the special needs of disabled students were the reasons given to his parents for keeping Peter out of a "normal" classroom. In his case, the problems were solved by the assistance of his mother.

In Peter's early school years, his mother did everything that made it possible for him to be in school. She drove him to school every day as there was no transportation, then carried him up the steps into the school, placed him in a seat, arranged all his materials, located reference materials and library books, and otherwise assisted. The school environment provided no support for his needs, and few were met by his hand-powered chair since he lacked the strength to move it more than a few feet. Peter learned at an early age that to succeed in the academic goals set by his parents and himself would require extensive dependence on others to meet his physical needs.

Peter's decision to leave home and seek a more independent lifestyle was tied to his desire to continue his education. He had received an undergraduate degree in philosophy from the University of Arizona while living at home. His parents always encouraged him in academic pursuits, and going away to graduate school was a logical extension of his education. Anticipating that his parents would find this break hard to accept, Peter made elaborate plans with his brother long before he revealed his intentions to his parents.

His approach was to describe going away to graduate school as one of many possibilities under consideration. He wrote to several schools, investigated many programs, and selected the University of California at Berkeley based on the program available at Cowell Hospital and on the educational options. Having made this choice, he drew up extensive lists of everything that could possibly go wrong: he could not find an attendant, he would not be able to get into the buildings his classes were held in, his head would fall to the side in an out-of-the-way place and he could not get help, he would not be able to get to places to complete assignments. Peter then made a visit to Berkeley with his parents. List in hand, they investigated all the foreseeable risks. The major problems Peter anticipated were environmental (barriers, hazards, absence of transportation) and social (how to meet specific needs in

a community unknown to him). The Cowell residence program provided an excellent temporary answer to all these issues. He could live in and operate out of a protected environment with no more risks than he faced at home, while simultaneously investigating the best way to seek a still more independent life in the larger community.

For Peter, the semisheltered environment at Cowell was important for two reasons. First, it allowed him to leave home, assuring his parents that he would be cared for as long as necessary. Second, it gave him a sheltered situation in which to overcome his dependency on his home environment and find new role models for an independent life.

Peter sees the Cowell program as having been rehabilitative in a very limited sense. It essentially placed disabled individuals in contact with one another and provided a place to stay while "you got your act together." The important lesson that it taught him was "If I couldn't do it, it was due to my hang-ups and not to my disability." Having disabled friends whom he cared for and respected increased his self-respect. He could not devalue himself because of his disability if he valued others with similar limitations.

Peter is now a doctoral candidate in philosophy; he has completed his qualifying examinations and is writing his dissertation on Spinoza. He is well-suited to the academic life and is considering a career as a teacher at the university level. Yet the major benefit from his years of education is independence and a commitment to work actively for disabled rights.

Peter is extremely articulate and presents himself well in public. As a result, he has become a spokesperson for groups seeking disabled rights and has become friendly with a wide assortment of people. His participation in the 1977 sit-in at the San Francisco Department of Health, Education, and Welfare (HEW) office to demand passage of the Rehabilitation Act of 1973 was the culmination of an increasing awareness of and involvement in the movement. For him, it was a beautiful experience characterized by shared emotions and loving concern; the depth of commitment of a group who were willing to take serious risks with their health and well-being for the sake of a shared belief moved him profoundly. It created a closeness with others that Peter had not previously experienced. The signing of federal regulation 504 was a victory, but for Peter only a small part of a continuing battle.

In his personal life as well as in his public in-

volvements, Peter is actively seeking to increase awareness and acceptance of disabled people as valued members of society. He stresses the potentially liberating aspects of disability. "When you are disabled you just don't have time for all the false values, the materialism, the 'modesty.' You have to define your values and devote your energy to the things that are important." This philosophy is evident in his way of life.

Peter has chosen to be very direct about his disability. His environment reflects all his special needs, and he makes no effort to disguise special equipment. He has fully accepted his disability, it is part of the only self he knows, and he expects his friends will accept him with whatever supportive devices he requires. He distinguishes between "friends" who come to his home, understand his limitations, and offer assistance when needed and "acquaintances" whom he meets in the world outside and with whom he maintains a fairly normal posture to avoid embarrassment. The boundary between the two types of relationships is a difficult one for Peter (and many other disabled people) to cross. It is built, at least partially, of ignorance and embarrassment. Able-bodied people may find Peter interesting and wish to pursue the friendship, but are uncomfortable with questions they are too polite to ask and are unsure of what limits might be necessary. Peter may wish to pursue the relationship, but does not want to place anyone in an awkward position of having to assist and may be embarrassed at the need to seek help. With people who are familiar with disability, these barriers do not exist.

Peter's home is a first-floor, two-bedroom apartment shared with a disabled fellow student. It is located within a few blocks of campus and is close to a neighborhood shopping center that provides most supplies and services. The unit itself is easily accessible as there are no steps from the street. The entry door is generally propped open. The door into the apartment itself is also usually ajar, but is rigged with lengths of cord and a lever handle to facilitate operating it when closed.

The interior of the apartment is "Berkeley standard": a tiny, inaccessible kitchen with a dining area at one end, a medium-size living room looking onto a planted courtyard, two bedrooms, and a bath down a rather narrow hall and through doorways obstructed by closets. There are few pieces of regular furniture in the apartment; a dining table and two rickety straight chairs in the dining area are used by attendants. The table is too low for either Peter or his roommate to use comfortably. The liv-

ing area originally contained only three out-of-service wheelchairs for various purposes and a high, hospital-type table at which his roommate works, along with overflowing bookshelves. Recently a couch was added, which is often occupied by lounging attendants. The bathroom is not directly used by either person and is carefully arranged with the various items their attendants must find available for expedient care.

The rooms with character are the sleeping spaces of both occupants. The most interesting is Peter's. It is a space about 10 by 12 feet (3 by 3.6 meters). The hospital-type bed dominates the space, along with the high-back custom-made power chair arranged alongside. When lying in bed, where he may spend several days a week recuperating or getting his strength Peter faces the door and sees everyone who enters. If he turns his head to the right, he has a full view of the street through floor-to-ceiling sliding glass doors. This is a good arrangement as there is less of a feeling of isolation during the day when he is alone.

The space, which has no particular character as an architectural design, has been embellished with an array of posters, prints, and drawings. Many of these are over-life-size posters of favorite personages—Paul Goodman, Einstein, Thoreau, Socrates, Christopher Isherwood, Bertrand Russell, Murray Rothbard, and two basketball players. There is also a painting of Peter by a friend and drawings by various children. The impact is personal and lively. The portion of Peter's room not filled by the bed is occupied by piles of books and papers, references, and portions of work in progress that he keeps easily visible so that he can direct attendants who place current materials within reach. Peter's life and his apartment in Berkeley have been carefully tailored to meet his needs.

When Peter now makes visits to his parent's home, many of the situations that existed as he grew up are still in effect. Peter's mother is very reluctant to permit him to have attendants or use outside help when he is in her home; she is insulted at the implication that she cannot provide for his needs. Realistically, as she ages, it becomes increasingly difficult for her to lift and otherwise assist him. It is also true that his needs and expectations have changed. The relatively independent life he is able to lead in Berkeley is based on a support system of attendants, drivers, friends, and roommates who meet his regular needs. Peter also has an extensive list of helpers for special needs or emergencies. All the people forming this service network are paid in some sense

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 state-wide. 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."