



Design for Independent Living

**The
Environment
and
Physically
Disabled
People**

**by Raymond Lifchez
and Barbara Winslow**

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For the Center for Independent Living

It is not without reason that the world of physically disabled people in our society is cloaked in mystery. It is a historic truth that a society will isolate those who jeopardize the collective image of what is desirable in life, and physically disabled people are a case in point. They raise the specter of our own frailty and, in America, create a certain guilt that with all our belief in community we cannot contain them, with all our technology we cannot "heal" them. The authors believe that much of this anxiety can be alleviated by demystifying that world, for it is a fact that fear is largely born of ignorance. It is toward this end that this book is dedicated.



Foreword

In this book we are introduced to a group of physically disabled people who, escaping lives of safety and isolation, are seeking independence and community. Raymond Lifchez and Barbara Strong Winslow liken them to immigrants coming to a foreign country. Berkeley, California, is the land of the free; it offers a fair degree of accessibility and an unusual degree of social services. A community of people has grown up whose members travel in electric wheelchairs and live their own lives in their own self-determined lifestyles. In a city of many cultures, they have formed another.

The book has an unusual approach to environmental design, in that it overlaps with sociology and anthropology. It builds empathy with a group of

people with whom most designers have no familiarity. This not only can increase our respect for wheelchair-bound disabled people and stimulate an intention to include them in society and the built environment, but can also promote an attitude of awareness towards special groups in general—children, the poor, the elderly. Our definition of the norm is enlarged.

I recommend this book to those who are politically and sympathetically interested in making better environments for disabled people. These would include the general public, as well as architects and planners, social scientists and medical professionals.

Sarah P. Harkness, AIA
The Architects Collaborative, Inc.
Cambridge, Mass.



Center for Independent Living: a center for Berkeley and an emerging center for the physically disabled coalition in the United States.

Introduction

Berkeley, California, is a much talked about community: an important resident center of counterculture in this country, the home of an internationally known university, a focus of liberal thinking and liberal lifestyles. Under sometimes foggy skies, it sports a year-round temperate climate in an attractive physical setting of bays, views, and hilly landscapes. As an inhabited place, it resembles more-rural communities in that small businesses still outnumber large concerns or chain operations in the shopping districts and individual homeowners in individualized dwellings outnumber those in multistoried apartment complexes. But Berkeley has certain similarities with large cities in the assortment of cultural and social events and activities available, in the mixture of ethnic and subculture groups, and in the general urban pace of public life. It is a special place where one can drink very good espresso, learn Zen meditation, and phone one's political representative all at the same time. As Charlotte Painter put it in her book about Berkeley, *Seeing Things*: "Paris it is not, but also it is not foreign. Or Godforsaken like New York. Some say rather that it is God-infested."¹

Geographically, Berkeley consists of two distinct districts: the hills and the flatlands. The center is the university—the University of California at Berkeley. Demographically, a further distinction can be drawn between areas south and north of the university. The area south of the campus is occupied primarily by students. There is more low-cost rental housing, a higher crime rate, and many people who identify with a counterculture lifestyle. The heartbeat of the area is Telegraph Avenue—a strip of small shops, inexpensive restaurants, bookstores, coffeehouses, and so on.

The area north of the campus is primarily occupied by more conventional families. The population is older, mainly professionals and professionally oriented people. Many students attend the various religious institutions located on this side of the campus. Here, the terrain is hilly, the foothills of the "hills" section to the east and north. Shopping and services are dispersed, and both are more expensive than on the south side of the campus.

Of particular interest is that Berkeley, with its

counterculture reputation, liberal attitudes, hills and flatlands, is also a center for physically disabled people. This disabled population is concentrated on the south side of the campus and toward the flatlands. Here the terrain is more suited to those with impaired mobility; the housing is cheaper and older, more easily modified; shopping is concentrated; the able-bodied population is younger and consists, in general, of a mixture of students and others with a certain counterculture spirit and lifestyle. Perhaps these attributes provide a more appealing attraction for the predominantly young, disabled population that lives there. Disabled people often point out that they come to Berkeley precisely because varied and deviant lifestyles are accepted. They feel that this society will be open in accepting them; that they can, in a sense, go relatively unnoticed in this environment of "freaks."

There has been no exact census of the disabled population in Berkeley. The Research and Evaluation Division of the Center for Independent Living (CIL) determined in 1973 that there were about 12,000 disabled people between the ages of eighteen and sixty-four in Berkeley at that time.² These people live predominantly in an area of approximately 2 square miles (5 square kilometers), with Telegraph Avenue its center.

It is along Telegraph Avenue that disabled people are most visible in numbers. There the obvious, taken-for-granted freedom and independence of disabled people is quite astonishing. With the help of electric wheelchairs, prosthetic devices, and good attendant care, many of the disabled population go everywhere and do everything. And, perhaps what is more significant, once they get where they are going, they become an integral part of the activities of urban life. They are present in coffeehouses, restaurants, parks, theaters—drinking coffee, dining, sunning, passing time in conversations.

If one views street and city life as a visitor, this presence and integration of disabled people into community life might only be a matter of passing interest. However, if one is concerned about the environmental adaptation and accommodation for and by disabled people, this phenomenon is of paramount importance. Here is a population com-

monly thought of as shut-in or institutionalized, living a free and active life in the public world.

What has happened in Berkeley? What is the role of the environment in determining this phenomenon? Are there environmental or social approaches characteristic of Berkeley that would work as effectively in other communities? Can knowledge gained about Berkeley be used to help create more communities offering full access to disabled people? And, more important, since the disabled population appears to be so well integrated, leading full social, work, and political urban lives, what can be learned from Berkeley that would encourage or enable other disabled people to have richer experiences in the world?

If one is planning environments or policy for physically disabled people, the Berkeley of today is an appropriate place to learn about these environmental needs. But for Berkeley to serve as an example, it must be approached conscientiously. Aspects or attributed meanings of Berkeley that are unique should not be stressed. For example, physical or climatic conditions indigenous to Berkeley should not be accented because their applicability is limited. Such conditions are exclusive and cannot be altered or changed by the exertion or desire of those who live there. That which makes Berkeley special as a place is what people have accomplished or are in the process of accomplishing there. What must not be suggested is that to become independent, disabled people must come to Berkeley. Nor do places have to become exact copies of Berkeley to assist disabled people. Independence can be pursued and achieved in many places. It must, like all human acts, originate in the individual. Berkeley is only an example of what can be achieved and what the process of achieving may entail.

The aim of this book is to aid designers, planners, students, and others concerned with the design or planning of the built environment in developing an approach to integrating physically disabled people into the fabric of their communities. It is also intended to give others who are not specifically concerned with this issue some perspective on what it means to live as a disabled person in a world that has been conceived as a setting for able-bodied people.

This book originated in 1975 with a course in the Department of Architecture at the University of California at Berkeley. For some time we had been concerned with issues related to environmental access for special populations, such as the frail elderly

and physically disabled persons, and we decided that major problems of access were confronted by those who use wheelchairs. We therefore set aside an eight-week period to look at this question closely in the company of those who use wheelchairs.

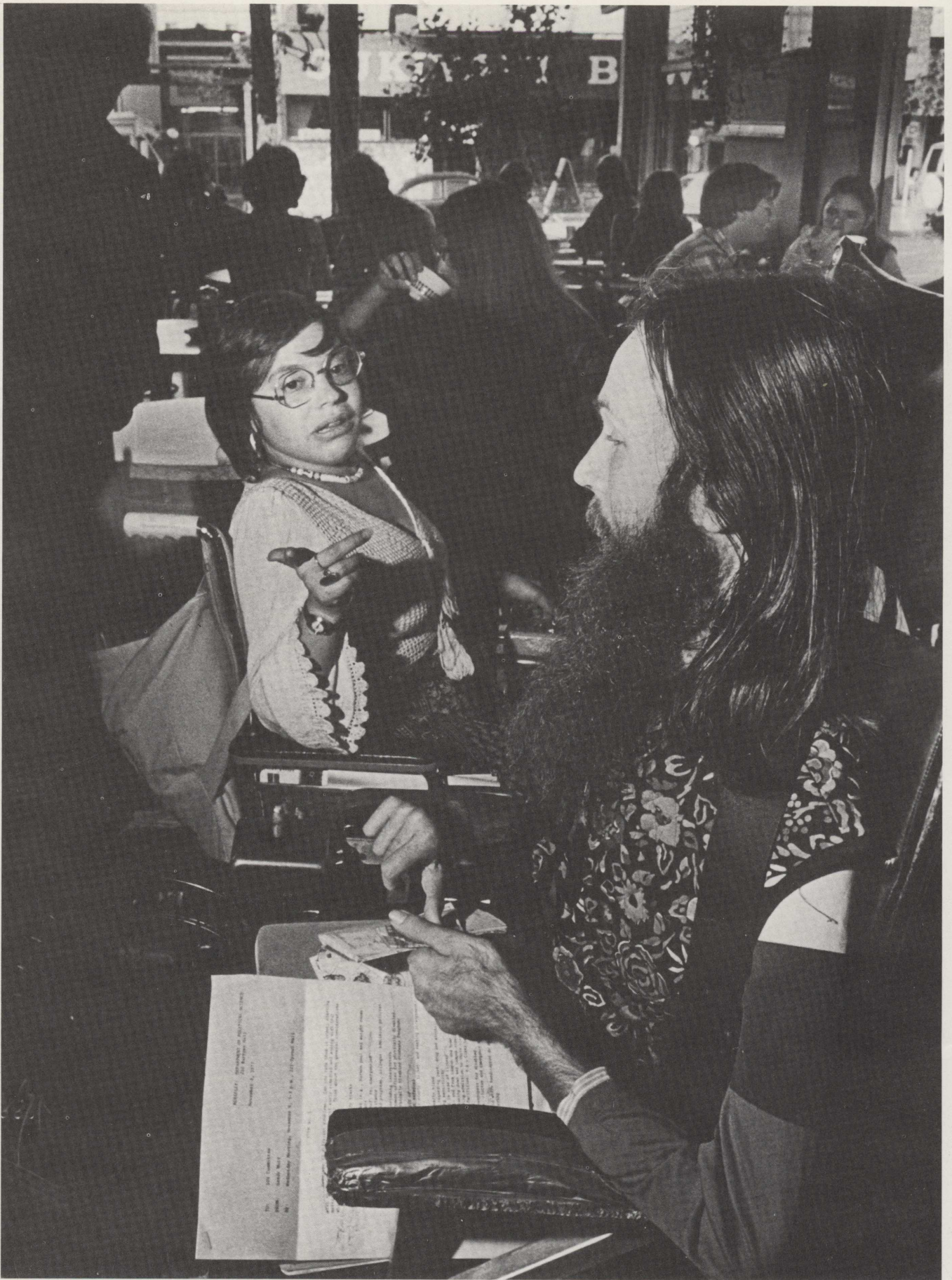
The "client" for that course was the Center for Independent Living, which was examining the possibility of building barrier-free housing in Berkeley to ease the severe shortage of accessible facilities and accommodations. The project was assisted by a dozen disabled consultants who spent a great deal of time and energy discussing, evaluating, formulating, and communicating their environmental needs, both spatial and psychosocial. The information gathered in this process proved, as expected, very useful in the design task for which it was intended.

It was, to say the least, a consciousness-raising experience for all. The consultants, often for the first time, examined the spaces they occupy, their environmental values and biases, and the emotional as well as the physical demands that they placed upon their surroundings. The designers found themselves involved in a process that demanded an understanding of the whole person and his or her interaction with others. The screen through which we usually filtered our view of those different from ourselves became a real barrier to effective design. Solutions that were based on dimensional or purely physical requirements were rejected as inadequate. And attempts to find useful sources to guide the design process were fruitless—the only effective resource was the consultant group.

Like all people, the disabled consultants wanted to influence their lives and their physical, lived-in worlds. They wanted their lives and their environments to say something about themselves—to say what they valued. And what they valued was independence, deinstitutionalization, and freedom from the stereotypical images that they felt limited their hopes and growth. Each had had experiences of living in places, rooms, and buildings that said little to them, or nothing worth listening to. Each had had to exert considerable effort to determine how the environment should be altered and changed so that it afforded an opportunity and a potential for living a fuller life.

At the end of that summer we who taught the course began to see Berkeley through new eyes. We assume that the same desires for an independent, fuller life exist throughout the country: that given the opportunity, everyone, disabled or not, would

prefer a lifestyle that offers not only choices but also a sense of belonging, that is, a sense of being a meaningful part of all that is taking place in any physical location. Making this happen for disabled people requires an understanding of their environmental needs that goes beyond meeting government regulations, building ramps, or adapting bathrooms and kitchens. This understanding—how it can be disclosed and incorporated into the designed world—is what this book is about.



Part 1

Disclosing an Ongoing World

There are very few communities in the United States that give disabled people the resources necessary for independent living. Berkeley, however, has become identified with a social, political, and physical environment that is highly supportive of this goal. The Berkeley image has grown measurably over the past several years, and each successive newcomer confirms that this image remains strong in the eyes of others across the nation. And by coming to Berkeley, each successive newcomer confirms that the Berkeley image is genuine.

In each case those who have come have altered their own environments in order to support their way of living independently. Independent living and the environment are made congruent. Thus Berkeley has been given additional meaning as a place because physically disabled people have chosen it and by their choice have affected it.

Mainstreaming in Berkeley

Over the years, programs and informal service shops have been developed in Berkeley by disabled and other interested people to assist those who wish to become independent. In the early 1960s a residence program for severely disabled students was initiated in the student health center, Cowell Hospital, at the University of California. Although the program was located in a medical facility, it was not completely devoted to medical care. The disabled residents lived separated from the wards and were obligated to find their own attendants among the community and, in general, to regulate their own lives. The hospital was there when needed. Around 1970, however, those living in the Cowell facility began to move out and to live in the community, for it was unavoidable that living in the health facility would eventually be seen as a compromise solution to full independent living. In 1975 Cowell was closed, and today those severely disabled students new to the campus who prefer a period of transition between institution or home and a fully independent university life may spend their first year as

Paris-Vienna-Berkeley: the coffeehouse continues its historic role in planning and shaping society.

Berkeley students in one of the regular residence halls among able-bodied students. This transition period is made possible by a university back-up system of attendant care within the residence hall. Through this route perhaps a dozen severely disabled individuals begin their first experience of independent living each year.

One of the first students in the Cowell program and several of his classmates founded the Physically Disabled Students Program at the University of California to further assist disabled students. It was predominantly this same group of people who later founded the Center for Independent Living, Inc. (CIL), in 1972 after they had graduated from the university. CIL functions as a workshop and growth center for the physically disabled people of the east San Francisco Bay area. With the university, CIL is the most important aspect of the Berkeley image. At some point in his or her life in Berkeley, every disabled person enters the CIL, and at almost every point each one benefits by the presence of this organization in the city. For example, when the city of Berkeley and the university began programs to make the town and campus environments more accessible, much of the political impetus and knowledge for doing so stemmed from CIL's activities.

What is significant is that these social and environmental changes and movements have been brought about by the physically disabled population itself expressing its own needs. That disabled people have effected such changes, not just in their own lives but in society at large, is impressive. It forces one to speculate on the changes that other physically disabled people, who for whatever reasons live institutionalized lives, might effect on their environments if given some model for doing so.

The authors believe that *mainstreaming*—a term commonly interpreted to mean that disabled people should have opportunities similar to those of the nondisabled—has a broader meaning than just noninstitutional living. In fact a significant insight gained from writing this book is that our perception of mainstreaming has changed. We now perceive that mainstreaming can be as much a state of mind as a way of acting in the world, and it may, under the right conditions, be carried out anywhere. Of

the disabled informants who made this book possible, all had some history of institutional care before coming to Berkeley. They believe that disabled people who require long-term care in residential facilities can also mainstream, though they feel that the impetus to do so may have to come from the institution itself.

Long-term care facilities are not exactly known for their social and political programs. In fact, they seem to be devoted to only one purpose: maintaining biological life. And in this society, which places great emphasis on social and political involvement and productivity as aspects of the whole life, biological care is indeed a reductive program. To focus only on the maintenance of physical health is too narrow a program for the development and sustenance of human potential. So that those who are institutionalized can mainstream, the institution must have the avowed purpose of keeping its residents in the world: the capability for productivity must be enhanced by real programs related to the marketplace (not reduced to arts and crafts); and interest in the affairs of society must be operationalized by allowing the residents to take part in these affairs (not reduced to voyeurism via television sets). The requirement for mainstreaming is that people be truly in the world, spiritually and mentally, even though they may not be on the street or entirely on their own. No matter what an institutional program is, if it does not have this avowed purpose and the means of implementing it, it becomes nothing more than a warehouse. And it is largely for this reason that all the disabled people who contributed to this book have rejected institutional life.

In certain cases, by choosing to mainstream informants also rejected homecare by relatives. But that choice was not based so uniformly on the same jaundiced view as that of institutional life. While living at home, a disabled person is not necessarily a shut-in; there is always the potential for mainstreaming if the caring can accept such a role for their disabled relative. Effort needs to be directed toward the maintenance of social and political ties with the outside world that parallel those of the family itself. However, it is important to recognize that mainstreaming works both ways: both parties—those cared for and those caring—must continually look outside their immediate environment for interests and relationships. Families often keep their disabled relatives at home at great financial and emotional cost, but this kind of heroism is only acceptable when it does not disable the caring

themselves. When caring for the physical well-being of the disabled person becomes an exclusive pursuit, then the act of caring can become a damaging sacrifice that may prevent any of the people involved from mainstreaming. In many instances the informants chose to leave home—to mainstream—so as not to jeopardize their family's potential for mainstreaming as well.

The Interactionist Position

The research orientation that provided the theoretical and practical framework for this book is the stance in the social sciences that is called *interactionism*.¹ What is most applicable in interactionism is that the individual is regarded as an active agent, determining the nature of his or her world by giving meaning to it through his or her interactions with it. Interactionism is a commitment to seeing and accepting meaning in the physical environment in terms of the ongoing dialogues and acts of human beings.

The interactionist position is synonymous with an empathic commitment to understanding another person. Interactionism is not observing; it is being with. An important aspect of the stance is that through empathy one conveys that one values the other person and his or her world. As Carl Rogers has said, "It is impossible accurately to sense the perceptual world of another person unless you value that person and his world—unless you in some sense care."²

The research strategy for this book has been mainly a form of the psychosocial interview; we talked with disabled people and have been present in their world without using a prescribed formula to interpret it. A portion of the material was obtained by participants who were physically disabled. However, we chose to collect most of the data as able-bodied individuals and not by posing as disabled people. Role playing would have been a limiting experience; and those who are physically disabled do not confine their activities to events or situations with others who are disabled. In view of the aim—to disclose the meaning of the physical environment to its inhabitants—the researcher's relationship to the world into which he is looking should be one of *empathic presence*. If the researcher is genuinely concerned about the lived experience of disabled people and honestly respects it, then his or her picture of that world will be very close to the world as it is experienced by disabled people.

From among the many disabled people inter-

viewed, seven were singled out who were designated the *key informants*.³ Part 2, Profiles, is devoted to these people. The selection of the key informants was an instrumental step in uncovering environmental needs that have implications for proposed and planned environments for the physically disabled population. For, as with any other population, disabled people who use wheelchairs do not share the same personality. Nor are they a group or a gang with corresponding traits and characteristics. Some are determined, some are not, and others represent all the stages between the two extremes. The key informants had to be those whose acts and biographies revealed active wants and the accomplishment or the state of accomplishing personal goals. They pointed the way by their adeptness in identifying, constructing, and using meaning in their environment.

From the seven profiles and many other encounters with the disabled community and the community at large comes Part 3, Networks. This section recognizes the more formal networks, principally those of government and private agencies, which provide disabled people with social services, but it focuses on the other contacts that assist or contribute to the social life of disabled people. These contacts are most evident in grassroots organizations initiated and maintained by disabled people themselves. When viewed as a network, these indigenous organizations and their linkages are the context in which Berkeley is distinguished by disabled people from any other place.

In Part 4, Places, the environmental supports necessary for living independently are reported. Environmentally, this is the most significant section.

Disabled people historically have been subject to environmental deprivation. Physically and socially, they have been confined to a limited number of settings. In Berkeley disabled people are expanding their horizons, introducing new environments as well as changing old ones for new needs. This section is organized according to the framework of archetypal places developed by Mayer Spivack, who has proposed thirteen places that he feels must be accessible for one to lead an optimal life.⁴ This schema has been employed not only to organize the data but also for purposes of comparison, so that disabled people can be seen in relation to an optimal human schema.

In Part 5, How to Research, we pose some questions to ourselves as designers: beyond taking a position, what can we tell other designers who wish to design environments that are truly barrier free? What tools and methods are available for understanding those who are different from ourselves, so as to proceed with that understanding in our professional work? In Part 5 four ways of gaining an awareness of the environmental needs of others unlike ourselves are described, using physically disabled people as a case in point. We discuss techniques and methods for gaining an awareness which we feel comfortable with and which we have used in our professional work and teaching.

The Epilogue contains a few essential thoughts that came to mind only after the study was completed. Finally, a photographic Catalogue gives some clues about how simple it is to alter the environment to make it work if time is taken to observe how people do it for themselves.