Chapter One

Introduction:
The Field, the Questions,
and the Researcher

Throughout much of the world in our times there has been a dramatically heightened awareness of the existence, and the due rights, of people who have been traditionally repressed. These include people of ethnic minority status, people of various sex and age categories, people of unusual physiology, and others. Anthropological and sociological research has attempted to keep abreast of this tide, and considerable effort has been directed to pertinent areas of specialization, such as ethnicity and gender. The present work seeks to contribute to one of these emergent fields of inquiry—the anthropological study of disabled people.

Disability studies are one of the more recent of the new socioanthropological specializations. The basic premise of disability studies is that physical conditions do not, by themselves, determine the roles and positions that disabled people fill in society. Rather, it is the culture of both able-bodied and disabled people in any given society that conceptualizes and moulds conditions of disability. According to this view, disabled people fill roles in society that are an outcome of cultural mediation. This theoretical anti-positivistic stance is not unique to disability studies. It pervades current studies of gender, ethnicity, and much of the range of contemporary social science. In the present work I extend that perspective, to explore in detail the social construction of one particular disabling condition, that of blindness.

The juxtaposition of apparently synonymous terms, "sightless" and "blind", that figure in the title of this work encapsulates the contemporary theme of disability studies, in the context of blindness. In both popular parlance and in that of professionals specializing in sightless people, the terms "blind" and "blindness" are much more common than the terms "sightless" and "sightlessness". This usage

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reflects a particular facet of Western culture: people who lack sight are not viewed by the able-bodied as merely people who have a condition of limited physical disability. Rather, they tend to be viewed as people in whose existence sightlessness is all encompassing, overarching, total. The condition of sightlessness is symbolically enriched and magnified, sometimes mystified and even demonized.

Thus, in popular culture, delimited sightlessness becomes "blindness". That familiar term conveys much more than a particular condition of physical disability. It carries, in addition, a rich content of attributes—beliefs, prejudices, fears—that culture has associated with sightlessness in many (perhaps most) times and places. The peculiarity of the symbolic elaboration of sightlessness is not unique to that condition. Such conceptual elaboration of the environment in which humans live is a fundamental element of the cultural process, and lies at the root of belief and social order. Some of the finest achievements of cultural and social anthropology entail uncovering this process. In the context of the present study, it is notable that conceptual elaboration is common to many disabling conditions. The hearing impaired are considered "deaf" in popular parlance, sufferers of Hansen's disease are "lepers," and a great variety of muscular and orthopedic disorders lead people to become "cripples" in the general cultural understanding.

In a different but not unrelated way, some of the major diseases of our times, such as tuberculosis, cancer and AIDS, have become richly symbolized. These diseases have become metaphors for attributes that popular imagination attaches to patients, as has been eloquently described by Susan Sontag and others. Why some physical conditions capture the imagination in this way and others not, why some to a greater and others to a lesser extent, is imperfectly understood at this time and remain major open questions. There are great differences between various societies in these matters. Thus, deaf people were not considered at all remarkable in a nineteenth century New England locality described by Nora Groce (1985). Impairment of hearing was not much elaborated by culture and symbolized in that society.

Sometimes dramatic changes within the same society occur over time, as Zachary Gussow (1989) has demonstrated in connection with Hansen's disease in the United States, which became increasingly enriched in terms of symbolism in the nineteenth century. John Gwaltney (1970, 1980) who studied in the 1960s and 1970s a Mexican village afflicted with a high incidence of infectious blindness, has depicted the original remarkable social integration and acceptance of blind people among the sighted. However, as a result of certain socioeconomic developments in that village, the niche that blind people filled disappeared and their position in society changed markedly.

The upshot of this is that in real life one rarely encounters "sight-lessness". The latter is primarily a heuristic term that can serve the description of human physiology. But it is not an apt term for medical discourse since that is infused with cultural and social considerations, as medical-anthropological research in general has demonstrated. In real life one usually encounters people whose sightlessness has been conceptualized and symbolized in various ways, in short—blind people. The term "sightless" is of even less use in a discourse, as the present study is, focused on socio-cultural matters, than it is in medical discourse. In fieldwork I did not encounter sightless humans, but blind people (more particularly, blind Israelis). Hence it is the latter term that figures in the main title of the study and that recurs throughout the discussions that follow. My purpose in retaining the bland physiological term in the subtitle is to highlight the analytical thrust of the study, the socio-cultural construction of a physical condition.

Blind people occupy a particularly salient position in the Western popular imagination. Of all people afflicted with disabilities and diseases, the blind probably attract the most attention from the able-bodied. The contents of a recent review of disability drama in television and film (Klobas 1988) illustrate this well. Of 435 pages of reviews, material featuring blindness fills 113 pages and constitutes the prime quantitative category of all disabilities. Blindness also constitutes, for those who are so inclined, a convenient avenue for the expression of altruism. Considerable resources often revolve around blind people, mediated by voluntary benevolent associations. Such associations are often well endowed, both in finances and in manpower of eager volunteers. This lies, I suggest, in the fact that blindness can be readily conceived as unambiguous, more so than other, far more common physically disabling conditions.

Many afflictions, such as muscular degeneration, brain damage, hearing impairment, not to mention debilitating internal conditions, are not readily visible. Often they are highly variable and undefined. To the extent that those conditions are visible, they manifest themselves through a broad range of symptoms that differ from person to person. In the Western popular imagination the overt behavioral manifestations of those conditions are not always readily linked to the conditions. Sometimes popular imagination links the manifestations to irrelevant moral attributes. Thus, the behavior of people with spastic disorders is prone to be popularly interpreted as clownish, that of brain-damaged people as immoral, that of deaf people as feebleminded. (In Jewish rabbinical law this is expressed formally: In many contexts the deaf are categorized together with the feebleminded and with minors.) The outcome of this is that there is a tendency in many

times and places in Western society to arbitrarily impute various negative moral attributes to certain categories of disabled people (as demonstrated in the Klobas review; for two erudite reviews of the Jewish rabbinical material concerning blindness, see Cohen 1982 and Steinberg 1983).

Blindness is more varied than is popularly realized, and comprises a spectrum of visual impairments which includes many kinds and degrees of residual sight. Moreover, the sensation of the eyes as physical organs, even when sight is totally absent, is variegated, and people often suffer from pain in the organ. However, blindness has an essential distinctiveness and lack of ambiguity relative to other conditions. There is an immediate visible link between the condition and its behavioral manifestations, such as impaired mobility and lack of ability to read print. These clear-cut manifestations lead sighted people to overlook the forementioned details, within the condition of sightlessness, that blur the clear-cut image. The result is a stereotyped image of the condition which includes incorrect notions, such as most blind people being blind congenitally, and that they "live in darkness." This popular clear-cut image of blindness leads that disability to be an attractive object of philanthropic attention on the part of the able-bodied.

More precise elucidation of the problem of why and how various disabilities are conceptualized in society in different ways is a desideratum. Beyond its importance in the study of disability this problem leads on to some of the most profound issues of culture and society: the nature of symbolization, of fear and of belief, and the social sources of discrimination and disempowerment. But before significant advance can be made at the general level, we require limited and detailed accounts of symbolization of particular conditions, located in time and place. In the present work, my aim is to uncover how the social status of sightless people figures in social interactions; how sightlessness influences the exercise of tactile and other senses and at what social cost people engage in them; what stimulates sightless people to experience degradation and respect; what is the range of permissiveness that the sighted permit the sightless and what is permitted among the sightless themselves. In all these questions, the concern is to shed light on the symbolization process that occurs in interactions between able-bodied and disabled human beings who are situated in an environment that is governed by the former. In short, I seek to illuminate how sightless people act in a realistic context as blind people.

Such questions, varying in formulation along with different contexts and cultures, are the staples of the socio-anthropological endeavor. They are fundamental for understanding a vast array of hu-

man experience, irrespective of particular culture or specific physical condition. The focus in this study is on people, Israelis, who happen to be sightless. The disability is a very important element in their existential experience, but it is not the sole element. The aim is to convey the variety of humanity of these people, in a way similar to that in which anthropologists have described many other people, uncovering the commonality with other humans together with the uniqueness. This study aims to strike a balance between two extreme positions on blindness, both of which I consider misguided. One is the position of uninformed sighted people, who view the sightless in stigmatizing terms, mystifying the disability, and transforming specific sightlessness into diffuse blindness. The other position is that of some disability-rights activists who minimize disability, trivializing sightlessness by slogans such as, "Blind people are like everybody else; they just don't see," or "Blindness is an inconvenience, not a handicap."

The purpose of this monograph is to fill a lacuna in ethnographic coverage, the study of people who differ from most humans by having exceptional bodies, and whose culture usually disempowers them. The approach contrasts with that of remedial practices, such as rehabilitation and social work, not only because of the absence of a spotlight focus on disability, but also because in my role as anthropologist, I do not view blindness as "a problem" that requires eradication, so that people "cope" and "adapt successfully." In this study I adopt an intellectual stance that requires some courage: blindness is viewed dispassionately, as an interesting fact of life.

Despite the fact that socio-anthropological interest in disability is recent, there does exist a steadily growing body of literature. Several of the major disabling conditions have now been described by pioneering students who opened the field. On dwarfism there are two monographs by Joan Ablon (1984, 1988), on deafness the works of Gaylene Becker (1980), Paul Higgins (1980) and Nora Groce (1985), on epilepsy there is the work of Peter Conrad and Joseph Schneider (1983)[1], on mental illness Sue Estroff (1981), and on mental retardation Robert Edgerton (1967). These are just some of the monographs; there are also illuminating shorter accounts of other conditions. There are, for instance, notable papers on management strategies of stutterers among fluent speakers (Petrunik 1974), and of obese people among normal sized (Himelfarb and Evans 1974). In a more recent collection there are fine papers on identity management of people suffering from end-stage renal disease (Kutner 1987) and urinary incontinence (Mitteness 1987).

Also the socio-anthropological study of blindness has attracted some attention. The major study of the United States scene remains

Robert Scott's *The Making of Blind Men,* and there is the
forementioned ethnography of blindness in a Mexican setting by John
Gwaltney, *The Thrice-Shy,* both works of the late 1960s. In the past
thirty years at least forty social science oriented doctoral disserta-
tions on blindness have been approved in the U.S. Perhaps the most
insightful are those of phenomenologically-oriented sociologists and
social anthropologists, such as Stephen Ainley (1981) and Carol Goldin
(1980). Most of the dissertations are frustrating, however. Their per-
spective is mostly that of individual psychology, which implies the
examination of limited issues as dictated by the concerns of psycho-
logical theory. The other main line of research in the dissertations is
that of social work, which is geared primarily to interventive practice,
and only secondarily to an elucidation of social fields as such. A third
line is that of demographically-oriented sociologists, who have gath-
ered potentially valuable data, but due to their limited theoretical
concern, the data do not bring much insight to the field.

The method of this study is that of informal ethnographic obser-
vation. One must address therefore the question as to whether Israeli
blind people form social groups that are amenable to such observa-
tion. In general, although they are far from fully integrated into
many of the relationships that engage sighted people, blind people do
not usually congregate in secluded groups of their own. However,
powerful impulses that emanate from the able-bodied aim to segre-
gate blind people and to thrust them into particular social niches.
The issue of grouping among blind people is therefore an important
one, even in settings where no such grouping is overt, and it will be
discussed later (chapter 10). At present it suffices to note that the
conditions of the field lead me to engage in extensive individual visit-
ing, and also to observe and often participate in organized public and
semi-public settings in which blind people participated.

The study is based on fieldwork of about fifteen months' dura-
tion, from July 1983 to October 1983, and from January 1984 to
January 1985, among a population of blind people in the Tel-Aviv
area. The data and analyses that follow reflect the conditions of that
period, but it is my general impression that changes since then have
not been remarkable. All the people of the study were adults, the
youngest being in their twenties and the oldest in their early sixties. I
endeavored to uncover the nature of adult blindness: the population
includes only people who lost their sight during their teens at the
latest, before completing socialization to adulthood. These people had
to grapple with concerns of adult life as blind people, including such
crucial matters as the quest for work and spouses. The delimitation
of the field thus excluded army veterans, among others, since they
lost their sight as adults. Definition of blindness in terms of ophthal-
mology is complex, and actual conditions of so-called blindness are

variegated. The working definition that determined my own selection of people in the field was a functional one: people who required one of the standard mobility aids when travelling.

The people whom I selected to visit and befriend, and sometimes just to interview, were not statistically random. My initial entries into the field were through initiating contacts, separately, with the sighted manager of a sheltered workshop, and with a blind activist who headed an advocacy group. Eventually, people befriended me and led me from one acquaintance to the next. My universe of blind people came to number fifty-seven individuals, spread over numerous socio-occupational niches, of varying family status, and differing ethnic background. These people are fairly representative of blind Israelis with the exception of two minority categories, people living in outlying areas in the north and south, far from the metropolitan areas, and Israeli Arabs.

With eight of the people of the study I maintained, together with my wife, a mutual family-based relationship and exchanged visits and many telephone conversations. In research practice I was as unobtrusive as possible. I tried to avoid posing direct questions and preferred eliciting information by leading conversation indirectly onto topics that intrigued me. In particular, I sought information that stemmed from behavioral and verbal interactions in which both my wife and I were relatively passive. Twenty individuals we came to know well, but less than those in the first category. We visited them a few times at home and/or observed and interacted with them frequently in other settings. Twenty-five of the remaining people I knew only superficially from single or small numbers of visits or observations in various settings. Information about four individuals whom I never visited is also occasionally introduced into the study. Most of these fifty-seven persons were between thirty-five and fifty years old, about equally divided by sex.

I participated in several locales of blind people. One was the sheltered-workshop in which I worked on the shop floor virtually daily, threading steel nails into plastic rings, for the duration of three months. Another such setting was a social club that operated thrice weekly, a third one was that of the national association of blind people. There was also a circle of people who met as a kind of encounter group (they called themselves "the psychology circle"), and in which I participated for over a year as the single sighted member. Several other groups that I visited only irregularly will be mentioned later in the accounts. In all I interacted with, and came to be known to, well over a hundred blind people.

In the course of this fieldwork I encountered reservations from my professional and social ambience, such as I had never faced before in the course of a professional career that has spanned three decades.

Virtually all my colleagues queried as to what could have brought me
to study the blind of all people. In the past, when engaged in main-
line Middle-Eastern anthropology, studying immigrants, I was rarely
asked such a question. Some of my colleagues were skeptical of a
sighted researcher being able to study blind people, and one distin-
guished colleague strongly advised that I ought to experience living
with a blindfold. I continued to encounter reservations to the study at
later stages when I submitted papers that emerged, for publication in
general anthropological journals. Quite a few of the negative com-
ments I received struck me as deficient in serious academic engage-
ment. Amazingly, the editor of one mainline journal concluded her
letter of rejection by commenting, that my work did not raise impor-
tant anthropological questions. Although journals in applied anthro-
pology and disability studies did eventually accept the early versions
of the study, the experience was sobering for me. It reflected, in my
understanding, the present state of the discipline.

This brings me to outline my personal motivations and positions
in this field of research. I came to anthropology in the early 1960s
after a childhood in European Holocaust conditions and a tumultuous
adolescence. Since then I have invested many years of effort in the
area of Middle-Eastern Jewish studies, focusing on the ethnography
of North African Jews in Israel and on their historical background.
My motivation was heavily romantic, entailing a personal search for
roots. Also, I was moved by a feeling of profound affinity for people
who were considered inferior by those of the dominant strata. With
time, I have lost much of my attraction for this ethnographic field,
but some of the old motivations have remained with me, and that has
made me aware of the illuminating potential that lay in a study of
the physically disabled. Prior to this project I had no particular inter-
est in, or personal involvement with blind people. But by the early
1980s blind people struck me, for the popular reasons I outlined
earlier, as saliently exotic.

Further, I brought to the field an attachment to traditional Juda-
ism which entails commitment to charitable activities. However, my
initially weak support of the disability rights movement has increased
over the years of my involvement in this study. I am aware that some
of the questions I consider may be objectionable from some perspec-
tives of the movement (for instance where I discuss the question of
the aversion of blind people to each other's company, or the occupa-
tion of blind beggars and low-status generally). My comments do,
however, reflect realistic situations with which I am familiar, which
disability-rights activists sometimes seem to ignore. It is possible that
in Western countries such as the United States, the high visibility
profile of the disability-rights movement and its achievements, result

in obviating attention from morally reprehensible conditions under which many disabled people still live. Those conditions are ideologically unpalatable to the movement, and they clash with the public image that the movement seeks to project. Personally, I support the rights movement, but that ideological position does not preclude me from developing an analytical sociological perspective, in precisely the same way that religious commitment need not inhibit the development of an analytical perspective on religious phenomena.

Despite my attraction to the disability rights movement I have little patience for some of the infighting and quibbling within the movement over what I feel are trivialities, such as problems of terminology (e.g., the usage of the term "disability" in preference to "handicap"). I follow usages that are currently fashionable mainly out of respect for the people concerned, not out of personal conviction. Finally, I brought to the field a fear of blindness, and never ventured to experiment with the advice to play blind man's bluff. Such an exercise would, in my opinion, be futile in any event because, as I elaborate in this study, blindness is much more encompassing as an existential situation than sightlessness—and all the more so when simulated and the sightlessness is temporary.

Once anthropologists acknowledge such personal idiosyncrasies and prejudices, they may venture, I feel, onto whoever will tolerate their presence. The ensuing accounts should then be evaluated critically in the context of that personal background. There is no reason why a sighted researcher could not penetrate into the lives of blind people, just as a New York anthropologist can penetrate and uncover the nature of life in a Berber village, or of Harvard Business School alumni for that matter. Similar to conventional practice in traditional fields of study, the anthropologist of blind people will be expected to exhibit a measure of empathy—more than the superficiality that satisfies many sociologists, but less than might lead to full submergence and to "go native" in the culture that is being studied.

The latter point requires emphasis at this time. Much of contemporary socio-cultural anthropological writing is geared to a sensitive literary genre, that aims to evoke nuances of the atmosphere and of the drama of individual lives. In support of what Paul Stoller (1989) has termed "radical empiricism in ethnographic writing," the claim is currently being made, that optimally an ethnographic field project should extend over decades, virtually the lifetime of a researcher. Such immersion encourages vivid description and deep characterization, standards that anthropologists have frequently, if not always aimed for, and have attained with varying measures of success. I maintain however, that these emphases on empathy and literary quality, when linked to a second prevailing trend, that of reflexivity and

introspection, lead to a loss of vigor in the attainment of one of the major traditional goals of anthropologists: the raising of general theoretical problems and the attempt to resolve them. The increasing lack of coherence in the discipline ever since the early 1970s is, I suggest, linked with a loss of balance between problem-oriented writing and the striving for the production of descriptions that are of literary and humanistic quality. The imbalance causes many anthropologists to measure their achievements and those of their colleagues by the standards of others, namely of creative writers. Beyond doing themselves ill-service by this evaluation, it leads anthropologists to sterility in their own craft.

The present study is, in contrast, an apology for traditional social anthropology, in the sense that it is concerned with analytical descriptions of major issues in the lives of people. Therefore, contrary to the practice of many ethnographers of contemporary life, I deliberately refrain from presenting any detailed profiles of individuals. I feel that no analytic purpose would be served thereby. Also the craft of anthropology is not that of literary art, and anthropologists need not try to practice it. I could not rival a writer such as Ved Mehta, to offer the kind of profound insight into the lives of individual blind people that he does. The anthropologist is however, able to provide a picture that incorporates systematic linkages with facets of wider culture and society, and that is usually beyond the depth of other social commentators, including great literary artists. Though their doings are fractured according to the various subtopics I explore, individual people do nevertheless figure in this work. Anyone interested in them will be able to follow their traces by the help of the index—and produce indifferent literary profiles.

I am anxious to protect not only the privacy of these people, but also their sense of self-respect. Virtually any socio-anthropological study that is not founded on the assumption of total immersion has elements of debunking. The student's vision of people is bound to be different from that which they have of themselves. The latter vision is a result of laborious self-sustaining image-making, and chances are that the student's image of a person may be painful. It is the researcher's responsibility to avoid actually inflicting pain. Conventionally, I have therefore disguised the names of most persons and places. In some cases I have gone further, and also changed occupations, ages, ethnic identities, even gender—whenever these data were not pertinent to analyses in which the individuals figured.

The order of the topics of this study aims to present an unfolding of the life experience of blind people, starting from the most personal and private, and leading onto broad public concerns. The book is composed of four parts in which the lives of sightless people are

studied, beginning in part one with the immediate and intimate domain of the body. In part two the focus moves beyond the body, to the circle that is closest to the individual, that of the home and the family. In part three we follow people beyond the domestic setting, as they reach out to fill their material requirements. Part four focuses on the doings of people as they reach out for fulfillment, dignity, and integration, in circles beyond those of the home and work place; namely, activities and concerns in the areas of leisure, society and politics.

Part one is composed of two chapters. The first discusses problems inherent in the essential nature of the sightless body—how blind people manage it in a world that is governed by the sighted, specifically, the usage that blind people make of their unimpaired senses. The second chapter focuses on social problems that inhere in the usage of the main aids of blind people to compensate for their physical disability. Part two is composed of two chapters on relationships between parents and children. The first of these is devoted to the experience of growing up as a blind adolescent in a home governed by sighted parents, and the second deals with the problem of mature blind people who have come to raise their own sighted children.

The chapters that compose part three focus on the work situation and on the welfare system as it operates in the area of material needs. Chapter 6, the first of these chapters, describes the travails of obtaining employment, and in chapter 7 we enter the work place to describe the nature of that employment and the way employees experience it. Chapter 8 describes the nature of the social support system that sighted people, both public agents and private volunteers, provide. The impact of this system upon the blind clients and the way they experience it is described in chapter 9.

The four chapters that compose part four deal with public life. Chapter 10 focuses on the issue of socializing and reaching out for friendship, that is, the dilemma of disabled people associating with, or dissociating themselves from, people of similar condition. Chapter 11 focuses on a possibility of association that is common in Israel as an immigrant society, that of ethnic bonding, and discusses to what extent blind people are interested in such identities and divisions. In chapter 12, discussion shifts to what is in many ways the obverse of ethnic bonding; namely, nationalism and patriotism, and describes the views and doings of people concerning the latter. Finally, chapter 13 concludes with an examination of positions that lead to political activism, debates about the major public issue that blind people face, that of empowerment as against quiescence.