Reproduced from "All God's Mistakes: Genetic Counseling in a Pediatric Hospital"
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1

INVITATION TO ETHNOGRAPHY

What should couples with Huntington's chorea do about childbearing? What do genetic counselors advise them to do? Are there genetic grounds for compelling a couple to have a so-called therapeutic abortion? How are birth defects explained to parents who bear children with these defects? In this volume, I shall report on how these problems were managed in one workgroup: a genetic counseling team in an elite urban medical center. These observations are the empirical basis for a sociological discussion of problems in applying new technologies of prenatal monitoring and diagnosis. They serve as well as a springboard for considering the rights and responsibilities, duties and obligations embedded in role relationships.

I collected the primary data during two intensive periods of participant observation among a team of genetic counselors who invited me to join them because they were aware that the services they offered patients were bound to involve questions of a social sort.[1] These services included counseling couples who either al-

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[1] The invitation to observe came in the spring of 1976. Preliminary observation lead to a proposal which was subsequently funded by the National Institute of Child Health and Development. The first period of intense observation began in the fall of 1976 and ended in the winter of 1978. In the winter of 1980, I reentered the field, only to leave again in mid-autumn of that year. My comings and goings were not random or unmotivated, but were rationalized theoretically at the same time that they were personally necessary. For now, that is all that needs to be said about the matter. The confessional of the fieldworker (Van Maanen 1988) is more appropriately an appendix to a text than a sentence in a footnote.

ready had, or were believed to be at risk for having, a genetically defective offspring, as well as diagnostic testing. At the time of observation, no treatments for defects discovered *in utero* were available. The fact that this has changed and that for some rare deformities fetal surgery is possible only intensifies those questions of "a social sort."

As a result of the counselors' invitation, I joined their workgroup. I attended preclinic conferences at which management of upcoming cases was discussed, observed the counseling sessions themselves, and listened to the counselors evaluate their work in a postclinic conference. In addition, I interviewed a sample of parents whose counseling sessions I had attended in order to gather their understanding of the process. Finally, I was on call for those emergency situations in which physicians in the newborn nursery or the neonatal intensive care unit needed to consult with the physicians specializing in clinical genetics.

The interactional data from my first-hand observations is the starting point for each discussion of shopfloor work. But to write of genetic counselors ethnographically is not to write of some tribe isolated in the bush, impervious to the wider world around them. Both genetic counselors and sociological observers who trail behind them need to take that wider world into account. Ethnographic descriptions of the applications of clinical genetics in the modern American hospital need to be mindful of the legacy of earlier attempts at eugenics, as well as the legal, political, and cultural questions that current practices raise.[2]

Starting with interactional data, the lived experience of patients and their doctors, I will move beyond thick description (Geertz 1976) to an analysis of what these patterns of interaction say about role systems, their domains, and their boundaries; about areas of

collective consensus, uncertainty, or confusion; and about the policy alternatives we face as a collectivity.

An Invitation to Fieldwork

I was invited into this setting as a guest of the genetic counseling team because of their sense that as a sociologist trained to observe behavior as it naturally occurs, I would have something useful to add about how best to manage the myriad of social problems that trailed in the wake of new clinical developments. Since professional groups so rarely invite study by outsiders, it is first necessary to comment, albeit briefly, on this invitation and its implications for the ethnography before moving on to the substance of the text.

I received this invitation because I am a medical sociologist, an ethnographer of medical action. Here it is worth mentioning that today I would be unlikely to receive such an open-ended invitation. Since this fieldwork was done, formal institutions (ethics committees) and workers (bioethicists) have emerged for managing precisely the types of issues that the genetic counselors wanted help with. Back then, it was not so, and the help of any ethnographer was sought. By any technical, formal, scientific criterion, my data-gathering techniques are primitive, crude, and inevitably interlaced with my own subjectivity. I observe patients, physicians, and nurses as they go about the business of being ill, curing, and caring. My data comprises the behaviors I observe, the conversations I overhear, and the responses to questions I am not too timid to ask. At a phenomenological level alone, being a medical ethnographer is a peculiar occupation. For example, fieldwork on a genetic counseling service involves repeated voluntary participation in and observation of many of life's most awful moments, watching others cope with what the genetic counselors, ruefully echoing those who seek their services, refer to as "all God's mistakes."

However odd the work, anthropologists in the bush and sociologists on urban streetcorners have made ethnography a familiar mode of academic discourse. For the ethnographer in a medical setting, health-care workers are an exotic tribe; the bounded whole of the modern hospital is the bush. Our task is to report on the goings-on in this faraway province. At worst, we are voyeurs whose

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[2] The introduction briefly considered historical antecedents of current attempts at applying genetic knowledge. In assessing current attempts at applied eugenics, we need to consider as well contemporary attitudes about risk, technology, the nature of birth, and therapeutic abortion. In trying to parse the current meaning of clinical genetics, the behavioral events observed have little meaning outside their arenas of production and interpretation. Some areas of genetics have become social problems, while others are relatively unproblematic. Understanding why this is so is a major task of the sociology of social problems (Hilgartner and Bosk 1988; Schneider 1985).

reports are a source of academic cheap thrills; at best, we are witnesses reporting on the most profound dilemmas of the human condition.

Not surprisingly, I prefer the latter self-description. As witnesses, we have two objectives. The first is to provide an empirically thick description of what happened: who did what, to whom, in what circumstances, with what responses from others, to what end, and with what consequences. The second is to analyze this description of the everyday, ordinary business of being a provider or consumer of health services. We inspect the record, as it were, for the evidence it contains about what it means to be a person, a family member, a citizen in modern American society.

As a witness in the arena of everyday medical life, as a sociologist, my perspective is explicitly dramaturgical. I think of clinical action in terms of situations—in particular those in which clinical action is problematic. Procedurally, I examine these situations to uncover what rhetoric, rationales, maxims, myths, data, and bottom lines physicians arm themselves with when they recommend one course rather than another to patients, when they explain unexpected, unwanted outcomes, and when they search for reasons to explain pain and suffering.[3]

As a medical sociologist/ethnographer, I have spent time in a variety of settings. However the settings varied, the central feature of my work as a sociological ethnographer remained the same. Data were generated by my skill at manipulating my relationship with my subjects. Invariably, and at one level, ethnographers treat their subjects simply as means to the end of generating good data on how some intractable problem of the human condition is managed among a group of natives.

Ethnographers—to the degree that they think about this practice at all—justify it by sleight-of-hand. It is not particular people that we are interested in, but general types, diffuse social and institutional processes, or native understandings. If people are treated as a means to an end, it is not *qua* people, but as mere representations

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[3] This paragraph is an echo of Garfinkel's (1967) charge for the study of social life in "What Is Ethnomethodology?" The echo is meant as a gesture of respect and a literal description of how I try to frame situations that are meaningful to me as a medical sociologist who works methodically as an observer.

of categorical schema. In presenting data, we do not betray individual trusts and confidences; instead we generalize them.

Most fieldworkers are not invited into medical settings; they are more commonly self-invited guests, who find themselves backstage in medical arenas after complex negotiations to win institutional sanction. Most contemporary accounts of doctor-watching offered by sociologists stress the difficulties in gaining access to the private arenas in which medical activity takes place and in gaining the trust of physicians and other medical personnel. Fieldworkers invest the medical profession with many of the features that the nineteenth-century German sociologist Georg Simmel attributed to secret societies; then they describe themselves as minor Promethean figures eager to snatch secrets and place them in the public domain. In the most vulgar of fieldwork imagery, the medical profession is a living, breathing exemplar of G. B. Shaw's famous "conspiracy against the laity." The sociologist's task is to expose this conspiracy for what it is—the exploitation of pain and vulnerability for profit.

In characterizing the relations of doctors and patients, conflict is the social process and hostility is the emotional tone that are most frequently highlighted. Most medical ethnographer's heed Hughes' (1971) injunction to study the "rough edges" of medical practice, those areas where lay and professional expectations about what action is necessary are least likely to converge. It is tempting to interpret this focus as the result of the difficulties experienced in gaining access to the fieldwork setting.

But what happens when such resistance is absent? What happens when the fieldworker does not worm his or her way into a site to pursue a personal agenda, but is invited in by physicians who have their own version of what the ethnographer's task is and what it ought to be?

Most practically, I experienced none of the difficulties associated with gaining entrance to the field setting. There were no negotiations with hospital administrators, no multiple clearances from multiple clinicians, and no endless rounds of meetings to explain who I was and what I was about. I was never asked to make elaborate promises to safeguard the confidentiality and anonymity of the institution or its physicians. Never was there any suggestion that my work be subject to any sort of prepublication preview. I had to obtain the official approval of an institutional review board, but that had more to do with government policy toward research subjects than with physicians' distrust of fieldworker sociologists. Moreover, as we shall see, I was asked by counselors on numerous occasions not to gather a consent but, nonetheless, to be in attendance.

Pilot observations began before the institutional approval was granted. Beyond that, the genetic counselors had been observed regularly by social scientists long before I got there. In the previous year, four graduate students had done fieldwork projects; one faculty member in the Law School came to clinic and conferences quite regularly; and finally, a fifth graduate student was making observations preliminary to a dissertation proposal. At the same meeting at which the group asked me to join them, they worried out loud about "chronic crowding and being overstudied."

Of course, the absence of obstacles, as well as the plethora of observers, spoke of the desire of genetic counselors to receive sociological help. Their invitation to me was yet another artifact of their desire to provide their services as sensibly as possible. When they approached me, genetic counselors were aware that they were providing a new clinical service that intersected with some highly charged areas of social life, including the nature of parenthood and family bonds, and the permissibility of, and limits to, an actively preventive eugenics. In addition, the genetic counselors stated that there "were bound to be other difficulties that they could not foresee."

They asked for my help, which they envisioned as taking two forms. First, I could perform a hard-headed, objective, assessment of how they were managing problems. In addition, I could provide a catalogue of the typical problems that they face but lack adequate resources to resolve. In accomplishing the first task, I would serve as an efficiency expert for the genetic counselors, providing data which allowed them to improve the quality of their services. In accomplishing the second, I would be a "committed moral entrepreneur," providing the society at large with data that would confirm the need to commit an even greater supply of resources to genetic counseling.

The genetic counselors believed that such a commitment was necessary and that, if I came to know their world as they did, I too would find such a need inescapable. This expectation—that our sentiments and analyses of societal interest would prove to be congruent—was, of course, unstated at the outset. It came with the invitation, but I did not realize it at the time.

At those early meetings, I was most struck by the counselor's recognition that the application of genetic knowledge in clinical situations created problems and that an interdisciplinary effort was called for to resolve them. I eagerly accepted the counselors' invitation, unaware of the implications of being invited to join the team—unaware of the difference between being an invited guest and being, as is more typically the case for a medical sociologist, an uninvited, albeit tolerated intruder. Flattered by the idea that I might be useful, that I might have something to offer, I was seduced by the idea of pseudo-colleagueship. Not aware of the way this invitation, which amounted, after all, to nothing more than an opportunity to be an unpaid consultant, was a subtle devaluing of social science expertise, I joined the group. I joined unmindful of the consequences that belonging might have, first for observation, and later for reporting.

Invited Guests and Uninvited Intruders

If invited guest/uninvited intruder was a status distinction of which I was initially unaware, I quickly learned many of its nuances. In previous work, I had been an uninvited intruder (Bosk 1979). As such, I felt no special loyalties to the groups that I studied. I felt all the ordinary social constraints to treat them and their world with decency and respect, but I also recognized that in the course of things, I would bruise their cherished notions of their own goodness. But that was all part of making the latent manifest, of looking at social life unsentimentally, of revealing what goes on backstage. It was a part of all the formulas that sociologists have constructed to describe the unique perspective on the human condition that ethnography provides.

As an uninvited intruder, my relationships with my subjects were complex. On the one hand, in my day-to-day interactions, my subjects had no expectations of me. I was ornamental, decorative, extraneous, and dispensable. If I kept out of the way, if I was marginally helpful, if I filled rare down-time with interesting talk, whatever I wrote later was my own business. On the other hand, I was constantly tested, made the butt of group jokes, and accepted very slowly in the setting. What is critical is that whether I was an object of disinterest or suspicion for my subjects, I was expected to contribute nothing fundamental to the ongoing life of the group. When I did help, when I opened packages, passed supplies, or was simply an extra pair of hands, it was a welcome surprise to the surgeons. Expectations were low, and satisfying them was easy.

This was not the case when I was an invited guest. The genetic counselors had invited me to observe because they thought that I might help them. This expectation to be useful was unfamiliar to me. At case conferences, I was asked to provide concrete data about such things as how class differences or family structure affect patient understanding. I was asked to speculate about the handling of cases—to participate in the making of policy. How should couples who come in for sex selection be treated? What should the center's position on counseling for exposure to Agent Orange be?

Most frequently, the counselors asked for help on a range of clinical management issues: what social information to collect routinely for genetic registries, how best to give incoming patients reasonable expectations about their upcoming visit to the genetic counselor, how to avoid no-shows on clinic day, how to decide which patients needed which level of follow-up care, and so on.

> It is Friday afternoon, late in the fall. I am sitting, as I do every Friday afternoon, in a conference room for the postclinic wrap-up session that members of the genetic counseling team hold to report on their counseling sessions. Al Samuels (all names have been changed) is reporting on a case. Samuels characterized the session as "strange." He could not get a "fix" on whether or not the couple understood what he told them.
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> He emphasized that they appeared to take everything, yet as the information got worse and worse, their affect did not change. Samuels giggled nervously as he concluded.
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> Berger, chief of the Service, asked Samuels if he knew the parents' jobs. Samuels did not. Berger was displeased. He told the group that this was "standard medical information which should be on record." He added a sentence or two about the importance of this kind of data, and the group moved on to discuss other cases.
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> When the meeting broke up, I found myself going through the doorway with Berger. He led me a few paces away from the rest of the group and said, "I wish you'd push a little for medical records to include more social information. When I do, I sound just like a mother hen. But you, because you're a social scientist, perhaps you could get the others to see how important it is."

It was, of course, Berger who had initially invited me to join the workgroup. Here was a direct example of him telling me how he expected me to be useful, what he wanted me to do: Be a missionary for social science data on medical records. Other members of the team also felt entitled to make special requests of my services as an observer.

> The Mulroneys are coming to clinic for counseling.[4] They have a child with tuberous sclerosis. Mrs. Mulroney is pregnant. All the members of the counseling team save Berger are convinced that Mr. Mulroney has an extraordinarily mild expression of tuberous sclerosis. Berger is convinced that Mr. Mulroney is normal, and to the horror of the group, he intends to counsel the couple that they are not at any increased risk for having an affected child.
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> Bill Smith calls me at my office. "Bosk, you comin' to clinic?" I tell him I am. "Good, we want you to sit in on the Mulroneys and tell us what Berger says. We all think he's close to a serious error. But he won't listen to anybody. We want to know what happens."

This request—to monitor a colleague—was the most frequent special request that the counselors made of me. I was used in this way quite often when there was disagreement at Wednesday's preclinic

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[4] For further discussion of the Mulroneys and their problems, see chapter 2.

conference about how to counsel the cases coming in that Friday. Not infrequently, I would be asked in postclinic conference if preclinic understandings were implemented, although never so nakedly as that. More often, it was just a vague invitation to talk: "Bosk, what did you think of the session?"

Conventionally, the sociological literature on fieldwork instructs us to turn such special requests and demands into occasions for educating our subjects about what fieldworkers do, or to volunteer just enough to get subjects to reveal their own feelings. The latter is a standard method for generating good field data.

With the genetic counseling team, neither approach was totally satisfactory. Didactic lectures *in situ* about the ethnographer's code of conduct and the importance of not interfering unduly with naturally occurring phenomena did not appear to be an adequate response to people who asked me to watch their work so that I could help. Moreover, even if I had wanted to help (and I am not certain that I did), more often than not I did not know how.

Called on often by the genetic counselors, I found that I had nothing particularly useful to say. Yet those invited to social occasions have obligations that those who merely intrude on them do not. As someone watching genetic counseling under the guise of having something instantly useful to offer, I often felt like a fraud when I let my hosts down by failing to meet their expectations.

I mention this because we shall see that my major criticism of the genetic counselors is their failure to be useful, to meet the patient on the patient's own ground, and to address the patient's most pressing concerns. The counselors, I will argue, at times use the goal of patient autonomy as a ground for patient abandonment. Sometimes, I wonder how much this insight grows out of my own sense of frustration at not being able to help the counselors more with applications of my specialist's knowledge in those very difficult situations where my help was requested.

With this example, I wish to call attention to a similarity between the work of physicians and the medical sociologist who trails behind them. The work of both involves explaining imponderables, and the failure to do so occasionally feels like a failure to meet a moral obligation. This example is a miniparadigm of how I was

taught to act as a fieldworker, to use my own responses in a situation as a guide to the responses of others.[5]

I have mentioned that I thought the genetic counselors used the ideal of patient autonomy as an excuse for patient abandonment.[6] This is a sharp criticism, and since sharp criticism is often socially unpleasant (the essence of sheer effrontery), such sharp criticisms present a special problem to those invited into fieldwork settings: how to voice them in a way that does not give offense.

To use a social analogy, I was often in the position of the guest invited for a dinner where the experience of the meal itself is the entertainment—a feast. For this guest, nothing has been spared. The host has set the table with the best cutlery and china, given great attention to the menu, used the finest ingredients in preparing the dishes, and, nonetheless, produced an indifferent meal.

The guest is acutely aware of the meal's shortcomings; the host, however, is proud of his or her best effort. The meal consumed, the host turns toward the guest and awaits some comment. The host may grow anxious and fish for a response. The guest needs to find a way to respond to the feast that balances gratitude with honesty. That was my problem.

As hosts, the genetic counselors were unfailingly gracious. They offered me access to situations so acutely private that I sought rationales to limit my access. Gracious as hosts, the counselors were also anxious. They were constantly soliciting my evaluation of the fare they had placed before me.

Situations in which I had nothing to add presented me with one type of problem. My silence on troubling questions for me marked my failure to meet the moral and social obligations of the occasion

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[5] As a miniparadigm, it is a good example because it is so extreme, because it makes so much of the fieldworker's subjectivity, and because, like fieldwork itself, it is nonfalsifiable.

[6] While I speak in this volume about genetic counselors first and foremost, I do not feel that counselors alone are guilty of using autonomy as a warrant for abandonment. I am not singling out counselors as the solitary abandoners of patients amongst all the medical profession. Instead, I am using counselors to show how rather extensive patient abandonment can occur under the banner of more perfect patient autonomy. The very fact that counselors can abandon patients is noteworthy because it runs counter to so many elements of their occupational ideology.

to which my hosts had invited me. Situations where negative commentary was unavoidable presented another. What was the best response, if a commentary was requested, when I felt (as was most rarely the case) that the counselors had badgered their clients, or (as was all too often the case) when I felt that counselors had abandoned their patients by evading the real patient issues.

On the one hand, I did not want to insult my hosts' hospitality. On the other, I did not want to respond enthusiastically to dismal fare, only to see it served up proudly on all occasions. What did I owe the genetic counselors as a result of the unique field opportunity that they afforded me? At one level, I felt that I owed it to them to present my criticisms at a very high level of generality, so that it was not individual counselors that I was criticizing, but the structural arrangements of care and the organization of social roles. But this satisfies the social obligation at a great remove from the time when it was actually incurred. How in the everyday context did I mix candor and kindness to respond to the needs of the genetic counselors?

The Witness Role

If I could be neither a garrulous nor an enthusiastic guest, in the spirit of the genetic counselors' invitation to join their team, what role then did I come to play in my three years with the counselors? How did I balance the genetic counselors' expectation that I be useful with my own methodological determination to remain detached and objective?[7]

I defined my work in two ways. I watched doctors with a well-defined set of sociological purposes at hand. I watched them to learn about the doctor-patient relationship, the division of labor, and the management of risk in the academic medical setting. But I also witnessed for doctors, and this witnessing for doctors was a more complicated business than ordinary sociological watching.

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[7] Another old-fashioned aspect of this account was my determination to remain value-neutral. This is a role that both sociologists and anthropologists have long ago abandoned for a more forthright advocacy for the disadvantaged or paid consultancy for the privileged. Aware of the development of a more clinical sociology, I find it hard now to explain why I struck such a distant and remote definition of the task at hand.

During the time I observed them, the genetic counselors faced many of the dilemmas that have become so familiar in the bioethics literature. For example, on several occasions the genetic counseling service debated whether children with trisomy 21 should be allowed to die from repairable defects; decided how the marginally competent mentally retarded should be presented with their reproductive choices; discussed whether parents were under any obligation to abort defective fetuses; speculated upon whether surrogate motherhood was a permissible remedy for certain forms of infertility (this well in advance of media disclosure and judicial notice of the practice); and tried to formulate cases under which amniocentesis for sex selection was ever acceptable practice. And this is only a partial list.

On many occasions, I was present not by chance but because my presence was specifically requested. Like the witness to any ceremony, my attendance was supposed to act as some sort of guarantee that proprieties were observed, that patient rights were respected, and that all the acceptable alternatives for resolving a problem had been explored. At the same time, I was a witness to the pain and suffering of patients as well as to how seriously the counselors took that pain and how hard they worked to mitigate it.

What separates witnessing for doctors from merely watching them with some well-directed set of academic purposes at hand is this: Witnessing seems more directed to establishing or ratifying a moral community than mere watching. Over time, I came to realize that not only did I witness for a group of physicians, but that those physicians did precisely the same for their patients. They listened to their patients pains and problems, and the fact of the listening confirmed that the suffering was real and legitimate. Providing a place far from neighbors, friends, and family for couples to talk with specialists was all by itself something of a service.

Hearing a physician raise the option of artificial insemination by donor as a way to lower the risk of recessive disorder, or hearing a physician raise the possibility of institutionalizing a profoundly retarded child or discuss the possibility of abortion after a positive amniocentesis did not mean that the couple would necessarily rush to utilize these options. But it did mean that they had permission to think about them and that to do so was not necessarily immoral. If they did not do anything specific for a patient's pain, genetic counselors, at the least, gave a place to take that pain; gave them "frames" and supplied "options." Given the shame and guilt that often accompany the birth of a damaged child, this was no small thing. Counselors then witnessed the pain of patients, and I witnessed the pain of counselors as they came face to face with their limitations in palliating the pains of their patients.

In a curious way, I came to symbolize for the group the moral community outside the hospital—my presence in highly problematic situations became a sign of approbation from the larger community of whatever course of action was taken. At one level this exacerbated my difficulties in giving the group negative feedback, but it resolved them at another. In any situation, I could simultaneously provide criticism and provide myself distance from it.[8] I would routinely speak not as an observer, but for some identifiable segment of the community and raise my objections in a voice that did not seem to be my own. I would begin most negative commentary by saying, "If I were a . . .", thus separating myself from my spoken words.

When the fieldworker is invited to join a medical team, witnessing is part of the fieldworker role at three different levels. First, at the simplest level, the fieldworker provides counselors with a "reality check," a confirmation that things are or were as they seemed. As a mundane example, whenever the genetic counselors described to others cases that I had observed, they would pepper their accounts with asides to me such as "Isn't that right?" or "That's what happened, isn't it?" Just as often, this confirmation was of the "God, did you see that?" variety; I helped make the incredible credible.[9]

Second, and unbeknownst to me at the time, a fieldworker, especially one whose presence has been requested, provides his subjects with a sense of legal protection. Being used this way happened to me late in my fieldwork, long after I had built upon that initial but

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[8] For a full development of role distance and the repertoire of techniques that surgeons and teen-age girls on carousels use to achieve it, see Goffman's (1961c) seminal essay. Here I am simply describing one ethnographer's ploy for achieving the same end.

[9] Interestingly enough, I was used by surgeons in the same way. Some aspects of witnessing are built into the fieldworker role, whether the fieldworker is an invited guest or an intruder.

shallow trust that the genetic counselors extended with their invitation to observe. Rather commonly, I found myself being asked to observe cases which were complex and contested morally, bureaucratically, and legally. I was on a number of occasions asked to observe as a "working" member of the team, to forego obtaining an informed consent from subjects, and to desist from public notetaking. While it would have been both ethically safe (and correct) to refuse such offers, the actual situations, along with their attendant negotiations, were more complex than that. Did a refusal mean that I was unwilling to act as a member of the team? Did the counselors have the right to seek my aid this way? Did I have a duty to refuse?

The compromise we arrived at was to have me introduced as a sociologist working with the team. I did not take notes at the time of observation, but wrote the cases up from memory. When a lawyer came to gather data for a wrongful life case, whenever a couple sought amniocentesis for sex selection, whenever parents sought to withdraw treatment from neonates, the group could press me into service as a team member. I slowly came to realize—slowly, perhaps, because I was gathering such good data—that the genetic counselors expected that should the need arise, I could serve as an expert witness capable of stating what had really happened. I do not know why the discovery of this latent dimension of my fieldworker role surprised and disturbed me, but it did, despite the large role that expert witnesses play in the civil procedures of the society.[10] Moreover, I shared with my genetic counselor subjects the feeling that being called into service as a witness in this way was annoying and burdensome.[11]

Witnesses play a religious role as well. Like the rabbi at a slaughterhouse, the priest at an execution, or the airline chaplain who

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[10] Fieldworkers have long worried about being co-opted by those that they study, and this worry is all the greater when we are studying up the social structure rather than down. Empathy with the wretched in society is rarely, if ever, considered a methodological problem. On the other hand, empathy with the powerful, with physicians, is seen as considerable cause for alarm. Here, though, I am fretting about more than where my loyalties lay. I am concerned about what my expertise is as well: what does it mean to represent oneself as "a skilled ethnographer"; what, save writing skillful ethnographies, can others expect me to do?

[11] See Bill Smith's comments about being a witness in a wrongful life action (chapter 5).

consoles those awaiting passengers on a flight that has crashed, they purify and sanctify messy situations. In allowing me to view their uncertainties, anxieties, and doubts, the genetic counselors had allowed me to see their group function in an intensely religious and spiritual way. In hearing the genetic counselors discuss birth, life, and death, the boundary between them, and the permissible limits of human intervention, I was a witness to the group's "collective meditation on sacred things." For those social scientists who take their Durkheim seriously, such a meditation is the essence of religious experience. As such, it tells something of what these medical professionals hold sacred.

As I have stated, the genetic counselors were all too aware of the ways in which the organization of genetic counseling might disturb lay sensibilities. Having as their only treatment recommendation second-trimester abortion, and practicing in a society where the right to perform this procedure was a hotly contested political issue, they could scarcely avoid the ethical tensions created by their work.[12] When most aware of these tensions, the counselors often tried to draw me into their deliberations as a medical ethicist. I invariably demurred when called on to act in this way. I mention this now only because my silence on matters of medical ethics as they unfolded in clinical situations is in such sharp contrast to my volubility in the pages below, which are so far removed from the contexts in which words might have been helpful.

Soft Data, Hard Problems

I also mention my silence regarding medical ethics because if fieldworkers' canons of methodological purity commit them not to act as situations unfold, then it seems fair to ask just what do they contribute; why are they there, and are they necessary? Most simply, fieldworkers watch, listen, and use their own feelings and responses as guides to their interpretation of what is going on. In essence, this kind of observation is not terribly different from what psychiatrists, psychologists, and social workers are instructed to do as therapists. As Geertz (1976, 26) points out, ethnographic knowledge shares much with clinical inference.

The uniqueness of the fieldworker role comes from how that observation is used. Therapists are urged to use their feelings, instincts, and observations as a guide in responding to clients. For the therapist, for almost all those that use the logic of clinical diagnosis, the witnessing of action is a prelude to activity. This is true for other routine witnesses in the society as well, such as beat policemen and judges, basketball referees and baseball umpires, disability review panels and insurance adjusters.

This is not so for the fieldworker, who absorbs but does not respond to the situation. The task of the fieldworker is to witness again and again, but not to use the data gathered this way in interaction. Rather, the fieldworker observes to write. Patients, doctors, and most every other native ever observed, write as well. But unlike fieldworkers, they had to act; the fieldworker has only to observe. This freedom from intervention and from ordinary interaction allows fieldworkers their special purchase on social life.

Gusfield (1981) speaks of this purchase as an Olympian one. The image better describes the aspirations than the accomplishments of fieldworkers: namely, to describe without sentimentality the way the world works. The ethnographer produces a social description, which is an imaginative construct. This description unpacks the interlinkages between everyday understandings, power, authority, and routine social action in revealing why things are as they are. In addition, as Gusfield shows so masterfully in his analysis of drinking and driving, such a description provides a glimpse at alternative constructions of the social world.[13] Once the world is imagined in this way, it can be imagined differently.

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[12] The genetic counselors have much in common with the abortion counselors described so well by Joffe (1987). There is, however, this important difference: The abortion counselors were guided by rationales anchored in an applied social utilitarianism. The genetic counselors were also applied utilitarians, but they anchored their utilitarianism in genetic knowledge and paid virtually no attention to the social and economic contexts of pregnancy. For the genetic counselors, the only unwanted pregnancies were those planned pregnancies in which the fetus had an identifiable defect.

[13] Gusfield's analysis begins by questioning our collective conventional wisdom; for example, the taken-for-granted assumption that reducing the number of individuals who drink and drive is a policy lever for improving highway safety. Why, Gusfield asks, does not the lever lie elsewhere? He then identifies a number of plausible alternatives to conventional wisdom: improved mass transportation, safer

But what do sociologists as fieldworkers uniquely contribute to public life by imagining the world differently? This question has no simple answer. But if we return to the case of genetic counselors, we can provide a rough outline of the major dimensions of any adequate response to the question.

First, fieldwork alone places us in primary contact with social life as it is lived. The pains, the pressures, the perils, and the pleasures of the genetic counselor's work as well as the sorrow, shame, and existential guilt of parents are apprehended as they unfold in context, or are later commented on in soliloquies.[14] Fieldwork allows us to describe a set of fundamental life experiences as they occur—it provides us with words to inscribe the arc of human experience. In a field like genetic counseling, where the underlying technology threatens to revolutionize medical practice, it allows us to see the embedded tensions that lie beneath the surface of a rapidly advancing and dazzling medical technology: What is help? How is it provided in this society at this time? Fieldwork supplies precisely what other research methods drop out—the experiencing individual as a member of a community and the set of shared meanings that sustains that individual's action in an uncertain world. Fieldwork allows us to describe social life as we live it.

But that is not all fieldwork provides. It provides us with an opportunity not just to describe the lives we lead, but to analyze them. When it is performed with skill, it allows us to examine the shadow that falls between the image and the reality.[15] In the case of genetic counselors, this has meant matching counselors' statements about intent and purpose with daily encounters. For example, as we shall see in the next chapter, the counselors think of themselves as a support service, and as we shall see as well, that support is most routinely defined as factually correct medical information.

Fieldwork, then, provides a mirror for looking at who we are, as compared to who we would like to be. It provides us with soft data: observations, intuitions, and comments for rethinking some very hard questions about what it means to be a member of the society.

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highway design, more crash-worthy automobiles, or a reduction of societal dependence on alcohol.

[14] My collection of soliloquies is heavily skewed. I have a large collection of such asides delivered by physicians, but very few from patients. Part of the reason for this is structural: I was simply "backstage" more frequently with the genetic counselors than I was with patients. But while structure is important, it does not explain everything. I found my more private moments with parents, listening to their stories, painful. As a result, I did not do everything I could and should have done to expand my corpus.

[15] This paraphrase of T. S. Eliot's "The Hollow Men" is used here with some trepidation. For all I know, Eliot felt, like Auden, that thou shalt not "commit a social science."