

7 My Introduction to Diane

In 1976 I began writing about the life of Diane DeVries, a woman born with all the physical and mental equipment she would need to live in our society—except arms and legs. I was then twenty-eight years old and a graduate student in anthropology at the University of California, Los Angeles. Diane was twenty-six and an undergraduate major in sociology. It was the spring quarter, and Diane was enrolled in the large introductory lecture course on cultural anthropology, for which I was a teaching assistant. From my vantage in the back of the lecture hall I watched a blond woman enter the classroom in an electric wheelchair. She looked to be in the fullness of womanhood, wearing a sleeveless white top with narrow straps. Her tapered arm stumps seemed daringly exposed, and the mysterious configuration of her hips was encased in tight blue jeans that ended where her legs should have begun. She maneuvered her

wheelchair with a lever control mounted on one side to face the lectern. Leaning on a wood and Plexiglas desk fitted over her chair, she took notes holding her pen between arm and cheek.

As I observed this woman, I imagined that she lived at home with her parents in a sheltered and socially isolated household. I supposed that she would never marry or have sex. I guessed that she couldn't even masturbate. In short time I was proved wrong on all these counts, and perhaps I should not have been surprised. There was something of the sexual rebel in Diane's appearance, a touch of the "bad girl" that may have engaged my voyeurism and sexual fantasies at the same time that I tried to suppress and ignore them. My preoccupation with Diane's ability to marry and have sex revealed much more about me than about Diane. I hadn't met her. I didn't even know her name.

This book records the relationship that developed between Diane and me over the next twenty years. It is an experiment I call cultural biography, which combines the genres of ethnography and life history. Ethnography is the cultural anthropologist's stock-in-trade, a firsthand description of a people's way of life.¹ Unlike the early anthropologists, whose published works often consist of cultural inventories and static generalizations about the people they studied, contemporary anthropologists tend to write narrative ethnographies.² These are stories based on events we have experienced—more as observing participants than as participant observers—through which we try to convey how people within a particular group or tradition create meaningful solutions to life's challenges. Here I tell a story based on my observations while participating in Diane's life for more than two decades. Reflexivity, which has important precedents in ethnography, has been defined as "the capacity of any system of signification to turn back upon itself, to make itself its own object by referring to itself."³ This narrative ethnography experiments with putting the emphasis on reflexive issues: how I came to understand Diane, how working with her transformed my understanding of her life, and how our collaboration may have influenced the life story Diane has to tell.

The life history is a related anthropological genre that traces how a culture influences the experiences of a specific individual.⁴ Most life histories consist of autobiographies or life stories in the oral tradition. My

research about Diane, which has been published in numerous journal articles and book chapters over the years, includes her life story as told to me in formal interviews.⁵ My data also include documents, such as letters written by Diane, her unpublished autobiography, and her clinical records; interviews with key people in her life; informal conversations; and my firsthand observations. I focus equally on retrospective and contemporaneous materials, deliberately moving back and forth between Diane's narrated recollections and her observed actions.⁶

Cultural biography, then, is a synthesis of ethnographic and life history methods by which I have enhanced my understanding of both Diane DeVries and the culture to which she belongs. Diane's life is a powerful exemplar of changes in mainstream American culture during the second half of the twentieth century. I will argue that she offers a *perfect* example of an American woman of her era, especially regarding the position of people with disabilities. Diane's early life trajectory, starting with her birth in 1950, coincided with the peak of the American medical profession's cultural authority to define normalcy and deviance.⁷ The technical approach of biomedicine to biological, social, and moral problems coalesced into the new specialty of rehabilitation that was founded at the end of World War II.⁸ Much of Diane's childhood was dominated by surgeries and therapeutic regimens prescribed by physician-led rehabilitation teams. At the same time, Diane experienced a life fairly typical for a child raised in Long Beach, in a trim grid of single-family tract houses that was the prototypical American suburb. By the time Diane finished high school in 1968, she had effectively resisted being defined by the heavy impress of institutionalized medicine and had abandoned the artificial arms and cosmetic legs with which she had been supplied. Such antiauthoritarian attitudes and behaviors were becoming increasingly common among young adults with disabilities. Influenced by the gains of the women's and civil rights movements, a full-fledged movement for independent living and disability rights was emerging that was to have a profound effect on Diane's life and on American culture.

My reflections on reconstructing Diane's life provide the basis for a theory of biographical interpretation in daily life that I call the mirror phenomenon. When I first noticed Diane, I had no special interest in

studying disability. But I was attracted to phenomenology, a branch of philosophy that deals with the problem of intersubjectivity—that is, how people understand one another. My fascination with Diane prompted me at once to explore the sources in myself that made the image of a woman without limbs so intriguing. Through systematic self-reflection I probed my identification and empathy with her situation, uncovering my own invisible disabilities and then disentangling them from the way Diane sees herself.

Impressions of others' lives have an important element of empathy or mirroring that needs to be identified so that understanding (in philosophy, *Verstehen*) can take place. The *Verstehen* approach rests on three principles:

1. All human manifestations are part of a historical process and should be explained in historical terms. The state, the family, even man himself cannot be adequately defined abstractly because they have different characteristics in different ages.
2. Different ages and differing individuals can only be understood by entering imaginatively into their specific point of view; what the age or the individual thought relevant must be taken into account by the historian.
3. The historian himself is bound by the horizons of his own age. How the past presents itself to him in the perspectives of his own concerns becomes a legitimate aspect of the meaning of that past.⁹

Empathy has been central to the *Verstehen* tradition in modern American anthropology since its inception by Franz Boas, its popularization by Ruth Benedict and Margaret Mead, and the "interpretive turn" in the discipline in recent decades, led by Clifford Geertz. Attempts to clarify empathy, or the mirror phenomenon, can help to undermine oppressive practices that turn diversity into alienating "difference." Paradoxically, they also help in respecting the "difference" of disability—difference that must be recognized so that people like Diane who need accommodations can continue to gain independence through social and political action.

My first decade of getting to know Diane DeVries, from 1976 to 1987, was a period marked by her marriage and her college graduation. Diane

had met her husband-to-be, Jim DeVries, a good-looking Vietnam War veteran, just after finishing high school in 1968. Having lived together and then apart, they reunited, moved to Oakland, and married in 1978. Diane attended the University of California at Berkeley, the mecca of the independent living and disability rights movements and a vortex of feminist activity. Jim's problems with alcohol and his abusiveness when drunk led Diane to return alone to Southern California. Rebuilding her life in the Long Beach area, Diane was forced to reside in a convalescent home. Although Jim soon followed her to Southern California, he was still drinking. In 1980, Diane filed for divorce. She began attending services at a fundamentalist church and was "born again." I remember standing with the congregation to witness Diane's baptism by total immersion in the swimming pool of an apartment complex with a steep red roof like an IHOP restaurant. At Diane's urging Jim began attending church, and the following year he was saved and delivered of alcohol. Diane left the convalescent home to resume married life with him.

Thus began a long, stable, and rewarding phase of marriage for Diane and Jim: "seven good years," as Diane later described it. They participated energetically in their church community, attending Bible school daily, and planned to enter the ministry. But they became disillusioned with the church leadership—in fact, furious at its hypocrisy when their pastor denied Diane membership in the choir because having Diane on stage "wouldn't look good." Diane returned to UCLA with Jim as her driver and attendant, a job he supplemented by driving a cab. They took holidays together, including a great vacation in Hawaii. In June 1987 Diane graduated with a bachelor's degree in sociology.

In the next decade Diane completed graduate school and began her professional career. In 1988 she entered the master's program in clinical social work at the University of Southern California (where I was by then a faculty member in the departments of occupational therapy and anthropology). She and Jim lived near the ocean in Redondo Beach. They had stopped attending regular church services and instead considered themselves members of a TV ministry. While Diane focused on clearing the next hurdle toward a professional career, however, Jim began to drift. He now usually drank a glass or two of wine with dinner, discounting his

history of alcoholism. One night in May 1988 he failed to come home from work, leaving Diane stranded without an attendant. When he finally called, he said he wanted to split up. They had nothing in common anymore, he said. He was “burned out” from caring for Diane and felt he had no life of his own. Jim’s problems with alcohol worsened, and, as he later revealed, he was also feeding a cocaine habit. He lost his driver’s license and his job. Diane moved to a campus apartment that was adapted with wide doorways for wheelchair users.

Fighting fears of ruining her credibility as a serious student, Diane talked to a supportive adviser at the School of Social Work about her situation. The adviser arranged for Diane to receive a scholarship and encouraged her to switch temporarily to part-time student status. Jim lived in their van until he sold it to buy drugs. Then he dropped by, stole the keys to the new van that the Department of Vocational Rehabilitation had provided Diane for doing fieldwork, and left town. As Diane grieved for their marriage, she was overwhelmed by the logistical challenges of finding attendants and drivers, attending classes, writing papers, attending therapy and doctors’ appointments, and dealing with wheelchair breakdowns. Within weeks she landed in the hospital with an asthma attack. Back at home, she found herself crying uncontrollably and contemplating suicide. Following her therapist’s advice, she wisely let herself be treated for depression over the next two months at Parkside West, a locked psychiatric unit, in the outlying city of Covina.

Diane and Jim eventually reconciled and even moved to Utah to make a fresh start, but by the end of 1989 their marriage was over. Diane returned to Long Beach with a sizable loan from a wealthy friend who was also a local community leader in disability affairs. Through another friend at UCLA, Diane found work as a hospital discharge planner, but she was almost immediately fired, in a flagrantly discriminatory manner, because of her disability. She filed suit under California law and received a settlement. In 1991, Diane established herself in an apartment with an attendant near the newly built Metro Blue Line between Long Beach and downtown Los Angeles, which ran close to USC. She returned to graduate school and began a research project on the self-esteem and sexuality of adolescents with disabilities.

In June 1992, Diane met and fell in love with a handsome accountant and musician introduced by a coworker during fieldwork at an agency serving African Americans with AIDS. Her summer was very happy. I knew little else about Diane's life that year; my contact with her was devoted to resolving our disagreement over interpretations of her life that I had presented in a conference paper (described in a later chapter). In May 1993, Diane was awarded her master's degree in clinical social work from USC. Among the dozen or more celebrants at her "Emancipation!" party later that day at the Ports O' Call restaurant, Diane's boyfriend was notably absent. Things had not worked out, although Diane was having a hard time shaking him.

Straight out of graduate school, Diane was offered a job as a clinical social worker at Partners, a city-funded agency in West Hollywood that assisted senior citizens and gay men with AIDS. Diane loved the work and was rewarded with the esteem of clients and colleagues. In 1994, however, Partners lost its funding. She moved back to Long Beach. A series of crises kept Diane in hospitals and out of the labor market. When she needed to face down her landlord over an eviction notice in the summer of 1996, I became Diane's publicist. The story, broadcast on radio and TV, emphasized "how far Diane had come" and her need, not for charity, but for an appropriate job. Perhaps I was naive not to expect the gifts of cash that poured in, but what pleased me most was Diane was indeed offered a job, which she accepted, as a professional social worker.

In the early months of my relationship with Diane, before these and many other events unfolded, I was busy grinding my academic lenses, focusing my fantasies and projections about Diane into questions suitable for Ph.D. research. What were Diane's experiences of her body and self? What kind of life could she have in our society? More urgently, I wanted to know what it would mean to understand just one other person, a question of basic sanity that I needed to explore and answer.

Professionally, such a topic still seemed risky in the 1970s. As Sherry Ortner has written, "When I was in graduate school in the sixties, it was virtually unheard of to get the blessings of the department (not to mention a grant) to do American fieldwork."¹⁰ Writing about Diane obliged me on numerous occasions to account for my choices not only to remain

in the United States but also to study only one individual. Such accounting enabled me, however, to explore and make visible my own painful experiences and hidden disabilities. Without performing that ground-work, I saw little point in traveling to any of the remote places to which my teachers and fellow students had chosen to go. With what sense of myself could I do that? And with what illusion of helping whom?¹¹

The image of a graduate student in anthropology letting her gaze fall upon (and penetrate) Diane from a seat high in a lecture hall calls up a colonial (and patriarchal) era in the profession. A static snapshot of the past can be distorting, however. Just as there is no timeless “ethnographic present” for the people anthropologists study, anthropologists and their work are also products of history.¹² This book and its strategies for representation depend on processes of understanding over time. In the mid-1970s, Diane and I were women in our twenties influenced by the rising “second wave” of feminism. We were also engaged, respectively, with the disability rights movement and a movement in anthropology to recognize more fully the interests and voices of the often disempowered people whose lives were studied.

One anthropologist who attempted to give a voice to others and preserve their stories was Barbara Myerhoff, whose book *Number Our Days* is a remarkably life-affirming ethnography about a dwindling community of elderly Jews in Venice, California. One of the people Myerhoff interviewed was Shmuel, who had come to the United States from Eastern Europe early in the century, when pogroms against Jews were commonplace but before the Holocaust. He reminisced with Myerhoff about life in his childhood town in Poland before it was “wiped out like you would erase a line of writing”:

As long as my eyes are still open, I'll see those beloved people, the young, the old, the crazy ones, the fools, the wise, and the good ones. I'll see the little crooked streets, the hills and animals, the Vistula like a silver snake winding in its beauty, and then I fall into a dream. It's a dream you can feel, but you cannot touch it. . . . All is ended. So in my life, I carry with me everything—all those people, all those places, I carry them around until my shoulders bend. I can see the old rabbi, the workers pulling their wagons, the man carrying his baby tied to his back, walking up from the Vistula, no money, no house, nothing to feed his

child. His greatest dream is to have a horse of his own and in this he will never succeed. So I carry him.

And he explained: "It is not the worst thing that can happen for a man to grow old and die. But if my life goes, with my memories, and all that is lost, that is something else to bear."¹³

Marjorie Shostak, author of the exemplary life history *Nisa: The Life and Words of a !Kung Woman*, further articulated the goals of promoting tolerance and understanding cultural differences that guided Myerhoff's work and her own. In reflections written eighteen years after her relationship had begun in 1969 with Nisa, a tribeswoman of the Kalahari Desert, Shostak urged:

It is for Shmuel, Nisa, and the silent others they represent, as well as for ourselves, that we should continue to record these lives and memories. The ethical and methodological problems may be formidable, but they are small compared to the goal. Indeed, the most important ethical message regarding life histories is not a restriction but an obligation: we should make every effort to overcome obstacles, to go out and record the memories of people whose ways of life often are preserved only in those memories. And we should do it urgently, before they disappear. . . . As we cast our net ever wider, searching for those close as well as those far away, the spectrum of voices from otherwise obscure individuals helps us learn tolerance for differences as well as similarities. What better place to begin our dialogue about human nature and the nature of human possibilities?¹⁴

The life history method, through which individuals tell their own stories, is more than a tool for salvaging memories, however. Unlike most reports by social scientists or those found in commercial media, first-person narratives have the power to "liberate the subject" of history to express and represent herself in her own terms.¹⁵ I first knew the excitement and power in gaining a voice when L. L. Langness, my thesis adviser, invited me to collaborate in revising one of his books, a standard reference on the life history method.¹⁶ Lew made it a general practice not to edit what I had to say, although sometimes we disagreed hotly. On one such occasion, I remember striving to convince Lew, then editor of *Ethos*, a journal of psychological anthropology for which I was editorial assis-

tant, to implement the policy of using nonsexist language adopted in a 1974 resolution by the American Anthropological Association.

"Everyone who speaks English knows that *he* includes women," Lew objected.

"Women don't see themselves when they read *he*," I insisted. "Growing up, when I read *he*, I pictured a boy."

Lew had done his field research in Papua New Guinea. "Look, Lew," I said. "You went halfway around the world to listen to the natives. Why won't you believe what women tell you here?"

The policy was adopted and I carried it out with a certain fervor—striking sexist usage in manuscripts, demanding that authors clarify their meaning concerning women, triumphantly inserting "people" everywhere that "Man" had been.

In the introduction to our jointly authored book, *Lives: An Anthropological Approach to Biography*, I wrote:

In finding ways to give voice to persons in a range of societies—many of them members of subgroups shuffled about in the continual struggle of class interests and shifting national alliances—anthropologists who use the life-history method convey directly the *reality* that people other than themselves experience. But we do not want to dwell exclusively on the idea that other worlds are miles away or in some enclave—religious, geographical, or ethnic. Getting to know any person in depth is a major experience because we have to admit that another way of structuring the world truly exists.¹⁷

Now, two decades later, my claims about the life history method may be put to the test. First, at the outset I suggested that as an anthropologist I could "give voice" to Diane. In retrospect, I ask myself, Didn't she have a voice already? Did she need my help to be heard? And, if I have helped Diane to reach certain audiences, what has been their reaction? Has Diane's voice changed in the course of our long conversation? Has she been merely an informant, passive and compliant, recounting her experiences to me? Or an agent who has actively constructed her life in the telling? What uses has Diane made of the opportunity to tell and retell the story of her life?

Second, I claimed that a life history could convey the reality of experiences such as Diane's better than other kinds of reporting. Many critical and feminist anthropologists now argue that the use of life histories and life stories, compared to other kinds of ethnographic texts, is the most effective way to challenge stereotypes and correct misrepresentations of others' lives. Some go further and reject the life history approach in favor of the seemingly more egalitarian life story. They define a *life history* as an account constructed by an ethnographer that consists of data about the subject's life, whereas a *life story* is the subject's own self-construction.¹⁸ Could I portray the reality of Diane's experience "directly"? Since I acted as interviewer and editor, wasn't Diane's story mediated, perhaps even tainted, by my reporting?

Finally, I claimed that studying the life of any individual raises the possibility of encountering new ways of structuring the world. But this statement is problematic from the standpoint of anthropology. Doesn't a focus on one individual's uniqueness undercut the greater significance of a shared or common culture? Is Diane's world really so different from mine? What cultural influences have shaped her life, and what permits me to understand them? Is there a separate culture of disability? Is Diane interesting only because of her physical difference? Is she a different kind of woman because she lacks arms and legs? What exactly is different about Diane, compared to what or to whom?