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FOREWORD

MARCIA C. INHORN

There are some individuals in a profession who deserve special recognition. Joan Ablon is such a person. Professor Emerita of medical anthropology in the Department of Anthropology, History, and Social Medicine in the School of Medicine, University of California, San Francisco (UCSF), Joan continues to inspire on numerous levels, after a career spanning more than 40 years, 36 of them spent at UCSF. Joan is, in equal measures, (com)passionate ethnographer, path-breaking scholar of stigma and disability, committed action anthropologist, and mentor to generations of medical anthropology students, many of whom are now her colleagues in the discipline. It is for these reasons that a special session on "Stigma, Suffering, and Social Justice: Papers in Honor of Joan Ablon" was held to honor Joan at the 99th Annual Meeting of the American Anthropological Association in San Francisco in November 2000.¹ The articles in this special issue of *Medical Anthropology Quarterly* have emerged from that session with the encouragement of Pamela Erickson, as well as former *MAQ* Editor Mac Marshall.²

All of us who have been privileged to know Joan understand that she is a "rare bird," a special kind of medical anthropologist, who, as one of her students put it, "is a tough act to follow!" Why? In this Foreword, I would like to reflect briefly on Joan's career, focusing on four key dimensions: fieldwork, scholarship, activism, and mentorship. As will become clear, Joan has not only excelled in each domain, but she has also managed to integrate them in ways that are probably unique in our profession. Her career serves as an exemplar of what it means to truly love anthropology, particularly the ethnographic fieldwork process, and to be intimately engaged with the lives of both informants and aspiring medical anthropology students. It is this rare combination of ethnographer-scholar-activist-mentor that we honor here.

Joan Ablon as (Com)passionate Fieldworker

Joan Ablon dates the beginning of her career in anthropology to her undergraduate years at the University of Texas at Austin, when, at the tender age of 16,

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a friend convinced her to enroll in her first anthropology course. Calling it one of several "zap phenomena" in her life, she became "hooked" on anthropology, receiving her B.A. degree in the subject in 1955. She was soon accepted into the University of Chicago's prestigious anthropology doctoral program, where she would undertake her first two fieldwork projects. As a graduate assistant to Manning and June Nash, she undertook a project on religion, curing, and witchcraft in a small highland Mayan village in the state of Chiapas, Mexico. Although this was to be the only fieldwork she would ever undertake outside of the United States, it was the beginning of what she calls her "40-year love affair" with Chiapas and neighboring Guatemala, where she still returns to see old friends on a regular basis. This was also to be the first of eight, long-term, immersive fieldwork projects. As described by Joan in a paper entitled "A Passion for Field Work," which she delivered as the Distinguished Lecture at the Southwestern Anthropological Association Annual Meeting in April 2000 (Ablon 2000), "I must say unabashedly that fieldwork has been the consuming passion of my life and I've been blessed and privileged to enjoy eight, wonderful, consuming field work experiences. I think of my life in terms of epochs, if that's not too *grandiose* a word, with the chief characteristics of each being the respective field work experience that I was engaged in at the time" (p. 2; emphasis in original).

Although Joan could have continued her scholarly career in Mexico, inspired as she was by the carefully detailed ethnographic work of Robert Redfield, Sol Tax, and Manning and June Nash, she was drawn to issues facing the United States in the troubled period of the early 1960s. Thus, breaking entirely with University of Chicago anthropological tradition, she chose a doctoral fieldwork project in the urban United States, assessing how relocated American Indians in the San Francisco Bay Area were faring after government attempts to resettle and assimilate them into mainstream urban American society. Although Joan's rich ethnographic doctoral thesis documented the failure of this relocation experiment, the thesis itself was a success, and she was awarded her doctorate from the University of Chicago in 1963.

Following completion of her degree, Joan joined the School of Criminology at UC-Berkeley, where her third fieldwork project focused on alienated African American youth in the Oakland school district. However, Joan's career in medical anthropology really took hold after she joined the UCSF faculty in 1968 as an assistant professor in the Community Mental Health Training Program in the Department of Psychiatry. At UCSF, Joan embarked on an academic career in medical anthropology that was characterized by almost continuous major fieldwork projects, nearly all of them funded by either National Science Foundation or the National Institutes of Health. Indeed, a remarkable aspect of Joan's life is that she has never stopped doing fieldwork, providing an inspirational model for her many students.

Gregarious by nature but also an extraordinarily intent listener, Joan loved the hundreds of hours she spent during nearly every year of her tenure at UCSF actually doing fieldwork, mostly in informants' homes in the Bay Area, but also in local support group meetings, national conventions, and many weekend powwows, luaus, and faith healings to which her informants invited her. She never tired of this ethnographic aspect of the discipline. Joan thrived on her solo research projects, sometimes embarking on five-hour marathon sessions of tape-recorded interviewing or observing support group meetings late into the evening.

Because of her special ability to establish deep rapport with study informants, Joan was welcomed into many of her informants' lives as a special, honored friend. Entering into reciprocal relations of friendship at a time when this was unheard of, and frankly eschewed, in the field of anthropology is another of the remarkable aspects of Joan's ethnographic career. Joan's model of "informants as friends" certainly made an impression on her many students and probably shaped their own ideas about the role of the anthropologist in informants' lives. Today, Joan continues to maintain friendships with dozens of informants around the country, receiving updates on their lives and visiting many of them on a regular basis.

Joan Ablon as Stigma and Disability Scholar

Although fieldwork is the defining feature of Joan's career in her own view, her contributions to the scholarly literature in medical anthropology are what define her for most others in the profession. Joan is best known for her pioneering research on a variety of important medical anthropological topics. All of her studies revolve in one way or another around the themes of stigma, suffering, and social justice, as elaborated in this special issue of *MAQ*. Because Russell Shuttlesworth and Devva Kasnitz have provided an excellent and comprehensive overview of Joan's scholarly contributions to the anthropology of impairment-disability (this issue), I will only comment briefly on Joan's career as a scholar. But a number of important features are worth noting.

For one, Joan's scholarly contributions have always been, and continue to be, novel and prescient. According to Joan, the topics themselves were often revealed to her through what she would describe as "serendipity." For example, while studying migrant Samoans' adjustment to life in the Bay Area, she noticed burn scars on the skin of many informants. This led to her study of burn disfigurements and bereavement among the survivors of a tragic church social hall fire that affected nearly one hundred Samoan families. Her interest in family coping strategies led her to the study of alcoholism among white, middle-class families of ethnic Irish, Italian, and German Catholic descent. Presaging many future studies in the anthropology of alcohol and substance abuse, Joan's research focused on the role that problem drinking can play in family conflicts, as well as how the self-help organization, Al-Anon, helped some families to cope with alcoholic members.

While working on this project in a Catholic parish in the Bay Area, Joan encountered a family with a dwarf child. During an interview with the child's mother, Joan learned more about Little People of America (LPA) and asked the woman if she could accompany her to a local meeting. Over the next 12 years, Joan attended almost every local LPA event in the area, many regional meetings, and eight of the national conventions held in cities around the country. Her exhaustive research project, involving long-term follow-up with twenty-four adult LPA members and six families with a dwarf child, resulted in the first two of Joan's books, *Little People in America: The Social Dimensions of Dwarfism* (1984) and *Living with Difference: Families with Dwarf Children* (1988).

Joan's study of dwarfs marked the beginning of a long scholarly engagement with three genetic conditions. Unlike dwarfism, the other two conditions, neurofibromatosis 1 (NF1) (mistakenly called "The Elephant Man's Disease" for most of the last century) and osteogenesis imperfecta (OI) (so-called brittle bone

disease), can be accompanied by significant physical impairment and disability.³ As noted by Shuttleworth and Kasnitz (this issue), Joan's work with these single-gene disorders can be considered truly foundational to two of the "hottest" areas in medical anthropology and science studies today—namely, the growing field of disability studies in anthropology (part and parcel of the larger disability rights movement), and research in genetics, prenatal genetic testing, and the creation of genetic knowledge, particularly in the wake of the human genome project. Yet, even though numerous well-known medical anthropologists are now engaged in studying the fields of disability and genetics, Joan's own work continues to stand apart. Joan is one of a handful of medical anthropologists whose ethnographic projects are concerned *primarily* with the circumstances of the lives of those affected by genetic conditions. Her research is notable for delving into three major domains: (1) the kinds of (psycho)social experiences shared by persons with stigmatized genetic health conditions; (2) the impact of a genetic disorder and any accompanying disability on both individual and family life; and (3) the role of social support systems and particularly therapeutic self-help groups in maintaining the physical and mental health of members. As Joan notes (1992:10):

Considerable stigma adheres to genetic diseases in American society. Issues surrounding genetic conditions are often extremely painful for family members, involving guilt, hostility, and resentment. For parents who have knowingly or even unknowingly passed on a hereditary condition to their children, there is often a heavy burden of guilt.

My interest centers on how persons with stigmatized health conditions cope with the daily insults which endanger their personal identity and self-image, their social life, and their economic opportunities. What individual and social patterns have emerged to provide short- and long-term psychological and social survival?

Joan Ablon as Action Anthropologist

Joan's concern with the individual and social well-being of individuals with stigmatized genetic conditions extends into an activist concern for social justice and helping to improve the lives of those with whom she works. Joan's activist stance was inculcated early in her career through her most important University of Chicago mentor, Sol Tax. Tax's own brand of "action anthropology" differed from early applied anthropology, the latter of which had often been used to serve colonial purposes. Instead, Tax's ethical stance insisted that anthropology must be applied to help solve the problems of informants themselves and that, in order to do so, informants must participate in defining their own problems and setting research priorities. Presaging later community participatory approaches to field research, Tax's action anthropology was built on a social justice model that would take years to develop in anthropology, including in medical anthropology. Yet, it was a social justice approach that was very appealing to the students in Tax's "action seminars," including a young Joan Ablon, who was Tax's dissertation advisee and teaching assistant. According to Joan (2000:5): "Tax's unswerving concern for the socially significant, and his pervasive sense of conscience in research procedure has vitally influenced my own work and that of his other action students."

Joan's action orientation a la Tax is clearly manifest in all of her genetic research. When she began working with dwarfs, she came to realize the many

negative images of dwarfs, including as creatures living in caves, as magical beings, or as "exotic sidekicks," perpetuated in the media and in children's games and literature. Thus, she took it as a personal goal to help demystify dwarfism for both health care professionals and the general public. Furthermore, as she explained (Ablon 2000:12–13):

Concerns about reciprocity were immediate for me. The responsibility for helping little people was a tangible goal I thought about a lot. A major contribution that an applied anthropologist can make to the lives of those she studies is to provide little known information on life style and personal and family issues for affected persons themselves, for professionals who work with them, and for the general public. We must be concerned with both the *availability* and the *readability* of what we produce for those who will use it.

Eschewing high theory, anthropological jargon, and inflated prose, Joan has attempted to write *for her informants*, such that an intelligent layperson can read and understand what she is attempting to say. Before she submits her book manuscripts to publishers, she has her informants carefully read and critique the manuscripts, a practice that is probably rare in medical anthropology and anthropology in general. Not surprisingly, her books have been extremely successful among members of self-help organizations. As noted by Shuttleworth and Kasnitz (this issue), Joan was also the first nonlittle person nonclinician to be given a lifetime honorary membership in Little People of America.

Furthermore, in her more recent book on NF1 (Ablon 1999), in her many scholarly articles on dwarfism, NF1 and OI, including some published in major clinical journals, and in presentations delivered at medical conferences, Joan has sought to enlighten the clinicians who work with individuals and parents of children affected by these conditions. The goal of this "clinically engaged" anthropology is to prevent the kind of "poorly informed and insensitive statements by doctors [who] have often created parameters of horror within which their patients might live for the rest of their lives" (Ablon 2000:15).

Joan's goal when writing for both informants and clinicians is, in effect, to normalize these stigmatized conditions—to show the life course of those who successfully live with these conditions, including the realms of dating, marriage, work and family life, and to improve the self-image of those living with the condition by writing sympathetic accounts that deconstruct sometimes horrific media-generated images and frightening clinical scenarios.

Joan's attempts to normalize genetic disorders have also made an impression in medical anthropology. As noted in a moving paper called "Dancing on the Edge of Normal: Otherness, Health, and Social Justice," delivered in the honorary AAA session by one of Joan's former students, Suzanne Heurtin-Roberts (2000:16–17):

Joan's work is essentially a dance. It is the exploration of normalcy, of margins between Self and Other, an artful movement among perspectives. In Joan's choice of topics for study, she steps across the margins in search of the "Other." She engages with extremely stigmatized (thus exceedingly "Other") populations. She unflinchingly regards those to whom "polite" society might avert its eyes. And she listens.

She hears and gives voice to those whom many of us in the "normal world" would just as soon keep silent. She insists that we hear, too. She returns across

the margin, the "edge of normal," bringing back news of the Other's experience and humanity. In this dance, edges blur, and Joan shows us that those "outside the norm" really may not be outside after all.

Joan Ablon's life work is an exemplary performance of the essential anthropological act, seeking the Other and finding the Self. Joan's lesson for us transcends the realm of the professional. . . . What we have learned from Joan Ablon's work is nothing less than a model for using anthropology to achieve social justice through integration of self and other."

Joan Ablon as Mentor and Mensch

No description of Joan Ablon's life and work would be complete without commenting on her many students and her role as mentor to them.⁴ When the UCSF/UC-Berkeley Joint Program in Medical Anthropology received formal approval in 1975, Joan immediately became one of the core faculty members. From 1977 until two years before her official retirement in 1994, Joan served almost continuously as either chairperson or vice-chairperson of the UCSF side of the program, alternating in those positions with Margaret Clark. Yet, this heavy administrative load, including the writing and rewriting of training grants to support students, did not prevent her from maintaining an active teaching load of five alternating courses (Field Methods, Life History Methods, Stigmatized Health Conditions, Comparative Family Systems, Contemporary U.S. Society). Furthermore, she worked individually with scores of doctoral students from the joint UCSF/UC-Berkeley medical anthropology program, UC-Berkeley's general cultural anthropology program, and UCSF's nursing school.

Joan was more than just another professor to these many students. In a delightful paper called "Honoring Joan Ablon: Professor as Mentor and Mensch," which Lisa Handwerker presented as the introduction to the AAA 2000 honorary session, eight of Joan's former students, who Handwerker interviewed for the purposes of the paper, described Joan variously as: mentor, confidante, good friend, official advisor, unofficial advisor, cheerleader, matchmaker, counselor, role model, supportive listener, mother, and (super) mensch. Clearly, these are not terms that apply to every anthropology professor! Yet, Joan's entire persona can only be typified as "extraordinarily caring," not only about her informants, but also about her students' professional and personal lives. As one of Joan's former students told Handwerker (2000:2-3):

I think what it comes down to is how much she cares about everything. She cares deeply about her students and wishes their well-being and success in all aspects of their lives. She cares profoundly about her work and has a real sense of urgency about this. She cares about ethical standards and about the lives of her informants. The key to Joan is caring, how much she cares about human well-being, both generally and individually. Joan really "walks the walk." I say the following with all honesty and without qualification: I have never met a more sincere or caring person than Joan Ablon.

Another former student told Handwerker (2000:5):

[Joan] has always been deeply committed to students, their work, their lives, their process of becoming anthropologists. I don't think she ever said 'no' to

being on a student committee or to reading student work, or helping a student out in one way or another. She maintains deep and lasting relationships with students, befriending many, and shows a great deal of respect for students at every level. She is a role model as a mentor. In all these ways, she is truly a mensch.

This issue of *Medical Anthropology Quarterly* is a testament to Joan's dual role as mentor and mensch. Nearly all of the authors⁵ in this special issue were Joan's students, representing the long span of Joan's involvement in the UCSF/UC-Berkeley medical anthropology program. The intellectual mentoring that Joan provided to each of us is apparent in our papers. Joan attempted to instill in all of us a profound sense of concern for the themes of stigma, suffering, and social justice. She has always cared deeply about those most marginalized in society, about their physical and social anguish, and she has argued that a legitimate role for the anthropologist is to attempt to alleviate social injustices, partly by identifying those injustices through detailed ethnographic work. True to Joan's legacy, all of the articles in this issue speak to these themes in various ways, including through rich ethnographic presentations. Although social suffering in its many forms cuts painfully across all of the articles, the first four articles speak primarily to issues of stigma, while the final three highlight social injustices in health and health care, primarily associated with poverty.

To highlight briefly, Russell Shuttleworth's and Devva Kasnitz's "Stigma, Community, Ethnography: Joan Ablon's Contribution to the Anthropology of Impairment-Disability" provides a major intellectual overview of Joan's work, arguing for its foundational role in the establishment of the anthropology of impairment-disability and the inclusion of anthropology in disability studies. In particular, the article examines Joan's contributions to stigma theory as advanced by Goffman, as well as her ethnographic contributions to gender studies. This paper is accompanied by an exhaustive bibliography and is a seminal article for medical anthropologists working on issues of stigma, disability, and genetics.

My own article on "Middle Eastern Masculinities in the Age of New Reproductive Technologies: Male Infertility and Stigma in Egypt and Lebanon" follows on the issues of stigma and gender by exploring the implications of male infertility for Middle Eastern men's sense of masculinity. Based on two recent ethnographic studies conducted in Egypt⁶ and Lebanon (where men may be at increased risk of male infertility), the article examines men's experiences of infertility, including the morally problematic solution for male infertility offered by the "newest" new reproductive technology. As this article argues, the implications of male infertility for gender, including men's gender identity and women's marital security, are often ambiguous and perplexing, suggesting the need for further research on men and reproduction.

Linda-Anne Rebhun's article on "Sexuality, Color, and Stigma among Northeast Brazilian Women" examines social suffering in another global site, where moral stigma inheres in the color of one's skin. Despite official Brazilian rhetoric of non-racism, darker-skinned women are often accused unjustly of illicit sexuality in conservative *favela* communities, dooming them and their children to lives of sexual exploitation and sexual violence, including rape. Through poignant ethnographic stories and elaboration of Goffman's stigma theory, Rebhun shows how

color constitutes a significant social and economic disadvantage for women living within this sexual and moral economy.

Women's lives are also the subject of Juliene G. Lipson's "Multiple Chemical Sensitivities: Stigma and Social Experiences." Through ethnographic research carried out in the United States and Canada, she shows how women suffer and attempt to cope with Multiple Chemical Sensitivity (MCS), an intolerance to everyday chemical and biological substances in amounts that do not bother other people. Because most physicians continue to dismiss MCS as a gender-based psychosomatic complaint, women suffering from MCS are confronted with demeaning social interactions in medical settings, workplaces, and among friends and family members. Lipson's article attests to the difficulties of living with a stigmatizing condition that defies easy medical categorization.

Similarly, Norah Schwartz's article on "Childhood Asthma on the Northern Mexico Border" examines the consequences of medical indeterminacy on the families of children with asthma in heavily polluted Tijuana, Mexico. Because physicians themselves are unclear about the definition, diagnosis, and treatment of asthma, using a variety of biomedical terms to describe this condition, they generate considerable confusion among mothers who are attempting to cope with their children's often frightening breathing problems. As Schwartz shows, the result of this parental confusion is inconsistent and ineffective treatment, often delivered by pharmacy clerks who prescribe, among other things, inappropriate antibiotics. Furthermore, children most at risk for asthma and poor therapeutic outcomes are from poor, dusty, insect-infested homes in Tijuana, sometimes many miles from the nearest clinic site. Thus, Schwartz's article speaks to issues of poverty, social injustice, and lack of child health and well being in a region so close to the wealthy United States.

In another global site, rural Mongolia, Craig Janes and Oyuntsetseg Chuluundorj confront similar issues of poverty, social injustice, and poor maternal health and well being in their article on "Free Markets and Dead Mothers: The Social Ecology of Maternal Mortality in Post-Socialist Mongolia." Janes and Chuluundorj describe in painful detail the ill-fated, neo-liberal economic reforms taken in Mongolia during the past 14 years following the breakup of the former Soviet Union. The result has been increasing poverty and immiseration for both rural and urban Mongolians, and the breakdown of a once-functioning system of prenatal care and maternity waiting homes for rural women. Janes and Chuluundorj chart these dramatic changes, examining both epidemiologically and ethnographically the significant increases in maternal mortality in the country.

The final article in this special issue, by Gay Becker, is dedicated to issues of poverty, social injustice, and lack of health and well being for uninsured ethnic minorities in the United States. In her article entitled "Deadly Inequality in the Health Care 'Safety Net': Uninsured Ethnic Minorities' Struggle to Live with Life-Threatening Illnesses," Becker provides a moral critique of the structural inequalities in U.S. health care, which force uninsured individuals to seek care from a supposed "safety net" of service providers. Based on a large-scale ethnographic study among African Americans and Latinos without health insurance, the article examines this safety net from the perspective of chronically ill patients who must use it. Their narrative critiques of both the quantity and quality of health care services are incisive, leading Becker to conclude that the health

care safety net may, in fact, be injurious to the health of uninsured people in our country.

Together, these articles speak to the themes of stigma, suffering, and social justice, which Joan Ablon has always deemed to be profound issues facing medical anthropologists. For those of us fortunate enough to have worked with her, Joan taught us well. We can only hope that this special issue of *Medical Anthropology Quarterly* begins to attest to her tremendous intellectual and personal legacy.

NOTES

1. I am grateful to Sandra Lane for co-organizing this AAA invited session.
2. Not all of the 12 papers in the AAA session are published here. Calls for *MAQ* papers were issued after the session, resulting in a new mix of papers. All of the articles in this special issue also went through the normal *MAQ* peer review process, under the able direction of Pamela Erickson.
3. The primary manifestations of NF1 are neurofibromas, or internal and external nodular tumors, which develop in and along nerves and nerve sheaths. External neurofibromas may number in the hundreds and may be cosmetically disfiguring. Internal neurofibromas may impinge on vital organs, impede mobility, and develop into malignant tumors. Learning disabilities, scoliosis, and other skeletal problems may lead to dramatic impairment. The course of NF1, furthermore, is unpredictable and can manifest very differently among individuals. Osteogenesis imperfecta, or so-called brittle bone disease, represents a group of congenital disorders of collagen synthesis. Affected individuals are susceptible to multiple bone fractures, even with mild trauma, such that children and adolescents commonly experience more than 100 fractures by adulthood. OI often necessitates frequent long-term hospitalizations for repair of broken bones and highly invasive prophylactic measures. The most severely affected persons with OI are typically very small, weighing only 50 to 90 pounds, and have the need for motorized wheelchairs.
4. Although the role of mentorship has been little appreciated in our profession, the Society for Medical Anthropology has begun to recognize its importance through the creation of an annual mentoring award, to be given for the first time in 2004 at the American Anthropological Association annual meeting.
5. Only Oyuntsetseg Chuluundorj, coauthor with Craig Janes of the article on "Free Markets and Dead Babies," did not work directly with Joan as her student.
6. Joan actually came to visit me during my earlier doctoral dissertation research in Egypt, the only professor to do so. We traveled down the Nile together, and she also visited the small Egyptian Delta hamlet where Sandra Lane, another of Joan's former students who was also living in Egypt at that time, had carried out her doctoral research.

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Heurtin-Roberts, Suzanne

2000 "Dancing on the Edge of Normal: Otherness, Health and Social Justice." Paper presented in an invited session on "Stigma, Suffering, and Social Justice: Papers in Honor of Joan Ablon" at the 99th Annual Meeting of the American Anthropological Association, November, San Francisco, CA.

RUSSELL P. SHUTTLEWORTH

Institute of Urban and Regional Development
University of California, Berkeley

DEVVA KASNITZ

Institute of Urban and Regional Development
University of California, Berkeley

Stigma, Community, Ethnography: Joan Ablon's Contribution to the Anthropology of Impairment-Disability

Joan Ablon has helped establish the anthropology of impairment-disability and significantly contributed to the role of anthropology in disability studies. In this article, we review the development of and situate Ablon's ethnographic research in the anthropology of impairment-disability. We then address various methodological issues in her work including her ethnographic approach, her grounding in action anthropology and her support for the development of the academic study of disability in anthropology and the careers of disabled anthropologists. The next section of the article examines Ablon's use of the notion of stigma, her understanding of community, and her engagement with disability rights. As examples of themes important to disability studies, we present her discussion of the implications of the ideal of the body beautiful, and gender differences in negotiating intimacy for people with physical differences. We close with a discussion of the future of an anthropology of impairment-disability. [disability, impairment, Ablon, genetics, ethnography]

Joan Ablon has contributed immeasurably to the anthropology of impairment-disability. Anthropologists regard Ablon's research with stigmatized populations such as dwarfs (1984, 1988) and people with neurofibromatosis 1 (NF1) (1995, 1996a, 1999a) as important studies in medical anthropology and look forward to her upcoming book on people with osteogenesis imperfecta (1999b).¹ Disability studies scholars outside of anthropology and the voluntary associations of her informants read and promote Ablon's work. This article examines Ablon's topical, methodological, and theoretical perspectives. We assess her contributions

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