

**Thinking About Stigma:  
What the Health and Human Rights Movement and the  
Jewish Health and Healing Movement Can Learn From Each Other**

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It is an honor to be asked to deliver this paper to such an august gathering. I am very grateful to my old friend, Rabbi Bill Cutter, for inviting me to do so. I want to thank Lisa Kodmur, the Kalsman Institute's assistant director, and Mari Chernow, its rabbinic intern, as well.

I also want to thank Mark and Peachy Levy. Not only are they the Institute's leading benefactors, and two of Reform Judaism's most tireless and selfless supporters. They are dear friends of long-standing. It is in their honor that I wish to dedicate this paper.

I dedicate this paper, as well, to the memory of Herman Feifel, who died this past week. Dr. Feifel was a psychologist whose pioneering work in the field of death and dying predated by a decade the work of Dr. Elizabeth Kubler-Ross. I had the privilege of serving with Herman many years ago on the board of the Jewish Hospice Commission of Los Angeles.

The issue of stigma as a major barrier to effective health care has emerged in recent years as a leading-edge issue among public health policymakers. At the same time, among the public at large, and religious communities in particular, an intriguing discussion about what is healing and what is health has also been emerging.

My purpose this afternoon is to comment on ways these two issues -- stigma and healing -- affect and inform each other. A common link, I will suggest, is how each is concerned about overcoming separation -- stigma with respect to the self in community, and healing both in the experience of the self within, and in its relationship to God.

I stand on the shoulders of three teachers in this endeavor. The first is Rabbi Wollie Kaelter. Wollie was one of the five rabbinical students sent by Leo Baeck from Berlin to Cincinnati in 1935 to finish their studies, and to save their lives. Wollie came to my hometown of Long Beach, California forty-seven years ago, the year before I started kindergarten, and to this day remains a teacher, a friend, and an inspiration.

The second is the late Professor St. Clair Drake of Stanford University. Drake introduced me to the complex, subtle ways that stigma structures society, and was one of the pioneers in developing theory and analysis for undermining its pernicious effects. Drake was the co-author of the classic study of black urban life, *Black Metropolis*, and an intellectual disciple of that giant in the study of race, W.E.B. DuBois.

The third is Professor Kenneth Karst, now emeritus professor of constitutional law at UCLA. Karst's discerning work in the constitutional treatment of equality and difference is one of the most clear-sighted legal bodies of work on the subject. Ken's support was crucial during my first halting attempts to look at law, health and meaning.

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Like for so many of us in this room today, those first halting attempts to ask the questions that became the professional passion and expertise that bring me here began with a painful personal experience.

During my second year of law school, my great-aunt Edith took her own life rather than go into a hospital to die. Several of us knew of her general intent, but I was unprepared one Wednesday night in January of 1977 to realize during a visit at her assisted living facility that she was saying goodbye.

Incredulous and numb, I learned from my mother later that night that I had understood correctly. She would be doing it the next night.

"When we visited last Friday," my mother said, "she asked for two packs of cigarettes instead of her usual carton, and gave us a bunch of clothes to give away."

"But how do you know it will be *tomorrow* night?" I asked.

"Because [her son] is due to visit in the afternoon, and she wouldn't do it before then. But if she does it that night, then the nursing home staff will find her Friday, and the funeral could be Sunday. She'd always said she'd make sure not to inconvenience anyone with a weekday funeral."

The morning of the funeral -- that *Sunday* -- my mother rushed up to me. "You didn't tell anyone she took an overdose, did you? You didn't tell anyone we knew she was going to do it?"

There in Mom's fear was the truth of Erving Goffman's famous definition of stigma -- that it is "spoiled identity" -- in all its heart-wrenching power. We feared the shame and stigma in our community should anyone learn that we had "let" Aunt Edith die. My family's twenty-five year standing as decent, respected members of the Long Beach Reform Jewish community was at risk with such a disclosure.

Aunt Edith died just a year after the *Quinlan* case. That was the first case to ask when, if ever, we could “pull the plug”. To try and make some sense of the haunting moral questions posed by my aunt’s death, including the complex role of stigma and shame, I began to research and write.

The question Aunt Edith had no vocabulary to pose was this: “Why must I face the indignity of meaningless, invasive ‘treatments’ of multiple ‘symptoms’, while it is a whole ‘me’ who is going to die?” I soon discovered that hospice would have been an answer.

The hospice movement was then just emerging in the United States. There were only five programs in the country, but two were in Los Angeles, so I began studying them. But a concern soon arose.

This wonderful, well-meaning movement was pervaded by the Protestant Christian ethic of its founder, Dame Cicely Saunders of Great Britain, and the growing popularity of Dr. Elizabeth Kubler-Ross’s positivistic, five-stage schema for the “right” way to die.

“How,” I began asking, “could hospice’s marvelous core practice be adapted to resist these homogenizing tendencies and incorporate the ways *different* cultural, ethnic, and religious communities approach death?” In 1980, I had an opportunity to present those concerns to the Los Angeles Jewish community.

The Council on Jewish Life of the Los Angeles Jewish Federation, a blue-ribbon, commission of lay and professional leaders, invited me and a wonderful oncologist and colleague, Dr. Robert Taube, to present our thoughts on what a Jewish hospice might look like.

The Council, I should note, was led by a brilliant staffmember, Jerry Weber, *zichrono livracha*, the late husband of Sally Weber, an insightful and innovative thinker in her own right who is today a key advisor to the Kalsman Institute.

Following our presentations, a member of the Council, Maurice Lamm, a Modern Orthodox rabbi and author of a leading text on Jewish death and mourning practices, agreed to chair a committee to develop a plan in response. Herman Feifel, *zichrono livracha*, agreed to serve on it, as well. That committee soon became the Jewish Hospice Commission of Los Angeles.

Under the leadership first of Rabbi Lamm, and later of Rabbi Elliot Dorff, perhaps Conservative Judaism’s leading thinker on bioethics, we developed programs and materials that supplemented secular hospice care with specifically *Jewish* elements and practices. At the same time, we launched a parallel effort to educate the *Jewish* community about the potential of Jewishly-enriched hospice to deepen the meaning of Jewish dying.

Sound familiar? The short life of the Jewish Hospice Commission twenty years ago presaged the robust movement represented here today at this conference that proclaims that there is a profound, *necessary* place for a Jewish presence, and Jewish voices, and a Jewish *praxis* of health, and care, and healing.

And so now you know half the reason why it is such a special experience to address you today. Here is the other.

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Since 1986, I have been engaged in the emerging field of what is now called “health and human rights”. A core concern of this field -- which develops jointly out of public health and law -- is how stigma and discrimination create barriers to health and health care access.

I want to sketch a brief history of this field for you, and then comment on how the important religious insights emerging from the Jewish health and healing movement might by turns be illumined by, and further illumine, the powerful insights of the health and human rights movement about stigma and discrimination.

The movement emerged out of the AIDS epidemic, from the work of Dr. Jonathan Mann, in particular. Jon was the first global AIDS epidemiologist. While working for the World Health Organization in the mid and late 1980s, he sought to alert governments around the world to the impending devastation of HIV -- the impact of which, I might add, has only in recent years been “discovered” by the press and policymakers in the United States and Europe.

Like public health experts before him throughout the 20<sup>th</sup> century, Jon was trained to present compelling data, and have public officials respond. Public sanitation, clean water, vaccinations and antibiotics were such powerful disease-fighting tools that politicians could do no less.

So it was with growing shock that Jonathan found government after government turning a deaf ear to his projections, despite the compelling data at hand. And eventually, he came to understand why.

AIDS occurs in a *social* field of attitudes and beliefs about such provocative issues as sexual behavior and drug use. AIDS interventions challenge those attitudes.

Empower women to require their men to wear condoms? In many parts of the world, women are still expected to be compliant. Educate the working poor about condoms? The entire health budget of developing nations might be insufficient to provide condoms to everyone. Convince the ruling elite in such countries that they might bring home to their wives diseases from the sex workers they visited? The elite were the elite. They were not to be told to curb their passions and desires.

Even today, here in the United States, distribute clean needles to drug addicts? American policy under Clinton forbade the use of federal dollars to do so (a decision he now regrets). Teach abstinence *and* safe sex? Today, the Bush administration is re-directing dollars *away* from safer sex programs and towards abstinence only ones.

And from the beginning, here at home, stigma and prejudice against gay men impaired the alacrity with which policymakers came to understand that HIV was happening to *us*, not a despised *them*.

By the end of the 1980s, Jonathan Mann had begun to write about the inextricable link between health and human rights. At the same time, here at home, AIDS public health officials and the first AIDS lawyers were discovering a parallel understanding.

Domestically, we talked about the conflict between public health and civil rights as being false. Public health and civil rights were two means to collectively ensure the health of the body politic.

Public health officials understood this as they began to see how the fear of stigma and discrimination was a barrier to persons voluntarily coming forth to be tested. We AIDS lawyers learned the companion truth as we discovered that the civil rights laws we enforced required employers, landlords and business owners to learn the facts about HIV transmission, since only a medical justification could be an adequate defense to an AIDS discrimination claim.

Here in Los Angeles -- which enacted the world's first AIDS discrimination law - - and soon thereafter, in New York and San Francisco, my colleagues and I made the surprising discovery that civil rights enforcement could facilitate public health education.

In the course of investigations of landlords summarily evicting tenants suspected of having AIDS, dentists refusing to treat patients, and employers sending suspected employees home with the admonition, "You'll receive your paycheck every two weeks until you die. Just don't ever show up here again," we AIDS civil rights lawyers found ourselves serving as de facto public health educators.

Time and again, we found beneath the homophobia that there was also a profound, misplaced fear of contagion, that there was intense confusion over the basic facts of HIV transmission. Time and again, we found ourselves conduits of trusted information about how HIV was and was not transmitted, and in a surprising number of cases, watched fear and bigotry give way to, if not love and compassion, at least reasoned discussion about risk and transmission.

Jonathan Mann at the international level, and we at the local level, learned that health and human rights were inextricably linked because of stigma, shame and denial.

Jon's tireless advocacy eventually led to the establishment of the Center for Health and Human Rights at Harvard, the publication of a scholarly journal, and a series of international conferences that have continued since his tragic death in the crash of Swissair Flight 111 over Nova Scotia on September 2, 1998.

Because of Jon's work and that of his colleagues, health policymakers have begun to consider more deeply the role of stigma and discrimination as barriers to health and health access. Sixteen months ago, the National Institutes of Health convened an unprecedented three day conference solely on the topic of stigma and health, the proceedings of which are available on the NIH's website.

With specific respect to HIV, the Centers for Disease Control and UNAIDS -- the United Nation's global AIDS agency -- have also embraced this approach. Fourteen months ago, the CDC adopted a guideline recommending that all persons newly testing positive for HIV be referred promptly to attorneys for counseling on preventing discrimination by protecting privacy in employment, housing and public accommodations.

The CDC adopted this guideline because it was concerned that the rate of new infections has remained steady in the US at about 40,000 a year, and had already documented that the fear of stigma and discrimination was a major reason people were unwilling to come forward to be tested. The CDC concluded that by adopting this guideline, if newly tested persons counseled to protect their privacy suffered less discrimination, then their friends and others in their communities would be less afraid to come forward to be tested, too.

Meantime, UNAIDS has recently documented the global nature of AIDS stigma and discrimination, with case studies in countries as different as India and Uganda. Last month, the UN declared the theme of World AIDS Day to be combatting stigma and discrimination. And just this month, the *New York Times* reported from China on infected people's overwhelming fear there of revealing their condition to others.

Truly, the impulse to scapegoat and blame is universal. So what does that have to teach us about stigma and the Jewish health and healing movement?

Let me close this brief discussion of stigma, health and human rights with a story intended as a bridge to the final portion of my talk this afternoon.

As you heard from my introduction, I was the nation's first government AIDS discrimination attorney, and have now served in that capacity for a *very* long time -- seventeen years tomorrow, to be exact. Once I came to understand the complex nature of my *own* fears about HIV, and then to address others' fears, as well, I fashioned a language about our AIDS discrimination law that I want to secretly admit to you I think was very Jewish.

I argued that in past epidemics, law justified and reinforced the scapegoating and discrimination that has been a constant feature of epidemics and other social crises since time immemorial. I had in mind two examples in particular. One were the edicts and orders that permitted the drowning of Jews and “witches” for being “causes” of the Black Death in 13<sup>th</sup> Century Europe.

The other was the U.S. Supreme Court’s decision sixty years ago upholding the internment of Japanese-Americans during World War II, a decision that turned a blind eye to the government’s failure to be consistent in its strategies to root out “subversives,” since Italian-Americans and German-Americans were never subjected to similar orders. Again, “spoiled identity” -- Goffman’s term -- this time, spoiled for being racially distinct from the majority of Americans’, was crucial in determining who would be singled out for stigma and blame.

Law may have performed a different function for the first time in the AIDS epidemic.

In my work I have always argued that Los Angeles’s law, and the state and national laws that followed, resisted the virulent impulses that were breaking out to scapegoat and blame people with AIDS. Instead, our laws required that they be treated with dignity and respect, just like anyone else who was sick.

Like the ethic of Self and Other embedded in *halakha* -- to treat the Other who is poor, or a stranger, or widowed, or an orphan with justice and compassion “because remember, you too were once slaves in Egypt” -- modern civil rights laws, and by extension, the health and human rights movement, resist the impulse to fracture into “us” and “them,” resist the impulse to spoil others’ identities in order not to feel the threat to our own.

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And so now, for the final third of this paper. What about this conversation I’ve promised you between the Jewish healing movement and the health and human rights movement’s insights about stigma?

First, I would suggest that the Jewish health and healing movement must take a hard look at the role of stigma in Jewish life. Stigma -- and its darkest partner, the fear of death -- are not recognized well-enough as barriers to the opening up of American Jewish life to the rich potential of the Jewish health and healing movement.

The 60s folksinger Phil Ochs said it well: “A liberal is ten degrees to the left of center in good times, ten degrees to the right of center when it affects him personally.”

Liberal Jews -- whom I am assuming are the primary audience of the Jewish health and healing movement at this stage -- have long exemplified the mordant truth of Ochs’s observation. They have been good at addressing stigmas that do not affect them

personally -- the oppression of blacks in the early 1960s, for example, or of Soviet Jews in the 1970s.

But when it affects us personally, our track record is not so good. The Episcopal Church, for instance, far outshone the Reform Jewish community in its aggressive, organized response to AIDS. AIDS didn't occur "over there" somewhere. It occurred *within* our community, and when I served on the Reform Movement's national AIDS committee in the late 1980s, we heard story after story of the families of persons with AIDS terrified to turn to their rabbis and congregations for support for fear of stigma and rejection.

For reasons I hope we discuss throughout this conference and beyond, liberal Jews have not yet learned to overcome the ways we hide the daily truth of illness and suffering and death in our congregations, instead of acknowledging through ritual, word and deed that illness and death are *normative* parts of the human condition, and therefore of the *Jewish* condition.

They are conditions that require the best of community, and ritual, and the making of meaning. Instead, we hide -- and *stigmatize* -- illness and suffering in subtle, insidious ways.

We ask our rabbis to be our bearers of words of comfort and Torah, not ourselves. We ask Jewish health care professionals to bear the unreasonable burdens, to do too much of the work of healing, that society as a whole unreasonably asks of all doctors and nurses. Just weeks ago, a friend told me the following story.

Her elderly uncle had just died. In the days before his death, all his organs were failing. His wife, her aunt, bewailing his fate, implored her brother-in-law, my friend's father, the dying man's brother -- a doctor -- "to *do* something, can't you *do* something for him? None of his doctors will." My friend later turned to her father and said, "What was she expecting? You're a *doctor*, not a *magician*."

She was expecting that there is magic that can save us from the truth of God's world: that we sicken and die.

We burden doctors and nurses with too much, and then are surprised that they react by keeping us dependent, or at arm's length, or by pretending that they *can* play God. The Jewish health and healing movement needs to find ways to relieve health care providers of such expectations, so that they can better engage in the healing arts and skills that they *do* have.

The Jewish health and healing movement needs to continue its project of refining what we mean by healing altogether, and the role of community in it. This project is part of the larger movement of medical care away from its 20<sup>th</sup> century paternalistic roots.

Twenty-five years ago, Dr. Jack Provonsha of Loma Linda School of Medicine presciently noted that in moving out of the paternalistic model, medicine risked moving into one based not on *covenant*, but on *contract*. And that is certainly the dominant movement we have seen since. See “managed care” and “health maintenance organizations”.

But *care* can never be a *contract* between doctor and patient, like one between mechanic and car owner, because care is an art and a mystery, and not a set of techniques. It can't be based in contract. But it can be based on covenant.

We Jews know something about covenant. We need to develop the rituals and the liturgy and the places of study that allow us all -- lay people and rabbis, doctors and nurses, alike -- to root ourselves more deeply into the sacred work of caregiving . . . and care *receiving*, I might add.

For that, we need to begin to acknowledge stigma, for it is stigma that enables our rejection of the sick, and the suffering.

We must acknowledge that stigma does not just operate at the grotesque levels of racism and homophobia, for example. It operates within our communities at the most subtle level.

“Oh, I wonder where Bob is? He hasn't been at shul lately.”

Too often -- and hear I steal from our next speaker, Professor Adler -- we risk answering such questions with *techniques* instead of *ourselves*. Is it convenient when a congregation creates a “caring community” instead of making the praxis of the congregation more caring? Is it to distance the norm of the congregation from the reality of the sick and the suffering and the worried when it creates special healing services rather than worship that is more healing?

How can the Jewish health and healing movement resist the community's impulse to use the movement's wisdom as *techniques* to segregate the needs of the sick and the suffering from the congregational mainstream, so that the congregation, itself, remains *unspoiled*?

Yes, so that the identity of the normative congregation can remain unspoiled.

There was some work in anthropology decades ago the citation for which I have been unable to find, but the work called the process of shifting alliances of self and other “segmental opposition.” It works like this.

I normally can't get along with Otakwa here in my village. But when the neighboring village attacks, Otakwa's my best friend here along the warriors' line of defense.

Our village constantly quarrels with the next village, Tomah . . . until the villages from across the river, Rahak and Bonah, attack us both. Then the warriors of Tomah and the warriors of our village are as one.

And so on.

This impulse to define self or community by what is *not* -- by what is *spoiled* -- is universal. But it *is* capable of change, what we might even call redemption.

We have within our tradition the commandment to resist the impulse to define self by what is spoiled, for we are told over and over to remember the stranger, for once we were strangers, too.

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So let me close by discussing that most spoiled identity of all, the spoiled rot of death. Or to put it more lightly, Patrick Henry's second choice.

Death is the rot at the root of our life. It is the *tumah gedolah*, the greatest despoiler, the threat to all we hold precious, all we love, ourselves, most of all.

I learned something early in my hospice work about death I've always been sure to include in all of my talks on AIDS. I discovered its power the first time I spoke to a group of people *with* AIDS.

I was newly appointed to my position when I attended a community gathering to learn *from* the people there. And yet they wanted me -- the City's new AIDS lawyer -- to tell *them* something.

So carefully, with great trepidation, I told them this. I said, "I learned during my hospice work that as frightening as death is universally, we modern people have a particular, new problem with it.

"As recently as 100 years ago, people died at home. Animals were slaughtered in the back yard, or at the village butcher shop. Everyone, rich and poor, old and young, at all times and places, throughout the world, knew from childhood what death looked like, and smelled like.

"But today, we are the first generations of people -- if we live in a country that is rich enough, and if we are prosperous enough ourselves -- to have death removed from daily experience. People die at hospitals. Animals are slaughtered hundreds of miles away.

"We have specialized professions that are around death -- or its threat -- all the time: police officers, paramedics, emergency room workers, soldiers, clergy. *They* develop gallows humor to distance themselves from death's ever-presentness. Yet the

rest of us know in our cells that death is real, but lack the daily palpability of its presence. We can grow up and not lose a loved one until our thirties or beyond.

“So all of us -- those around death all the time, and the rest of us who ‘know’ it’s real but don’t know its face -- all of us modern people have problems facing its truth. And AIDS now is a terrifying, new sign that death is, in truth, still here.”

I have never forgotten the tears of relief from the men in that room who crowded around me afterwards. “Thank you,” they said over and over again. “No one is talking about death. It’s the great elephant in the room everyone’s pretending not to notice.”

Goffman knew that “spoiling identity” was a way to displace our fear of that ultimate despoiler. Ernest Becker in his classic, *The Denial of Death*, discussed that in great detail.

As the Jewish healing movement -- your programs around the country, the Kalsman Institute at Hebrew Union College, the Reform Movement’s Department of Family Concerns, and more -- mine the tradition for fresh meanings, renewed words of comfort and blessing and prayer, as we sing Debbie Friedman’s beautiful “*Mishaberach*” and encourage the composition of additional songs of comfort, we need to remember the rot at the root of our discomfort.

There is grief and anger, loss and abandonment, wordlessness and lament about the mystery of our bodies, our selves. Made in the image of God, the material of our making is of the earth -- bloody and unstable.

The Jewish health and healing movement must find ways to confront the truths of that instability, the truth that at root we rot, as well as dance and sing and love and pray. The encounter of stigma and health and human rights suggests that in doing so, we can redeem ourselves from the stigmatizing behaviors that that terror provokes.

In its place, we can create prayers and psalms and words of hope and comfort that address us all, not just the ones among us who are sick or suffering.

It is a tremendous challenge for the Jewish health and healing movement to find ways to assist synagogue communities to see that the dying and the “spoiling” are part of the *normative* body of the synagogue, to see that *they* are part of *ourselves*, part of *k’lal yisrael*.

I hope that as we struggle with that challenge this weekend, and when we return to our home institutions, that through the on-going, living Jewish covenant we might continue to create sacred space that overcomes the isolation of stigma and loneliness, a *makom kadosh*, a holy place for us *all*.

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