

# JEWISH AGENCY SERVICES TO PEOPLE WITH AIDS AND THEIR FAMILIES

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*[to serve AIDS sufferers is] to do work that is deeply empowering, life-affirming, and worthy beyond any question or doubt [giving] the opportunity to renew and clarify my own deepest commitments.*

**I**n my city, four people will be diagnosed with AIDS today. In all probability, four more will be diagnosed tomorrow, and the next day, and so on throughout the summer and for an indefinite period of time. And of these people diagnosed in San Francisco this summer, easily 25 of them will be Jews.

In May, the New York City health commissioner stated, "We've got to stop thinking of AIDS as just a public health problem and start thinking of it as a social phenomenon."<sup>1</sup> Clearly, we are all in the midst of a major crisis. This is a crisis that has not yet peaked, and, despite all our wishes and prayers, is not going away.

So what do we know as Jews about dealing with crises? By necessity, and by history, we know a lot. We know how a crisis can engender fear, and we unfortunately know what fear can do to people. They might turn their heads and hearts, pretending not to see what's going on; they might believe that if the crisis doesn't hit them visibly and directly, it doesn't affect them at all; or worse, their fears might seek out a target for anger, rejection, or scapegoating, in the attempt to find someone(s) to blame. We as Jews know that too well, during epidemics, and at other times of fear and instability.

But we also know the power of community, and that a crisis is a time to pull

together, not pull apart. We know that a united communal response doesn't make a problem disappear, but is far preferable to dealing with our fears as isolated individuals.

This report is of one Jewish community's response to AIDS, as it is evolving. We are creating one model, not the only possible model. We urgently hope ways will be formed to adapt it to your own communities.

Late in 1985, a group of Jewish agencies and synagogues came together in San Francisco to look at their own response to AIDS, and lack thereof. This group, the Jewish Emergency Assistance Network (JEAN), had come together a few years before in response to homelessness as a crisis in the community. Now it was time again.

JEAN members began to investigate issues and needs. They heard from Gay/Lesbian outreach congregations who had already been coping with AIDS for several years: tending to the sick, comforting the bereaved, collecting food, raising money, and providing emotional and spiritual support in countless ways. JEAN members studied requests for assistance which were beginning to emerge at Jewish Family and Children's Services, the Northern California Board of Rabbis, and at some congregations, including Temple Emanuel, whose rabbi had devoted his Kol Nidre sermon to AIDS. But the calls for help came quietly and tentatively, accompanied by fear of getting an ill-informed or unsympathetic response at a time of extreme vulnerability.

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Presented at the Annual Meeting of the Conference of Jewish Communal Service, Kiamesha Lake, New York, May 26, 1987.

1. New York Times, May 25, 1987

In addition to these direct human concerns, JEAN saw the unmistakable need for community education. Even among informed and sophisticated adults, misinformation and confusion about AIDS persisted. In addition to common myths about the virus and its transmission, people continued to believe that this wasn't really happening [or at least, not to Jews], that it might be okay for our young people to grow to sexual maturity without information that could potentially save their lives, or that it just wasn't clear what a Jewish response to all this should be.

JEAN wrote a proposal to the Jewish Community Endowment Fund to start a community-wide AIDS project based at Jewish Family and Children's Services. The consortium also published a brochure entitled "AIDS and the Jewish Community" and distributed it widely during the High Holidays of 1986. Meanwhile, the JEAN project was funded, a coordinator was hired, and we embarked on a new and dynamic phase of the work.

Much of what we do in the AIDS Project is inspired by the *mitzvah* of *bikkur cholim*, which I have come to understand in a new way. I see it as meaning not only "visiting the sick," but as a broader mandate to ensure that those who are sick or disabled are not isolated from community, especially at the times they need it the most. This means that we not only visit people, but that we offer counseling, support, emergency financial assistance, and all the services we provide to any Jew in need. *Bikkur cholim* also means advocacy: for example, to ensure adequate funds for home care, allowing people to be neither isolated at home nor unnecessarily hospitalized. And *bikkur cholim* means protesting—forcefully and unequivocally—the lingering stigma and discrimination that unnecessarily isolate people with AIDS, their families and friends.

The project has pulled together an AIDS Family Assistance Network, composed of lay people who take *bikkur cholim* seriously and want to do something to

help, whether that means picking a family up at the airport and bringing them to their son's hospital room, escorting a woman grieving for her brother to Shabbat services, or bringing food to a family sitting *shivah*.

One family we helped involved a man in his 30's—brilliant, creative, and seriously disabled by the AIDS virus—and his mother, who came from Florida to stay with him for the duration of his illness. A JFCS social worker saw the man every week at his home, helping him deal with pain, frustration, loss, and his own mortality. His mother came in to talk every other week, with more contact as the end approached, to spill out her own thoughts and feelings, to grieve in anticipation of her son's death, to speculate about life without him, and finally, to make funeral arrangements.

Another man in his 30's called us after returning home from the hospital. He was recovering well and was in good spirits, but had fallen behind on rent and utilities, and would now be subsisting on disability income. How would he catch up? We helped him financially, and other issues arose: Who could he talk to about Jewish attitudes and rituals of dying and death? And was there a rabbi in his home town who might talk with his parents? This man is now finding answers to his questions, is doing very well emotionally and holding his own physically. And his parents have two rabbis to call on, when and if they feel ready to do so.

There are many more, of course. They are men and women. Gay and straight. Americans and Israelis. All Jews. The web of people directly affected by AIDS continues to grow wider. And whether already known or not, they are in all communities. For the most part, they will not come forward unless specifically informed it's okay. This is true with AIDS, as it is true for other stigmatized issues we would often prefer not to look at (e.g., substance abuse, domestic violence). That speaks to the need for outreach and to the other

main component of our project program—education.

Jews, as others, have many questions about AIDS these days. What is the latest medical research? What is it like to tell your family about your diagnosis? Are we really sure about how the virus is transmitted? What about saliva, tears, mosquitoes? What about the blood supply? What is “safer sex?” What can a congregation, youth group, B’nai Brith lodge, etc., do about AIDS?

There are many questions out there, and much information and misinformation. People need a place to sort it all out, to ask questions, to get the facts. We need opportunities to come together as a community, voice our fears, and be empowered to act. And in Jewish settings, we can address these issues in the context of Jewish ethics and historical experience.

The educational programs the San Francisco project has done so far have been mostly for Jewish teens and their parents, with a presentation to everyone before separating for questions and discussion. The information is presented carefully, with the assumption that our young people may or may not be sexually active now, but will at some point need this information, or know other people who do. Information about drug use and sexual practices is explicit, as it must be. You cannot talk about a sexually transmitted disease without talking about sex, and, we must understand, we are talking about saving lives. We are talking about *pikuach wefesh*, which takes precedence over our comfort. And once a difficult but important issue is brought out in the open, it’s not quite so uncomfortable anyway.

So we speak to confirmation classes, adult education programs, *chavurot*, singles groups, USY conventions, ORT chapters . . . anyone who will listen. And more people are listening, with their hearts as well as their ears.

There is another component of our project—participating in positive interfaith

responses to AIDS. Several of us in JEAN were actively involved in planning and speaking at a major conference on AIDS and ARC in March, which took place in a synagogue, as well as a Catholic and a Lutheran church. We also work closely with sectarian social service agencies in our community. This activity is especially important given the judgmental negativity, the exploitation of people’s fears and prejudices, or simply the deafening silence that came from the religious community in the earlier years of this epidemic. Now, many faith communities are catching up to where we should have been all along.

So where does this all leave you? You have Jews with AIDS or ARC, their families and friends, or people with AIDS-related concerns in your communities. You have Jews involved as health professionals, as social workers, as educators dealing with AIDS, whom you can draw on as a resource, as you nurture and support them in their work. You may not have these people in great numbers, but they are there.

Now you need to educate. You need to advocate. You need to provide services to Jews and to others in need, the way you always do.

Jewish community centers can incorporate AIDS education into teen, singles, and general adult programming.

Jewish community relations councils can take an active role in protecting the civil liberties of people with AIDS, and in lobbying for funds for AIDS health care, social services, education, and research.

Bureaus of Jewish education can educate religious school principals and teachers, parents, and the staffs and teens on Israel trips.

Jewish vocational services can provide job counseling and referrals for people with AIDS and ARC who need to shift away from full-time or high-stress jobs, or are contending with job discrimination.

Hillels must educate college students, a critical population to reach on this issue.

Federations must incorporate these needs and concerns into the planning and budgeting process.

Jewish Family Services must extend all the work they already do to another group of Jews in need, building on what is known about crisis intervention, family systems, life-threatening illnesses, living with disabilities, bereavement, and, last but not least, human resiliency.

There is a part for all agencies to play. Those who do AIDS work know too well that no one person or agency can take this on by themselves, or should even try. There is just too much to do. So we also must learn the network of AIDS service providers in our communities and build the ties that need to be built. And we need to get the word out widely to the organizations and the media of the Jewish, Gay/Lesbian, and general communities, to let people know that we are here.

On a personal note: I've been doing AIDS work for several years now. I have known hundreds of people with AIDS. At

age 33, I have seen more of my peers die than I had expected in my entire lifetime.

So I am asked, "How do you do it?" Well, I don't do it alone. I count on family and friends and co-workers and community for support. But while the work may be painful and difficult at times, it is far more than that.

I have the opportunity to do work that is deeply empowering, life-affirming, and worthy beyond any question or doubt. I have the opportunity to come to terms with death in a way that has left me much less fearful. I have had the opportunity to renew and clarify my own deepest commitments. I have had the opportunity to see reconciliation in families and communities, healing wounds inflicted by homophobia and confusion. And I have been blessed with the opportunity to meet the most courageous, resourceful, loving, and lively people I've ever known.

I invite others to take these opportunities, too, and promise them that their lives will simply never be the same.