PROVIDING AIDS SERVICES IN A JEWISH CONTEXT
The San Francisco Experience

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The AIDs Project provides a comprehensive array of direct services for Jews with AIDS that enhance their quality of life and strengthen their connection to Judaism and the Jewish community. It also offers varied opportunities for members of the Jewish community to volunteer to help Jews with AIDS. Finally, Jews with AIDS are used as speakers in educational efforts directed to raise the awareness of teenagers and adults about AIDS.

This year David, a 34-year-old computer programmer from Cleveland, spent a lot of time sculpting in clay, a pursuit that gave him great pleasure and for which he had a natural ability.

This year Sara, a 27-year-old woman from an upper-middle-class home in Northern California, married her long-time partner in a small but dignified ceremony at City Hall.

This year Randy, a 46-year-old man who had migrated to San Francisco 20 years ago from New York, took a break from volunteer work and political activism to plan his first trip to Israel.

This year, David, Sara, and Randy (not their real names) — all three Jews — died from complications associated with AIDS.

This article follows their stories as they made use of the services of the AIDS Project of Jewish Family and Children's Services (JFCS) in San Francisco.

The AIDS Project was established in 1986 under the auspices of the Jewish Emergency Assistance Network, a consortium of Jewish agencies in San Francisco that responds to urgent needs in the community. Funding for the project is provided in part by a grant from the Newhouse Fund of the Jewish Community Endowment Fund and in part from JFCS itself through a combination of individual contributions, bequests, program fees, and grants.

The AIDS Project has three goals:

1. to provide a comprehensive program of direct services for Jewish people with AIDS or disabling HIV disease that enhances their quality of life, ensures continuity of care, reaches out to loved ones, and offers connection to Judaism and the Jewish community
2. to offer the Jewish community opportunities to volunteer in a variety of ways and with varying levels of commitment while providing ongoing emotional support for the difficult nature of the work
3. to provide education and training to teenagers and adults to reinforce prevention efforts, raise awareness, and encourage personal and political involvement

The program is staffed by a full-time AIDS Project Coordinator, who is a licensed clinical social worker, and a part-time AIDS Project Volunteer Coordinator.

CLIENT PROFILE

Each year the AIDS Project in San Francisco provides direct services to almost 100 Jewish people with AIDS or disabling HIV disease, as well as to their family members and loved ones. In addition, more than 1000 teenagers and adults are served each year through education, information and re-

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ferral, and community outreach, including consultation with Jewish agencies in other parts of the country.

All clients served by the AIDS Project are Jewish, meaning one or both parents are Jewish or they have converted to Judaism. Some are currently affiliated with a synagogue, but most are more loosely connected with their Jewish roots. Some come from interfaith households where Judaism was not practiced; some have felt alienated because they are gay. The AIDS Project is particularly committed to reaching out to the unaffiliated and alienated, who are often the most isolated in this population.

The clients served in 1992 ranged in age from 24 to 58. Five percent were women; an additional 8% were heterosexual men. Half of these clients were heroin addicts, about half were infected sexually, and one acquired AIDS through a transfusion. The other 87% of the clients were all gay or bisexual men, some of whom also had a history of injection drug use. These numbers parallel the statistics for San Francisco as a whole, where 85% of cases of AIDS are still being seen in gay and bisexual men. They differ widely from national figures and from those for other regions.

Drug and alcohol abuse affected just over a third of the clients served in 1992, a pattern consistent with previous years. Some of the clients had new or continuing success with 12-step recovery programs or had found other ways to maintain their sobriety. Some had serious relapses, putting their health in jeopardy, and some continued to use a variety of substances without much motivation to quit. Providing services for dually diagnosed clients continues to be a challenge for the program.

In 1992 four clients were psychiatrically hospitalized, three fewer than in the previous year. This may be more a reflection of budget cuts than of the severity of symptoms. For instance, one client who made a serious suicide attempt was not held for psychiatric observation. Two clients were incarcerated for crimes surrounding their drug use. These numbers may be incomplete since a handful of cases were closed when the clients' whereabouts became unknown.

Of the clients served in 1992, 25% died during the year.

CLIENT SERVICES

Case Management

Case management is an effort of coordination and teamwork, which joins programs in the Jewish community with the broader community of AIDS service providers and general resources. As in other settings, case management includes ongoing assessment, linkage of clients to appropriate services within the community or in the agency, monitoring clients' use of services, and advocating on their behalf.

All clients of the AIDS Project receive some level of case management, although the nature of the intervention varies widely according to the level of need and the number of other services being provided by other agencies. It is an important principle of the AIDS Project to maintain contact with the clients during periods when they may have few needs, so that when deteriorating health or other problems arise they are comfortable contacting the Project Coordinator for assistance.

> Sara was initially referred to the AIDS Project by a social worker from a home care and hospice agency with whom she was already involved. She had been evicted from her apartment and had been living in her car for over a month. She had been a heroin addict for several years, but was now enrolled in a methadone maintenance program and was doing well.
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> The home care agency enlisted the help of the AIDS Project in placing Sara in a single-room-occupancy hotel, one that had a large clientele of people with AIDS and that welcomed the outreach of several AIDS organizations that were serving them. An arrangement was made to pay the required security

deposit with the stipulation that when Sara found an apartment the deposit would be returned to the agency.

After about 6 months, Sara and her boyfriend Doug, who also had AIDS and was a recovering heroin addict, found a small apartment with the assistance of the home care agency social worker. They requested that the security deposit be transferred to the new apartment and this was done. Sara continued to receive Chicken Souper meals (see below) and to enjoy special holiday deliveries. Her contact with the Project Coordinator was limited to occasional "check in" phone calls and a few visits. When the couple found a nicer apartment the security deposit was returned to the agency since their financial situation had stabilized. Soon after Sara and Doug's wedding the Project Coordinator called her, and Sara shared her excitement and joy even as she acknowledged that her health was continuing to deteriorate.

Financial assistance, available through a special grant from the Newhouse Fund of the Jewish Community Endowment Fund, is often a part of case management, and all assistance is tied to a case management plan. Clients receive financial assistance on an emergency need basis in the form of grants, loans, or food vouchers. Sara's case is a good example of how one-time assistance helped a client achieve stability and improve her quality of life.

Counseling

Each year about a dozen clients with AIDS or disabling HIV disease are seen in ongoing psychotherapy by the AIDS Project Coordinator. In about a third of these cases, therapy is long term and ends when the client dies. In another third of the cases therapy ends because clients relapse into drug use, develop more severe symptoms and require psychiatric intervention, or are referred to other therapists because their desire to be involved with other program activities (e.g., speakers bureau, support group) conflicts with the therapeutic relationship. About a third of the clients continue in therapy into the following year.

In addition, many other clients receive occasional supportive counseling or crisis intervention on an as-needed basis as part of overall case management. Family members and significant others are also seen, usually in one-time or intermittent couple or family sessions or for bereavement counseling. The demographics of San Francisco are such that only a handful of families live in the area, and thus the ability to do ongoing family work is limited.

Many clients of the AIDS Project already have therapists when they come into the program. Others need a variety of other services from the Project Coordinator and are referred elsewhere for the therapy component. An increasing number of clients have mental health concerns requiring a psychiatrist or a clinic with psychiatric back-up, and the Project Coordinator becomes involved in finding an appropriate resource. Other clients are referred for drug treatment.

Common themes in therapy include both practical and existential concerns related to death and dying, loss at various levels including the cumulative loss of friends and lovers to AIDS, family issues, and how to lead a life that is not completely consumed by AIDS.

When Randy began therapy with the Project Coordinator he was newly diagnosed with Kaposi's sarcoma, a cancer of the blood vessels common to AIDS. He was 4 years into recovery from drugs and alcohol, having made successful use of 12-step programs. He talked about experiencing his feelings for the first time in his life and what a rich and exhilarating time this was for him.

Testing HIV-positive had propelled Randy toward getting clean and sober. Being diagnosed with AIDS had led him to become more introspective, more spiritual, and more compelled to "put his house in order." Therapy focused on making sense of his life—his broken home, difficult relationship

with his father and stepmother, early entry into delinquency and drug abuse, and his coming to terms with his homosexuality. HIV was still abstract to Randy.

Then one day, about 6 months into treatment, Randy arrived at his session with the news that he now had Kaposi's sarcoma in his lungs, a disease with a dismal prognosis. Suddenly his desire to do insight-oriented psychotherapy vanished. Understanding his past lost its importance. Survival and how to maintain his quality of life were now the key issues.

Randy was determined to live life to the fullest, and he set his sights on becoming a speaker for the "Putting a Face to AIDS" education program and participating in the first Jewish Support Group (see below). Because of the conflict with the therapeutic relationship that this created, the Project Coordinator terminated therapy and helped Randy find a new therapist at another agency when he was ready. He became both a Jewish Support Group member and an important contributor to the education program.

Flexibility is an extremely important element in working with people with AIDS. One of the luxuries of a multifaceted program is being able to choose among different modalities of treatment and to alter the overall plan as the clients' needs change.

Jewish Support Group

In January 1992 an 8-week support group addressing spiritual issues and connection to Judaism was created. It was co-facilitated by the Project Coordinator and the West Coast Director of the Jewish Healing Center. The group combined elements of teaching, responses to readings, and peer support in a structured format. Topics included grief and loss, hope and strength, God and our spiritual struggles, and Jewish practices in death and dying. Participants were one heterosexual woman and six gay men, all with disabling HIV or AIDS. The group provided participants a forum in which to reconnect with their Jewish selves in a meaningful manner, to undertake spiritual exploration, to look at possibilities for Jewish living, and to make decisions about such important issues as cremation versus burial.

Randy was a member of the Jewish Support Group. In the first session participants were asked to "tell their Jewish stories." Raised in a Reform Jewish home, Randy's strongest memories of Jewish tradition came from his grandmother, who died when he was 5. After his parents' divorce, he lived with his father, who had become wealthy and wanted Randy to have his Bar Mitzvah at the large wealthy synagogue across town.

Randy had early memories of feeling different from his peers. Around the time of his Bar Mitzvah he realized that he felt different because he was gay. He talked to his rabbi about his feelings, but was told it was a passing phase.

When Randy looked at Jewish tradition he saw a focus on marriage and family. Sadly he felt "there was no place for me," and so he turned away. He spent years denying that he was Jewish at all, and his drug addiction served to further bury his connection.

Choosing to receive services from a Jewish agency opened a new path for Randy. Twelve-step programs had led him to spiritual exploration, but not with a Jewish identity attached. The group provided a way for him to "come home" and to see there was a place for him in Judaism. He found support in realizing that his alienation from Judaism because of his homosexuality was a common thread in the group.

Randy and two other group members became close friends, regularly attending Friday night services at Congregation Sha'ar Zahav, the San Francisco congregation with an outreach to the gay and lesbian community, and Monday evening healing services at the Jewish Healing Center. They joined the synagogue, celebrated Pesach together, and talked of starting a support group for disenfranchised gay and lesbian Jews. Randy said, "My whole life has taken on a Jewish fla-

vor." An old desire to travel to Israel was also rekindled, but Randy's successful attempt at raising the funds for a congregational trip was not enough to keep him alive to realize his dream.

VOLUNTEER PROGRAMS

Chicken Soupers

The Chicken Soupers are a group of volunteers who prepare and deliver meals to clients of the AIDS Project twice a month. In 1992, 719 meals were delivered to 56 clients, with an average of 31 clients served with each delivery. One hundred and thirty-five volunteers contributed 2,053 hours during the year.

The program was begun 4 years ago by Congregation Beth Sholom, which was later joined in its efforts by Sherith Israel synagogue. All of the fund raising, shopping, menu planning, food preparation, packaging, and deliveries are done by volunteers from the two synagogues, as well as from the larger community. Each synagogue has a coordinator who is in close contact with the AIDS Project Volunteer Coordinator, who oversees the program.

Each month clients receive a letter with a stamped return postcard on which they indicate whether they want the home-delivered meals. The letter often includes information about community services, AIDS Project events, or special greetings for different holidays. It serves as a link to clients whether or not they are receiving meals that month.

Meals are delivered two Sundays per month. Each meal contains several different foods and usually provides enough food to last several days. Included in the delivery are notes and drawings from children, as well as special foods and treats for different holidays.

The Chicken Souper volunteers provide a vital link between clients and the Project Coordinator by reporting on the status of each of the clients. These "eyes and ears" in the field provide the Project Coordinator with feedback about clients' changes in health status, living situations, finances, drug involvement, or family situation. Clients are then contacted as appropriate.

David, as did many clients, became involved with the AIDS Project when he was in relatively good health. He had been on disability leave from his job for about 9 months, and the pace of his life had slowed considerably. Although he had called JFCS because he felt a Jewish agency could help him, it was initially difficult for him to accept the idea of receiving meals.

The Project Coordinator explained to David that there are certain givens about HIV disease: "You have less energy than you did before and you have less energy than most other people. We don't expect you to be bedridden to be able to benefit from a little extra time to spend on something more important to you than cooking."

Soon after David received his first meal and a short visit from a volunteer, the agency received the following note from his mother, who had been visiting at the time: "Please accept my contribution to help your much-appreciated services to persons with AIDS, and especially for my son. I was so deeply touched by the care and concern you show for those who truly need it."

David himself later wrote, "It gives me comfort inside to know that my community is reaching out to help me when I'm most in need. These are people who don't even know me; but because I'm Jewish and have AIDS they come to my aid."

In 1992, for the second time, Chicken Soupers as well as many other volunteers from the Jewish community, delivered meals and gifts on Christmas Eve and Christmas Day for Project Open Hand, a meal delivery program serving close to 2000 people with AIDS. The effort was co-sponsored by Congregation Sha'ar Zahav and the AIDS Project. In all, 350 volunteers participated and once again gave the

powerful message that the Jewish community supports this important program.

Practical Support

The Practical Support Volunteer Program began in November 1991. By the end of 1992, 20 volunteers had provided either short- or long-term assistance to 14 clients, contributing 721 hours of service to the AIDS Project.

The Program pairs volunteers with clients to perform basic housekeeping tasks: cooking, grocery shopping, laundry, running errands, and other chores. As the relationships develop, elements of companionship and emotional support come into play. The idea is to make "matches" while the client is still reasonably healthy so that a bond can be formed before more intense involvement is needed.

Each volunteer fills out a detailed application and has a screening interview with the AIDS Project Volunteer Coordinator. All volunteers take part in a training program that includes an introduction to JFCS and its policies regarding volunteers, a medical overview, a review of psychosocial issues, a look at what to expect, and an opportunity to voice fears and concerns.

When a client requests a volunteer, the Project Coordinator screens the request. In some cases she assesses the need for a volunteer before a client feels ready to accept help and then works slowly with the person to explore the meaning of such acceptance.

Once the request has been screened, the Volunteer Coordinator makes a home visit to assess the specific needs in the home. She and the Project Coordinator then discuss possible matches. Because this is a small program it is possible to make matches in a very personal way, pairing people with similar backgrounds, interests, and temperaments. The Volunteer Coordinator returns to the client's home with the volunteer to introduce them to each other and clarify what the tasks will be.

Bimonthly support meetings for the volunteers provide ongoing education and a forum for discussion of their emotionally charged experiences. Recently the group has focused on the loss of several clients.

Volunteer-client relationships often become extremely close, and the practical support provided becomes central to the clients' care. Although the expectation is that a volunteer will work 2 to 4 hours per week, as relationships deepen and new needs develop, many volunteers increase their involvement. They regularly visit their clients who are in the hospital or hospice, they become involved with their families, they bring special food, and they take clients on special outings.

> Both David and Randy were assigned volunteers in the end of 1991. David's volunteer was a gay man of the same age and from the same part of the country who did almost precisely the same kind of work as David did. Randy's volunteer was a 78-year-old woman who was recently widowed and who had never ridden on a motorcycle until Randy took her for a spin.
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> Both relationships, in their unique ways, became extremely close. Although both centered on a weekly visit — David's around housecleaning and Randy's around shopping and meal preparation — deep bonds developed that were nurturing to client and volunteer alike.
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> David, who had a hard time asking for help, found it much easier to do so from a trusted volunteer. Randy particularly enjoyed hearing the perspective of an elderly person about death and loss.
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> Each relationship lasted about 18 months. And each ended in the death of the client.

It is a testament both to the value of the experience and to the level of support volunteers receive that both these volunteers, after a short break, are returning to the program to work with other clients. And in testimony to the value of the volunteers' presence, a mother of another client writes: "[My son] loved [his volunteer], and so do I. She's like family, a close sister walking a

road that only family can walk together."

EDUCATION PROGRAMS

"Putting a Face to AIDS"

In 1992, the Project Coordinator and eight clients who served on the speakers bureau (and who contributed 135 volunteer hours) gave 17 presentations to over 615 participants, twice the number of talks given in 1991. Presentations were given for students in sixth through tenth grades in religious schools and Hebrew day schools. Adults were addressed in presentations to synagogues, single groups, summer camp staff, volunteers, committees, and special events commemorating those who have died from AIDS.

"Putting a Face to AIDS" brings people with AIDS into the classroom, the board room, or the social hall to discuss what it is like to live with this disease in the Jewish community. The focus is on helping teenagers and adults make an emotional connection to the speakers, which will then motivate them to heed prevention precautions, raise their awareness and level of compassion, and challenge them to become involved in the fight against AIDS.

The Project Coordinator serves as moderator and AIDS expert for each talk. She is accompanied by two speakers who are clients of the AIDS Project. Speakers are paired so as to represent contrasts in as many areas as possible; for example, age, Jewish upbringing, former occupation. The Project Coordinator asks each speaker in turn to discuss such issues as his or her medical condition, day-to-day routine, life before AIDS, changes in lifestyle and perspective since AIDS, family and extended family support, Jewish connection, and emotional impact of AIDS. Questions are taken throughout, and responses are given in an age-appropriate manner.

> Randy and David both served as "Putting a Face to AIDS" speakers, and pairing the two of them for a presentation exemplified the concept that, in fact, a range of faces were being presented.
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> While David talked about the work he did before he was diagnosed — developing and implementing computer training programs — Randy talked about being a drug dealer and how his life revolved around obtaining drugs. While David talked of a family that supported him and siblings who took turns visiting and caring for him, Randy spoke sadly of parents who had died and siblings who had rejected him, first for being gay and now for having AIDS. While Randy spoke of recovery leading to spiritual awakening and a return to Jewish faith and practice, David spoke of his connection to the Jewish people and the comfort he took in knowing he was part of the continuity of that people.
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> Both Randy and David did many presentations, and for each of them speaking about their lives to help others became a source of strength, comfort, and exhilaration. So devoted were they to this endeavor that Randy did his last talk just 9 days before he died, and a few months later David died 10 days after speaking to a group of eighth graders.

"Putting a Face to AIDS" seems to be meeting its goals of sensitizing its audience and making the disease real for young people and adults. An eighth-grader wrote to one of the speakers:

> For many years we have learned about AIDS, but never before have we had such an interesting and in-depth discussion with people who actually had the virus. I always thought of the disease as something that only happened to other people, people I don't know, but after this discussion it really made me aware that it is happening and it can very well happen to me.

Her sentiment is echoed in dozens of other letters that students write to speakers telling them what they learned from meeting them.

AIDS Video History Project

In May 1992, the AIDS Video History Project grew out of one ill client's request. One of the members of the Speakers Bureau became quite ill and asked if he could be videotaped. The Project Coordinator, with another client from the Speakers Bureau serving as a cameraman, went to the ill client's home to tape a 20-minute interview. And so the AIDS Video History Project was launched.

This program has several objectives. Many clients have a need to tell their story, and videotaping is a therapeutic tool to allow them to do so. Many have a desire to pass on what they have learned through their illness, either directly with a copy of the tape to give to family, or indirectly through knowing others might learn from them. The AIDS Project has an ongoing commitment to education, and videotapes of clients telling their stories can be used in various settings. A long-range goal is to produce a documentary from a series of edited interviews looking at AIDS in the Jewish community, which could be distributed as a tool for education, training, and general community awareness.

COMMUNITY INVOLVEMENT

AIDS Project Advisory Committee

In November 1992 the AIDS Project Advisory Committee, under the auspices of the Jewish Emergency Assistance Network, held its first meeting. The purpose of the committee is to enhance support for AIDS-related issues and activities in the Jewish community and to provide technical assistance to the AIDS Project.

Members of the committee are either associated with Jewish agencies or institutions or have professional expertise in such areas as law, public policy, education, medicine, or spirituality. Several members fall in both categories. Two clients of the AIDS Project and one volunteer also serve on the committee.

Issues addressed in the first two meetings included providing representation on various AIDS committees in the general community, conducting a marketing study of the need for and barriers to services of the AIDS Project, developing mechanisms for technical assistance and direct service (e.g., providing pastoral counseling to clients), and reviewing policy issues, such as whether the agency should serve as durable power of attorney for clients.

Current projects of the Advisory Committee, which meets bimonthly in addition to meeting on an as-needed basis by subcommittees, are as follows:

- *Outreach:* Responses to surveys about barriers to accessibility showed that many people feel they are "not Jewish enough" to come to JFCS for help. It is estimated that the Project now serves only about half the Jews living with disabling HIV in San Francisco. The Committee has developed a publicity card that announces, "If you are Jewish and you have AIDS or disabling HIV, the Jewish Community wants to help you." On the back of the card are listed myths about who can use the services. The card is being placed in physicians' offices, clinics, and waiting rooms of various AIDS organizations.
- *Rabbinic subcommittee:* For several years the AIDS Project has relied on a small cadre of local AIDS-sensitive rabbis to provide pastoral counseling, hospital visits, and funeral and memorial services to clients and other people with AIDS in the community, most of whom are not affiliated with a synagogue. The Rabbinic Subcommittee, under the leadership of the Community Chaplain, has now taken over the responsibility of maintaining and gaining access to a pool of rabbis for this purpose, as well as developing training and outreach strategies to widen the pool and increase AIDS awareness in the rabbinate.
- *Family Resource Guide:* A small group of committee members is developing a guide for out-of-town family members

who come to San Francisco to visit a loved one with AIDS. The guide will cover such topics as what to expect when you call a rabbi, what you need to know about getting medical information, how to get around in the city, and where to find a bagel. It is not meant to duplicate existing directories but to help families get their bearings in unfamiliar territory and to know that the Jewish community, particularly the AIDS Project, is there to support them.

- *Curriculum project:* "Putting a Face to AIDS" has always been a single presentation usually unaccompanied by any educational support. More than once, speakers have arrived at a religious school only to find that the students had no idea they were coming and certainly no preparation for the topic. This subcommittee, working in cooperation with the Bureau of Jewish Education, is developing a modular curriculum for religious schools that will allow teachers to use some or all of a program that teaches about communication, sexuality, risk reduction, homophobia, and Jewish values related to healing and caring for the sick. Exercises, role plays, and videos will be used in addition to lecture and discussion. Any school requesting a "Putting a Face to AIDS" presentation will be sent a copy of the curriculum.

CONCLUSION

The AIDS Project of Jewish Family and Children's Services is a dynamic program that is always evolving to meet the needs of the clients and the community. It is the combined efforts of clients, volunteers, committee members, staff, and the Jewish community at large that have enabled this program to provide a variety of services and prevention programs in a Jewish context.