AIDS Service Providers Association of the Bay Area

NEWSLETTER - DECEMBER, 1989

10 United Nations Plaza, Suite 200 San Francisco, CA 94102 (415) 241-5519

MEETING CALENDAR

December 6, 3-5 pm: **SF AIDS/ARC HOUSING COMMITTEE,** 25 Van Ness, 3rd Floor Conference room.

December 7, 4:30 - 6:00 pm: **MARIN AIDS TASK FORCE.** Alissa Ralston will provide an update on AIDS and adolescents. Room 254, Marin Civic Center. Contact: Mary Jo Buerger, 499-7804.

January 22, 3:30 - 5 pm: **SAN MATEO COUNTY AIDS NETWORK** will meet at the County Health Department, 225 W. 37th Street, San Mateo. Contact: Jonathan Messinger, 573-2588.

January 23, 12:30 - 2 pm; (no regular December meeting): **ALAMEDA COUNTY** AIDS Service Providers Network. Mercy Care Center, 3431 Foothill Blvd., Oakland. Contact: Isabelle Hamilton, 763-6612.

February (not yet scheduled): **SANTA CLARA COUNTY** AIDS SERVICE PROVIDER NETWORK quarterly meeting. Contact: Nianne Neergaard, (408) 299-4151.

This Newsletter is published monthly by the AIDS Service Providers Assocation of the Bay Area, a non-profit membership organization linking agencies providing services related to HIV infection. Articles, announcements, and job listings should be mailed to the Association at 10 United Nations Plaza, San Francisco, 94102 by the 15th of the month for the next month's newsletter.

MEETING ON POLITICAL ADVOCACY

The AIDS Service Providers Association held one of its quarterly meetings on Friday, October 27. The topic was political advocacy. Speakers included Jessie Ortiz, an organizer with Health Access; Brandy Moore, on the staff of State Assembly Speaker Willie Brown and with the Black Coalition on AIDS; Paul Boneberg with Mobilization Against AIDS; Rand Martin, lobbyist with LIFE, the Lobby for Individual Freedom and Equality; Diana Kuderna with EBARO, the East Bay AIDS Response Organization; and Jesse Dobson with ACT UP. The following are notes from the discussion, not a complete transcript.

Ortiz: Even though it's difficult for people in AIDS organizations, we need to focus on larger health care system issues. People concerned with HIV and AIDS need to address access to treatment, drugs, money, long term care, hospice, and convalescent care. These system issues are being addressed by various organizations, including "Vote Health" in Alameda County and the Community Health Coalition in San Francisco.

Comment: What about building coalitions, for example with the elderly to lobby for better long term care?

Moore: HIV disease carries a stigma - we need to work on it by itself so it won't be swept under the rug. We need to keep the HIV disease banner visible. Broader-based organizations, such as the NAACP and the National League of Women Voters have had opportunities to advocate for HIV disease, but it hasn't happened.

Boneberg: AIDS groups perceive themselves not to be political. Also, we have been in crisis mode, but now we're in for the long haul. Agencies have had a hard time taking the long view, partly because they perceive it as political. The long run is a rational health care system.

Martin: There are 65 affiliates in the LIFE lobby: AIDS organizations, political organizations, people of color organizations. LIFE deals with AIDS policy, programs and funding in Sacramento and increasingly in DC. About 100 AIDS-related bills were introduced in Sacramento this year. Most didn't go anywhere and will come back next year in the second year of this 2-year session. Major issues are early intervention and treatment. Early intervention projects include case management with clinical management added. A subsidy for HIV-related drugs was enacted on a permanent basis: AZT, aerosol pentamidine, and others as deemed appropriate. The subsidy will operate on a share-of-cost

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ANNOUNCEMENTS

The **CALIFORNIA ASSOCIATION OF AIDS AGENCIES** will hold its 1990 Annual Meeting January 24-26 at the Capitol Plaza Holiday Inn, Sacramento. Sessions will focus on meeting the challenges of the 1990s. For information and a brochure, call (916) 447-7199.

HOUSING FOR HIV+, PWAs, PWARC: HIS HOUSE, a permanent group home, has 6 openings for people interested in living in the Russian River area. For information, call (707) 433-5116.

HUMAN RESOURCE DIRECTORS GROUP FORMING: Tim Teeter of Shanti Project is convening a group of personnel directors of AIDS organizations. If you are responsible for human resources/hiring in your agency and are interested in participating, please contact Tim at 777-2273.

LEARN MORE ABOUT IMMIGRANTS AND HIV: The HIV Task Force of the Coalition for Immigrant and Refugee Rights and Services was founded in 1987 and assists the HIV positive immigrant community by providing direct services and advocating for reform of the HIV exclusion rule. Legal services and referrals are available. For more information, contact Jorge Cortinas at the Bar Association of San Francisco, 685 Market Street, Suite 700, San Francisco, CA 94105; telephone (415) 764-1600.

AIDS AND THE DEAF COMMUNITY: Taking Responsibility, a conference sponsored by the AIDS Education for the Deaf Project, will be held January 21-24, 1990, at the Asilomar Conference Center, Monterey Peninsula. For information, call 213 654-5822 TDD or 213 654-5942 voice.

AIDS AND VISION LOSS is a conference to be presented in San Francisco January 25 and 26, 1990, by the Lighthouse for the Blind and Visually Impaired and the American Foundation for the Blind, Western Regional Center. The conference is an opportunity for agencies providing services to persons with AIDS to interact with agencies and health care professionals providing services to the blind. Early registration (until December 1) is $130; $175 thereafter. For additional information, call Edward Straub or Lisa Christie at The Lighthouse, (800) 541-2453.

POLITICAL ADVOCACY, continued

formula for people with adjusted gross incomes under $50,000. This program will require continued lobbying for adequate funds.

This focus on programs contrasts with the policy focus during 1984-85: discrimination, and Doolittle's response. There was a $14 million increase last year, mostly for early intervention and the drug subsidy. It is increasingly compelling to get service providers more involved. I don't expect them to spend lots of hours on political advocacy, but it is critically important to be available and provide information needed by LIFE, as well as direct contact with their local legislators. People should be willing to do this in a timely fashion. Legislators tend not to hear from constituents -- as few as 5 letters on an issue can make them sit up and take notice. They may not change their minds, but it indicates that the issue is important. The problem now is not that there is a problem -- there was overwhelming support for early intervention -- the problem is funding. There are not enough dollars in the state or federal budget, under current priorities, to provide needed services. We need new priorities based on coalition-building. We can embrace broader health care needs and still keep a particular focus on HIV disease. Money won't be there as a line item for AIDS; we need national health care or a similar approach. An emerging trend is for politicians to say, "We're spending all this AIDS-related money -- $76 million at the state level, $1.6 billion federal -- where's the money for cancer, or Alzheimer's? We're sensitive, but need to concern ourselves with other priorities." The earthquake can further tighten spending. AIDS is not a crisis like it was a few years ago.

AIDS service providers can take time in the fall, when legislators are home, to get them out to see programs, to know that AIDS is not going away. It may be chronic, but not like diabetes; AZT hasn't cured it. When given the offer to see a program, very few legislators refuse. I can suggest legislators who really need to see programs. That, and being in touch with legislators around issues are important. Long-term issues, broad issues can be left to those with the time and energy for it, including LIFE, which has resources for longer-term issues. Mobilization Against AIDS, and the AIDS Action Council. You can do effective lobbying by letter, or by a personal visit. People tend to be intimidated because legislators are elected officials -- big muckety-mucks. Don't be intimidated -- you are the AIDS experts.

Moore: To play devil's advocate, AIDS is not a chronic disease, it is not manageable, and it's not going away. The manageable chronic disease is true only for people in clinical trials, research studies -- not true for most people with HIV disease: people of color, and women. Women have no access to residential care, or child care. Look at the people at the bottom of the ladder and see how they're doing; the top of the ladder is not important. This perspective led to identifying the need for residential care for women with AIDS. That's how we've taken local participation to the state level. Also -- AIDS won't work as a coalition issue. I'll cling to that view until I see coalitions that are inclusive and have stars to pull them along. What is the role of HIV

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POLITICAL ADVOCACY, Continued

disease in a coalition? The Black community hasn't done its part -- adolescent syphilis rates are phenomenal! AIDS is clearly political. In the last two years, people have become familiarized with HIV disease, thanks to Mobilization, for example. They've raised awareness; now its familiar but they haven't paid attention to it. It's more like "magazine" awareness; check off answers to questions 1 through 10. They're not aware that HIV disease hasn't been looked at in a comprehensive way in terms of its fiscal impact, especially given Hurricane Hugo and the earthquake. When communities wake up top how many of their children are dying -- which I expect will happen in fall, 1990, when children are missing from school -- there'll be a huge outcry. Then legislators have to take a second look -- at work force impact. Young people won't be available. Black minister in the East said that most people are trying to get out of the work force and look to the next generation to take care of them. Groups need to form: People of Color Against AIDS. I hope it'll be a regional approach. We can come together in the next year with LIFE and other lobbies to deal with women, people of color, gay men, etc. Get legislators to advocate against HIV disease! The SF Supervisors were reticent to lobby against the governor's cuts. The last piece is people of color need to accept ownership of HIV disease and expand that back to the population originally hit by the disease. We need to come together as a lobbying force, as a rainbow array of colors and lifestyles. The AIDS Service Providers Association has a huge mailing list - let's start there and use our own next year. AIDS service organizations need to link with other ASO's nationally. Go to Washington, send postcards, get a 30,000-name mailing list, make sure the organization has some clout. Ultimately, we should be able to deal with candidates around HIV disease because there are civil rights issues, women's issues, etc.

Boneberg: Mobilization Against AIDS has been active since 1984, in the No on 64, No on 102, and Doolittle bills. Focus now is on treatment issues. We see ourselves as an organization coming from the lesbian/gay community. We are distressed that ASOs see themselves as non-political. I suspect a lot of people may not be at this meeting because they don't see themselves as having political components. Groups starting to model themselves like large national organizations, like the Red Cross. The title of this meeting - "cooperation between ASOs and political advocacy groups" symbolizes the problem; the we/they denies the essential political nature of ASOs. Regarding Proposition S: most ASOs refused to sign the ballot argument because they said they were not political organizations. If we can't get organizations to sign regarding hospital visitation rights and bereavement leave, what will they sign? The same was true on Proposition 102, even though many ASOs realized they'd have to shut down in 102 passed. Very few ASOs are on the LIFE Board despite only about $1,000 fee to join. In the AIDS Service Providers Association, political groups are only Associate members, not full members. That codifies that ASOs don't see themselves as political. I agree with Brandy Moore -- all ASOs are about to be overwhelmed in the next 15 months. They'll see an increase in volume equal to the total for the last 8 years! The solution is greater governmental action, which requires political action. If ASOs say, "We're not a gay/lesbian group; we're not political" -- how can they deal with civil rights issues, such as invasion of the physical body? The AIDS issue is forced testing. ASOs should support the pro-choice movement, but they won't. The earthquake summarizes the problem: "The greatest crisis since 1906" - that's the Sacramento and DC perspective. Bush has had no visibility on AIDS, said no to the Quilt, won't be at the VI International Conference next year. All AIDS groups need to debate in their Boards of Directors that there are political components to their jobs, some staff time that should be spent. All should consider joining LIFE or other groups -- it cues you in where the governmental dollars are becoming available, also focuses the lobbying effort.

December 1 - World AIDS Day - there will be several actions, including mass unrest at the White House. We're asking ASO Executive Directors, especially those serving women, people of color, and especially those from outside of New York, Los Angeles and San Francisco - to help make the point that we're being overwhelmed, that AIDS is not over - accompanied by a full-page ad to clarify the intent. Massive increases in dollars at the federal level are the only hope to stem the tide of this disease.

Kuderna: EBARO has been active since 1983. We lobbied to create the Alameda County AIDS Coordinator position. In 1986-87, the county's AIDS budget was less than $100,000. We were active in establishing the AIDS clinics at Highland and Fairmont Hospitals, and active in expanding those services. The hospitals didn't ask for it; the community asked for it. We worked to establish anti-discrimination ordinances in Alameda County cities: No on 96, 102, 64. etc. We are lobbying for increased funding in Alameda County. We sponsored the AIDS Action Alameda Conference - this year was the second one. ASOs, PWAs, community activities came together to create unified response plans. EBARO lobbied to support a $2.5 million budget. The county proposed $806,000. The AIDS Commission supported $2.5 million; got $1.1 million from the general fund and expect another $1.1 million from the cigarette tax fund. My suggestion for ASOs: from my background as a benefits counselor - 70% of people nationally support fundamental changes in the health care system. Billions of dollars are wasted in overhead costs; access issues could be addressed. Support the drive to create awareness/demand in health care delivery. Document access problems. Eligibility determination change could make a big difference; for example, you need an AIDS diagnosis to get Medi-Cal, and then a 29-month delay to get MediCare. People need to get care earlier, prior to a formal AIDS diagnosis. If we document these issues, legislators may begin to build mechanisms regarding the eligibility requirement. Regarding volunteer-based services in Alameda County, they are overstressed and crumbling. The AIDS Project of the East Bay and The Center are largely volunteer-based. The Center has no government funding - all private dollars except for training practical support volunteers. By 1993 there may be a 400% increase in case load. We need to demand re-prioritization

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POLITICAL ADVOCACY, Continued

of the entire budget to deal with the needs that are coming - and federal disaster relief for care.

Dobson: I have been working for the treatment issues committee of ACT-UP for about three months. ACT-UP is a very political organization. It exists mostly to allow people to aim their frustration at breaking down some of the logjams we've complained about. Not just government, but medical and pharmaceutical community -- they also fight us at the government level. We put pressure on Burroughs-Wellcome to drop the price of AZT; we need to set an example with them. Organizing a boycott of Burroughs-Wellcome products, and putting pressure on Henry Waxman to hold hearings and subpoena Burroughs (they refused to come last time). Lyphomed also a big issue. Global to very small issues: immunoglobulin: we protested the placebo IV study on infants; support passive immunotherapy protocol approval: went with Project Inform to the FDA regarding Compound Q; with ACT-UP New York re DDI release even though it's still pathetic; we're trying to support the parallel track. We think that everyone willing to take the risk should be allowed to. Early intervention centers, pentamidine - we're working to lower prices and defuse the smokescreen of free distribution. We're advocating combination therapies, not single-drug trials. Trial design and followup: people who go through trials and fail, or get ill and can't get into other trials. Dispel media myths, including in the gay press, such as ddI parallel track has not been implemented.

Help us with information: who's out there. getting sick, not getting ddI. funding getting cut - give us information to target ourselves and focus so we don't go and just say "increase AIDS funding". Come to our actions; endorse; it's sad to hear that ASOs won't endorse political issues.

Personally, I hope that the AIDS Service Providers Association will call representatives to get arrested at the Federal Building in SF in support of the DC action on December 1. It';s hard to get people in SF to go to DC. We need more than gay white males with the pink triangle; we need to focus on the national nature of the issue.

HIV is not a manageable disease, regardless of how much money you have, with current treatments, you'll die. AZT doesn't reduce the cost of hospital stays, it delays them. How do we keep HIV in the national eye? Make sure it's part of the list pushed by advocates of a national health care system. We'll keep HIV first on our own list.

The AIDS community is going to have to state its anger regarding the earthquake and the national response. If Bush had showed up 8 years late for the earthquake . . . we have responsibility for communicating AIDS in terms of deaths, dollars, etc. People talk about the earth shaking -- what about your body crumbling?

Work door to door and government. Hold political leaders responsible for leadership on AIDS. Lionel Wilson has really avoided it; there are no City of Oakland dollars for AIDS, in contrast to Berkeley. What we need is information on the actual suffering that people are seeing. If you force people to see suffering, their first reaction is to flee - but if they stay, they'll eventually come through.

Ron Rowell (National Native American) We see ourselves as political, and observe the 5% limit on lobbying activities. Also Native American we have certain limitations regarding our own bureaucracies, such as the Native Health Service. ACT-UPs anarchistic disruption at the National Minority AIDS Conference, interrupted a native American drug user who was intimidated and stopped. We part company on tactics and targets although we share many goals. Felt like Native Americans were the target. It sometimes feels like ACT-UP makes itself an issue and that keeps us from the real AIDS issues. Effectiveness has been in very focused actions when the end result is very clear, but the Opera and Bridge actions, perceived by the public at large and many int eh AIDS community as ACT-UP . It's hard to deal with ACT-UP, unlike working with Mobilization, LIFE, etc.

Dobson: ACT-UP is anarchistic. On treatment issues, it's been very effective. some people are "cause junkies", trying to dissociate with some actions like the Golden Gate Bridge and Opera. I go off and do what I want to do; others do what they want to do. When all rational methodologies have been tried and don't work, that's what ACT-UP is for.

Comment: ACT-UP meetings are open; ASOs could go to voice their views.

Rowell: I feel like ACT-UP has turned on us. Let Act-UP come to us.

Comment: The more extreme positions taken by ACT-UP mean that other voices sound more reasonable by comparison.

The adversarial nature reflects the split from advocacy of ASOs. When people can distance from AIDS -- what have ASOs themselves done about the political issues? Professionalization leads to inertia -- even around coalition building to address benefits. What is each ASO's role?

Boneberg: I like ACT-UP, SANOE, and other groups like them.

SEND YOUR ANNOUNCEMENTS, JOB POSTINGS, AND ARTICLES TO THE AIDS SERVICE PROVIDERS ASSOCIATION BY THE 15TH OF THE MONTH FOR PUBLICATION IN THE NEWSLETTER.

SUBSCRIPTION RATES:

- ONE COPY FREE TO ORGANIZATIONS PROVIDING HIV-RELATED SERVICES.
- ADDITIONAL COPIES/INDIVIDUALS: $15 PER YEAR.

AIDS Service Providers Association of the Bay Area
JOB LISTINGS - NOVEMBER, 1989
PLEASE DUPLICATE, DISTRIBUTE, AND POST

CONTINUUM HIV DAY SERVICES is hiring an **Activities Coordinator** to plan and implement recreation, educational, and creative arts activities. This program, geared to participants' interests, will offer a full range of activities that provide life enrichment and support to persons living with AIDS/ARC. Salary: Low to mid-20s. Preference given to persons with experience and knowledge of specialized services and sensitivity for persons living with AIDS/ARC. BA in recreation or certification in dance, art, music therapy, or related field experience. Send resume and cover letter to: Personnel, Continuum HIV Day Services. 10 United Nations Plaza, Suite 200, San Francisco, CA 941202. Minorities and bilingual persons strongly encouraged to apply.

MISSION NEIGHBORHOOD HEALTH CENTER is recruiting for several positions. If interested, send resume to Mission Neighborhood Health Center, Attention: Adolfo Mata, 240 Shotwell Street, San Francisco, CA 94110 by December 31. Be sure to specify which position you are applying for.

AIDS Project Coordinator will supervise, plan, develop, implement and coordinate all aspects of the Mobile Outreach/Education and Peer Group Leader Training Program to the general public. Special emphasis will be placed on the following groups: youth, homosexual men, bisexual men and women, lesbian IV drug users/partners and heterosexuals not reached by traditional health education methods. Also will act as coordinator for the Latino Council of Health and Human Service Providers. Reports to the Executive Director. Requirements: MPH or equivalent years applicable experience. Bilingual Spanish/English. Minimum 1 year experience supervision of paid/volunteer staff. Working knowledge of the principles of health education; proven ability to plan, organize, and implement AIDS health education/training programs; sensitive to the unique needs which Latinos, youth, women, gay men, lesbians, and IV drug users have for AIDS services.

AIDS Outreach/Education Coordinator will supervise, plan, develop, implement and coordinate all aspects of the Mobile Outreach/ Education and Peer Group Leader Training Program. Reports to the AIDS Project Coordinator. Requirements: BA in Health Education or related degree; equivalent work experience may be substituted. Bilingual Spanish/english. Experience with AIDS educational needs and interventions for targeted risk groups; minimum 1 year work experienced with social service programs; valid California driver's license and currently insured automobile; sensitivity to the unique needs which Latinos, youth, women, lesbians, homosexual men, IV drug users/their partners, and chemically dependent persons have for AIDS services.

AIDS Outreach/Education Specialists will provide direct AIDS prevention education services to the general public with special emphasis on youth, homosexual men, bisexual men and women, lesbian IV drug users/partners and heterosexuals not reached by traditional health education methods. They will report to the AIDS Outreach/ Education Coordinator. Requirements: High school diploma or equivalent; bilingual Spanish/English; experience with the AIDS educational needs of the target risk groups; minimum one year work experience in a social service program, preferably AIDS-related; possession of valid California driver's license and currently insured automobile; sensitivity to the unique needs which Latinos, youth, women, lesbians, homosexual men, IV drug users/their partners, and chemically dependent persons have for AIDS services. Preference will be given to those possessing on-the-job experience working with high-risk target group community members in the health education or substance abuse field.

AIDS SERVICE PROVIDERS ASSOCIATION OF THE BAY AREA
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