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THE JEWISH HEALTHCARE FOUNDATION OF PITTSBURGH

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A few things I thought might be of interest. I'm looking forward to seeing you at 4 p.m. Tues

Dana Phillips

More "stuff" from Pittsburgh

THE JEWISH HEALTHCARE FOUNDATION OF PITTSBURGH

PHOTOCOPY PRESERVATION

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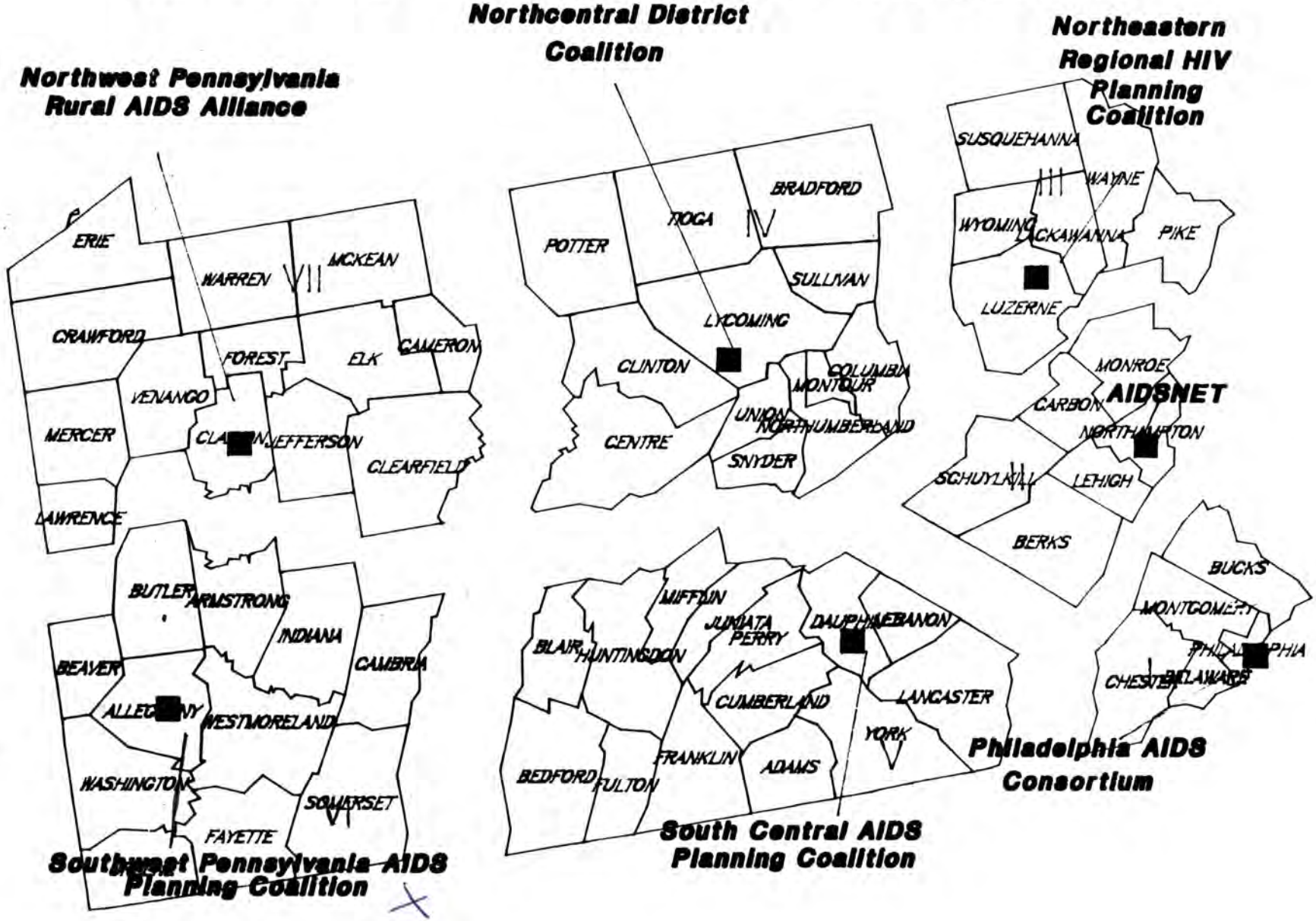
REGIONAL HIV PLANNING COALITIONS



PERSON DIAGNOSED WITH AIDS
AS OF JUNE 4 1993

COUNTY	TOTAL CASES SINCE 1981	DECEASED	ALIVE
ALLEGHENY	811	577	60.68
ARMSTRONG	15	8	20.41
BEAVER	36	24	19.35
BUTLER	28	24	19.35
WASHINGTON	43	29	21.02
GREENE	7	4	17.69
FAYETTE	21	16	14.45
WESTMORELAND	70	54	18.9
CAMBRIA	42	25	25.76
SOMERSET	10	4	12.78
INDIANA	10	7	11.11

PERSONS DIAGNOSED WITH AIDS
AS OF 4-1-93

COUNTY	TOTAL CASES SINCE 1981	DECEASED	ALIVE
Allegheny	786	559 (71%)	227
Armstrong	13	7	6
Beaver	33	23	10
Butler	27	23	4
Cambria	41	25	16
Fayette	19	15	4
Greene	7	4	3
Indiana	10	7	3
Somerset	10	4	6
Washington	42	28	14
Westmoreland	67	54	13
TOTAL	1055	749	306

AIDS ACTION PLAN

COMMUNITY ADVISORY COMMITTEE CHARGE

As the HIV epidemic has progressed in Southwestern Pennsylvania, the region has been both blessed and endangered by being a low incidence area. Blessed in having fewer infected people and fewer deaths over the last decade than many areas of similar size; endangered in the fact that the lower incidence and the absence of the immense healthcare crisis that hit New York and San Francisco has meant that our community has not yet come together to develop a common vision for a regional response.

This Community Advisory Committee on AIDS, convened by the Jewish Healthcare Foundation in cooperation with the Southwestern Pennsylvania AIDS Planning Coalition, represents the first non-provider group to systematically consider the variety of issues surrounding the epidemic.

After attending the briefings and reading the material provided by staff, we expect this committee to provide knowledgeable review to the comprehensive plan developed for the region by the AIDS Planning Coalition and the Foundation. This plan will provide a framework for decisions by public and private providers and funders in the decade ahead.

One of last year's AIDS projects.

April 8, 1992\AIDS.SUM\ms

This one pager was background for the AIDS Action Plan Committee last year.

PLANNING FOR SERVICES
FOR PERSONS WITH HUMAN IMMUNODEFICIENCY VIRUS INFECTION
IN SOUTHWESTERN PENNSYLVANIA

The HIV Epidemic in the Region

The area surrounding Pittsburgh, Pennsylvania presents a profile similar in many respects to other sections of the United States currently experiencing the second and third waves of the epidemic of Human Immunodeficiency Virus (HIV) infection. At the center of the area are Pittsburgh and Allegheny County with a combined population of 1,336,449 people (1990 census). Compared to the major epicenters of the HIV epidemic, this area has had a low incidence (619 through 2/28/92) of people with AIDS although increasing numbers of people are being diagnosed with AIDS and are being infected with HIV. The ten surrounding counties have a combined population of just under 1.6 million people living primarily in small towns and rural areas. HIV has just begun to emerge as a problem in these counties with four of them (Armstrong, Greene, Indiana, and Somerset) reporting fewer than 10 cases since the beginning of the epidemic and a total of only 224 cases reported for those 10 counties since 1981. Cumulatively 72% of the people diagnosed with AIDS in the 11 counties have already died.

While the region is still considered an area of low incidence, the patterns of infection seen in the first wave cities (New York, San Francisco, Washington, etc.) are beginning to emerge. During the last 18 months, public health officials have seen a marked increase in the number of African Americans and the number of drug users infected as well as a moderate increase in the number of women who are HIV positive as a result of heterosexual contact with men who practice high risk behaviors. In 1986, for example, African Americans represented approximately 20% of the AIDS cases diagnosed among Allegheny County residents; by 1990, that figure had doubled and data through the first nine months of 1991 indicate that two-thirds of the cases diagnosed this year are Africans Americans. Seroprevalence rates among intravenous drug users tested have almost tripled during the same time frame although this shift has not yet been seen in the cases of full-blown AIDS reported.

Despite these alarming recent trends, the disease locally is still seen as one that largely impacts the gay and bisexual community. This interpretation has hampered attempts to mount a prevention program that clearly targets persons most likely to become infected during the next phases of the epidemic.

A complete, accurate inventory of HIV-related service resources in the region is not available. More is known about those services available in Allegheny County than in surrounding counties. However, none of the inventories developed by local service groups quantifies the extent of service availability. None has an adequate systematic way of updating information, and to date, none of them have fully merged information for regional use. To date, HIV-focused planning efforts in the area have had limited mandates and narrow foci, have been splintered, and have had goals of identifying resource use or service needs without taking the next step of developing a plan and strategies for its implementation.

Breakfast briefings over the next four months will begin to fill in the picture presented here.

1992 AIDS Action Plan
Community Advisory Committee

Co-Chair: Carol R. Brown
President
Pittsburgh Cultural Trust

Co-Chair: Farrell Rubenstein
Chairman of the Board
Montefiore University Hospital

Committee

Bruce W. Dixon, M.D.
Director
Allegheny County Health Department

William Evers
Ford Motor Company

Barbara E. Galderise, M.S. Ed., R.N.
Director, University Health Services
Duquesne University
representing John E. Murray

Sr. Margaret Hannan, R.S.M.
Associate General Secretary
Diocese of Pittsburgh

Earl F. Hord
President
Minority Enterprise Corp. of
Southwestern PA

Stanley Marks, M.D.
Chairman
Allegheny County Medical Society

Alan Meisel
Director, Center for Medical Ethics
University of Pittsburgh

Brad A. Meneilly
Cohen & Grigsby

William J. Meyer
President and CPO
United Way of Allegheny County

Benita Morris
representing Barbara Burns
Pittsburgh Public Schools

Thomas H. Nimick, Jr.
President
Nimick Company

Anne O'Connor
Pittsburgh Cancer Institute

Thomas D. O'Shea
Director
Allegheny County Department of Aging

Harry Palkovitz, M.D.

Mary Pat Parell
Assistant Vice President
Allegheny General Hospital

Azizi Powell
Program Director
Three Rivers Adoption Council

James F. Smith
Vice President, Loss Prevention
Thrift Drug, Inc.

Douglas R. Spencer
Alternative Program Associates

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December 1, 1992\commlist.aid\dmp

Ex-Officio:

Karen Wolk Feinstein
President
Jewish Healthcare Foundation

N. Mark Richards, M.D.
Senior Program Officer
Jewish Healthcare Foundation

Staff:

Dana M. Phillips
Director, AIDS Action Plan
Jewish Healthcare Foundation

JEWISH HEALTHCARE FOUNDATION
Centre City Tower, Suite 2550
650 Smithfield Street
Pittsburgh, PA 15222

SCHEDULED INFORMATIONAL SESSIONS
Community Advisory Committee

Session I: **Overview of the Problem** **April 8**
7:30-9:00 a.m.

AIDS in Southwestern PA

Presenters: Bruce W. Dixon, M.D.
Director
Allegheny County Health Department

Margaret Ragni, M.D.
Director
Hemophilia Center of Western PA

This session will provide a baseline of information on AIDS and the current demographics of the epidemic in the region. The intent of this session is to assure that the committee has the latest factual information about the epidemic in our region rather than only media reports to undergird their subsequent deliberations.

Prior to this session, the committee will receive a four to five page briefing paper on the history of the epidemic in the region, the efforts to respond to date, and a glossary of terms in common use.

Session II: **Living with AIDS** **April 22**
12:00-1:30 p.m.

The Other Side of the Epidemic

Presenters: People living with AIDS

NOTE: Lunch will be served.

Session III: **Publicly funded services for people with AIDS** **May 6**
7:30-9:00 a.m.

Presenters: Carol Ranck
AIDS Coordinator
Office of Program Development
Department of Public Welfare

Michael Carbine
Director
Bureau of AIDS
PA Department of Health

The intent of this session is to give the committee an overview of current policy issues and services for people with HIV Infection on a regional, state, and national level. This session is purposely designed to provide this information without involving local providers in order to avoid any perception of favoring a single agency or approach to services. Later sessions will address service funding from a provider perspective.

Session IV: **AIDS in the Workplace and Classroom** **June 10**
7:30-9:00 a.m.

Presenters: Carroll Curtis, M.D.
Corporate Medical Consultant
Westinghouse

Jon Rudnick, M.D.
Corporate Medical Director
Consolidated Natural Gas Co.

Patricia A. Crawford
Director of Public Information
Pittsburgh Public Schools

Edward K. Zechman, Jr.
President
Children's Hospital of Pittsburgh

This session is designed to share policies and practices of local employers and school systems as well as share concerns and realities about employee and student public relations.

Session V: **Review of Regional Services** — **June 24 7:30-9:00 a.m.**

Presenters:

Michael Neal, Executive Director
Pittsburgh AIDS Task Force

Fr. Lynn Chester Edwards, Director
Shepherd Wellness Community

Session VI: **Review of Services, cont'd** — **July 15 7:30-9:00 a.m.**

James Huggins, Ph.D.
Associate Director, Persad Center

Katherine Codd-Powell, CRNP
Pittsburgh AIDS Center for Treatment

Session VII: **Prevention** — **July 29 7:30-9:00 am**

Karen Reddick
Pittsburgh AIDS Task Force

Laura Leviton, Ph. D.
University of Pittsburgh

TO BE SCHEDULED:

Legal Issues

Wm. Rubenstein, ACLU AIDS Law Project

Other Perspectives on Prevention

TBA

AIDSCOMM.SCH\dmp

JEWISH HEALTHCARE FOUNDATION
AIDS Action Plan Project

PROPOSED FALL SESSIONS
Community Advisory Committee

Session I:	**Outstanding Issues & Preliminary Recommendations**	**October 21***
Alternative Date for Session I		**November 4**
Session II:	**Review & Discussion of Draft Plan**	**November 18***
Alternative Date for Session II		**TBA**

Presentation of Plan to the Community tentatively scheduled for December 1, 1992 from 10am until noon.

draft

AIDS Action Plan

A Community Commitment

We must unite to acknowledge that AIDS is not someone else's problem but is an epidemic that has killed almost 800 members of our community who were diagnosed here and several hundred diagnosed elsewhere who subsequently came home to die.

BACKGROUND

In December of 1991, The Jewish Healthcare Foundation proposed, in collaboration with the Southwestern Pennsylvania AIDS Planning Coalition, establishment of a community advisory committee supported by a part-time staff person to review existing information, develop and collate additional information, and, with the Coalition, recommend actions to improve the response to the HIV epidemic in Southwestern Pennsylvania. Extensive input from consumers, health and human service providers and purchasers (including public sector providers and purchasers), educators, and the region's religious community who together represent the collective resources and influence to improve the region's response was solicited as part of this process. This report summarizes the results of that effort.

The HIV Epidemic in the Region

The area surrounding Pittsburgh, Pennsylvania presents a profile similar in many respects to other sections of the United States currently experiencing the second and third waves of the epidemic of Human Immunodeficiency Virus (HIV) infection. At the center of the area are Pittsburgh and Allegheny County with a combined population of 1,336,449 people (1990 census). Compared to the major epicenters of the HIV epidemic, Allegheny County has had a low incidence (708 through 10/31/92) of people diagnosed with AIDS although increasing numbers of people are being diagnosed and are being infected with HIV. The ten surrounding counties have a combined population of just under 1.6 million people living primarily in small towns and rural areas. HIV has just begun to emerge as a problem in these counties with only five of them reporting more than 25 cases since the beginning of the epidemic. A total of 240 persons in those counties have been diagnosed with AIDS; 174 of them have already died.

Allegheny County experienced its first case of pneumocystis carinii pneumonia (PCP) in 1979. In 1981, after the Centers for Disease Control began tracking cases of AIDS, this case was classified as the first case of AIDS in the region. During the next four years of the AIDS epidemic, the number of cases identified in Allegheny County each year remained in single digits. In 1985, the reported incidence jumped to 28 cases; in 1986, 39 cases; in 1987, 73 cases; and in 1988, 68 cases. By October 31, 1992, 708 cumulative cases of AIDS among persons living in Allegheny County at the time of diagnosis had been reported by the Health Department.

The AIDS epidemic in the counties surrounding Allegheny County has emerged in a parallel but delayed basis. As of October 31, 1992, Westmoreland County had reported 63 cases of AIDS; Cambria, 36; Washington, 34; Beaver, 30; Butler, 26; Fayette, 18; and Armstrong, Greene, Indiana and Somerset counties each had had 10 or fewer cumulative cases of AIDS reported.

Approximately one-third of the hemophiliacs in western Pennsylvania were infected with the AIDS virus prior to 1986. Of the approximately 90 persons infected, 50 are still alive and being followed by the Hemophilia Center of Western Pennsylvania. No new incidences of infection among the population of hemophiliacs or their spouses have been reported since 1986 when new procedures for handling blood products were instituted.

The region is still considered an area of low incidence, although the patterns of infection seen in the first wave cities (New York, San Francisco, Washington, etc.) are beginning to emerge locally. During the last 18-24 months, public health officials have seen a marked increase in the number of African Americans and the number of injection drug users infected as well as a moderate increase in the number of women who are HIV positive as a result of heterosexual contact with men who practice high

risk behaviors. In 1986, for example, African Americans represented approximately 20% of the AIDS cases diagnosed among Allegheny County residents; by 1990, that figure had doubled and data through the first nine months of 1991 indicated that two-thirds of the persons newly diagnosed that year were Africans Americans. Seroprevalence rates among intravenous drug users tested have almost tripled during the same time frame although this shift is only beginning to be seen in the cases of full-blown AIDS reported.

These trends have shifted the overall demographic profile of the epidemic in the region. Publicity about that new profile has sometimes obscured the fact that gay and bisexual men in the region, particularly younger men, are continuing to become infected. Same gender sex between men remains the risk factor most often reported among people newly diagnosed with AIDS.

The numbers reported locally only tell part of the story of the epidemic in the region. Southwestern Pennsylvania is an area to which persons with AIDS or HIV infection diagnosed elsewhere have been returning. A survey done in 1990 by the Southwestern Pennsylvania AIDS Planning Coalition suggested that between thirty and fifty percent of the people with HIV/AIDS receiving services from local agencies had been diagnosed elsewhere and, therefore, are not reflected in the statistics above. The fact that HIV is not reportable also disguises the full impact of the epidemic on residents of the region and providers trying to respond. Current projections are that between 2000 and 3000 additional people are infected with HIV but have not yet been diagnosed as having AIDS.

The local perception of AIDS as a gay disease has been strengthened by the response. Organized religion has historically played a major part in responding to the health and human service needs of the region. Many of the area's nonprofit organizations serving the elderly and the handicapped have their roots in outreach efforts of the region's churches and synagogues. In Pittsburgh, as in other communities across the country however, the early response to AIDS came largely from a different source--the gay and lesbian community.

Over the last few years, more traditional agencies and organizations have begun to provide services. To some extent, this development has occurred as a result of a deliberate strategy on the part of the Southwestern Pennsylvania AIDS Planning Coalition of encouraging mainstream agencies by providing training and support. It has also, however, resulted from a spate of applications to a wide variety of funding sources as money has become available and agencies have tried to access those funds. In either case, the spread of services has occurred in the absence of a comprehensive regional plan and, more importantly, without adequately addressing strategies to prevent further spread of the disease.

The struggle to develop and fund services for people currently infected, the region's continuing denial of the problem, the lack of a means for adequately tracking trends of HIV-infection over time, the length of time people may be HIV positive without showing symptoms and often without knowing they are infected, and the inadequacy of resources currently available to quantify current and future needs of persons with HIV infection needs have all contributed to the region's failure to develop a plan for a comprehensive response to the HIV epidemic. The competition for limited service dollars among AIDS-specific programs has also sapped energies that might otherwise have been focused on developing such a plan.

The Region

The first decade of the HIV epidemic in Southwestern Pennsylvania has been a decade of change for the region. The area's economic roots were in heavy industry, especially steel and the aligned industries of coal, rail and river transportation, and in agriculture. It was primarily a blue-collar region with a strong family and religious base.

The ethnic background of the region, extracted from 1990 census data, shoes that approximately 11.2% of Allegheny County residents and just under 10% of the population outside Allegheny County identify themselves as being African American. Of the remainder, 30% of the people identify their family origins as German, English, Irish, Italian, Polish, and French with the large majority of others identifying their ethnic heritage as being mixed with one of the previously listed European groups. Less than 0.5% of the region's residents are of Hispanic origin, most of them in Allegheny County.

Neighborhoods within the region are often readily identifiable ethnic pockets with strong family and cultural ties within communities. These cultural ties have been significant shapers of social interaction among groups. Both residents and astute observers frequently characterize the area as provincial with a limited tolerance for non-mainstream behaviors and lifestyles. This is particularly true as one travels from the Pittsburgh hub into the surrounding counties.

Conservatism permeates the region. This conservatism is reflected in the local ethic, in the social mores, in the political system and in the region's institutions. Pittsburgh's economic base has shifted over the past fifteen years from heavy industry to a much more white collar economy linked to corporate management, institutions of higher learning, the health care industry, biomedical development, and a variety of other research and development initiatives. Despite this shift, much of the blue-collar social structure and conservative value system has remained. While a more moderate to liberal cosmopolitan value system is beginning to emerge, this has lagged far behind the economic shift. Outside the urban area, the economy remains depressed. Economic recovery and the shift to a more service oriented labor market are only beginning. The small towns and rural family farms still reflect the area's conservative history.

This sociological profile presents important challenges. Regional approaches to dealing with AIDS/HIV infection and the populations at highest-risk (gay/bisexual men and IV drug users) must always take into account the extant personal and institutionalized conservatism and homophobia in the region's communities. The responses of the business and religious communities suggested in the recommendations will be key aspects of any successful plan for prevention of further spread and provision of accessible and acceptable services.

Emerging Issues and Recommendations

Information for this report was gathered from previous documents/surveys developed by the Southwestern Pennsylvania AIDS Planning Coalition; a 1990 study done by the Health Policy Institute and used by the Coalition as a part of its needs assessment process; reports of planning days convened by the Pittsburgh Interorganizational Council on AIDS; transcripts of a series of needs assessment meetings in the region convened jointly by the Pennsylvania Departments of Health and Public Welfare during 1990 and 1991 to which providers, people with AIDS and their significant other were invited; transcripts of presentations to the Community Advisory Committee for this project; a series of individual and group interviews with 118 people living with AIDS/HIV infection, 31 family members and significant others of people with AIDS, numerous providers, many of the members of the Southwestern Pennsylvania AIDS Planning Coalition; and 25 "man-on-the-street" interviews with people in Pittsburgh, Indiana, Butler, Uniontown, Somerset, Greensburg, Washington, and Aliquippa.

A synthesis of the focus groups, individual interviews, presentations, and written materials described above resulted in a series of issues and recommendations being developed and discussed with advisory committee members and key informants. These issues and recommendations fall into six broad categories of concern:

- **Prevention**
- **Funding**
- **Agency/Staff Capacity**
- **Services**
- **Planning/Dialogue**
- **Systematic Information Exchange**

The need for coordination and cooperation is an issue overarching these six areas, an issue that is particularly critical in the current era of scarce resources. Each of these topics is discussed below.

Prevention

Issues:

There is no cure for HIV infection nor is there a vaccine. AIDS can, however, be prevented through **educational efforts that go beyond knowledge to change behavior.** Such efforts must be ongoing rather than episodic; must carry clear, credible, consistent and culturally appropriate messages; and must reach <u>all</u> sectors of our community. While some people interviewed argue that in 1992-93, all prevention/education programs need to be targeted, that is to say they argue that enough has been done to educate the general population, the interviews and focus groups do not confirm this.

> "*I babysat for a couple. When they found out I had HIV, I lost my job.*"
> Woman living with AIDS.

> *"One of my employees was asked to take her child out of a day care center when the media reported that we had an HIV-infected employee."*
> Hospital CEO.

> *"Some nurses say people are afraid to date them because our facility cares for patients with AIDS."*

Local nurse.

"We stopped drinking communion wine from the chalice because people were afraid of AIDS."
Fifty-seven year old woman interviewed on the street.

Clearly, prevention education is necessary in order to reduce unnecessary fear in the general population about transmission through casual contact. That fear represents a significant barrier to services for many people with HIV-infections. Broad prevention education programs are also necessary if we are to reach persons who are not open about behaviors that may put them at risk as well as reach everyone who is currently sexually active and everyone who may be sexually active in the future and may be at risk as HIV infection increases in the general population. Misperceptions about transmission risk continue.

"I don't have to worry about using a rubber with him. He don't have anything. You can tell just by looking at him."
18 year old woman describing her new boyfriend to other young women in a focus group.

Targeted prevention education work, focusing on gay and bisexual men, on injection drug users, and on groups whose incidence of other sexually transmitted diseases is high has not been extensive enough or effective enough to stop the spread of the disease. The local testing and counseling sites continue to see new cases of HIV infection each month and programs such as the Pitt Mens Study continue to report seroconversion among their study participants.

Several issues have been identified as barriers to adequate prevention education for our region.

There is no central coordinating point for prevention programs and no regional prevention plan. Within the public sector, the Allegheny County Health Department has public health responsibility for Pittsburgh and Allegheny County while the Western District Office of the Pennsylvania Department of Health has responsibility for the remaining ten counties of the region. Neither has adequate resources to mount a comprehensive HIV infection prevention campaign. Coordination of efforts between the two parties is voluntary and often fall through the cracks since there is no mandate for coordination and both agencies have many other responsibilities with limited staff to respond. Data gathered by these health departments is also not routinely available for use in planning prevention efforts and since HIV is not reportable to them, there is little effective feedback on the efficacy of prevention efforts that are being mounted.

Private sector prevention efforts have been even more disjointed than those within the public sector. As funds have become available, agencies have competed for them rather than working in collaborative efforts or as part of a broader plan. Much of the work has consisted of educational efforts have been directed to broad general populations or to staff working with populations that may be at risk. This includes work done in schools, worksites, health fairs, etc. Some private sector work has duplicated efforts being undertaken by the health departments. Other efforts have inadvertently targeted geographic areas already being served because information about projects or prospective projects has not been shared among providers of prevention programs or among those funding such programs.

Funding is inadequate and episodic. Prevention programs require trained staff as well as educational materials. Research suggests that it takes several contacts with information before people know enough to begin to be able to modify their sexual behaviors to reduce their risk of infection. Currently prevention activities compete with services for the very limited resources available for AIDS-related activities. State funds committed to community-based AIDS-prevention activities in the region continue to be inadequate and restrictive regulations may limit the initiatives those dollars support.

"You get one grant from the state and you have $10,000... and you go out and put a poster and brochures in every gay bar in town...and then nothing else happens for a long time... We're talking about serious behavior change... This [episodic approach] won't do it." AIDS Educator

Although some private sector dollars from foundations and corporations have begun to be directed to AIDS prevention activities locally, lack of a coordinated plan and the time-limited nature of most of those funds limits their impact. Foundations also tend to focus their dollars on new initiatives which has resulted in some agencies having to drop prevention programs they started when public sector funds did not emerge to continue the program. Those same agencies then began "new" efforts in order to get funds.

Too much time and effort are spent re-inventing. Over the last several years, many nonprofits have spent time developing materials and techniques to use in their prevention education programs because they have had inadequate access to the information and materials already available. While the recently published manual, "A Roadmap for Effective HIV/AIDS Prevention" authored by Laura C. Leviton, Eduardo Mejias, and Anthony Silvestre of the University of Pittsburgh's Graduate School of Public Health for the Pennsylvania Department of Health, offers some useful guidelines, more sharing of best practices and materials is needed. Recommendations from the 1992 PICA Planning Day on Prevention may be useful in this effort when they are published.

"Madison Avenue knows how to motivate us. Let's apply those techniques. It's a social marketing task."
Community Advisory Committee Member

Few efforts have been made to crosstrain indigenous outreach workers already placed in the community. Many areas have outreach workers in teen prevention programs, drug and alcohol programs, street outreach for the homeless, gang prevention programs, and a variety of community health programs. The populations being served by these outreach workers are at risk for HIV infection. Cross training could allow AIDS prevention education messages to be cost-effectively integrated into those ongoing efforts.

The general community---schools, worksites, religious institutions, social organizations---shows limited concern about the issue of prevention of HIV infection. Changing norms of behavior requires the development of a broad base of commitment and concern. If we as a region are to stop the spread of this epidemic, prevention must become a concern of everyone.

While AIDS education is mandated in the schools, the content and the required competence of the trainers/staff presenting the materials are decisions left to local districts. Quality and content vary widely and few school-based programs provide adequate information on prevention presented by staff who are up-to-date and comfortable with the subject. The area's largest school system, the Pittsburgh Public Schools, has significantly reduced its staff support for AIDS education this year, a potentially disastrous decision when all indications are that we should be increasing our efforts with school-aged students particularly with 10-14 year olds.

Early in the epidemic, some worksites in Pittsburgh provided AIDS education for their employees. Because Pittsburgh has been a low incidence city and workers in general felt little sense of risk, those educational efforts were viewed by some employees as a one-time curiosity. With more cases of AIDS having been diagnosed locally, and more highly-visible national figures speaking about their own HIV infection, this attitude is beginning to change but more work is needed there.

"It was real in 1985. I mean it happened in New York and places but not to me or my family. I heard the stuff at work but I never talked to my wife or kids about it. Now I know someone.

[My company] just had a training session. It was short but I learned a lot. I called my daughter at college about it."

Churches in Southwestern Pennsylvania, in contrast to churches in some other parts of the United States, have not generally seen themselves as a vehicle for health education.

Finally, single county authorities (MH/MR, Drug and Alcohol, Aging and other county human service programs throughout the region) have largely left AIDS and AIDS education responsibilities to the health department staff covering their counties.

RECOMMENDED ACTIONS:

Develop a central clearing point--A Prevention Network--for prevention activities. The Southwestern Pennsylvania AIDS Planning Coalition has the potential to link the two health departments and the private nonprofit organizations in a prevention network and develop a comprehensive plan for general prevention activities and activities targeted to groups at highest risk for infection.

Several steps would be necessary for this to occur. The two health departments and the private nonprofits would have to agree to collaborate; the coalition would have to agree to assume this task for the region; public or private sector funds would be necessary to support the staff time necessary to undergird this activity; and, most importantly, private and public sector funders would need to agree to work with this coordinating system to minimize duplication of efforts. The network would need to be open to working with indigenous groups in addition to the current small group of agencies providing prevention services. This network could play an important role in convening the experts on "best practice" and in **crosstraining outreach workers already in the community.**

Development of a prevention network could also help address the issue of evaluating prevention efforts. Under the current system, the health departments have incidence and prevalence data that could provide important feedback to prevention programs. The Network could offer a forum for discussion of the data and its implications on a periodic basis.

Develop the community commitment to use schools, workplaces, religious and social institutions as sites for HIV/AIDS education. A Prevention Network together with leadership from the Allegheny Conference for Community Development, other employer groups, unions, the United Way,the foundation community, the intermediate units and school districts, ministerial and rabbinical organizations, and public sector leaders should work together to prevent the further spread of this epidemic. Such a broad-based effort would require an commitment of will--a change of attitude--that has not yet existed in Southwestern Pennsylvania. The Community Advisory Committee to this project represents one resource for encouraging such collaboration.

We must unite to acknowledge that AIDS is not someone else's problem but is an epidemic that has killed almost 700 members of our community who were diagnosed here and several hundred diagnosed elsewhere who subsequently came home to die.

Funding

Issues:

Public sector dollars have not begun to keep pace with the increased demands for service to HIV-infected people. **Prevention education competes with direct services for the limited dollars available.**

Currently almost all public sector monies for HIV/AIDS prevention and services are state and federal dollars. The majority of communities in the region have provided no local financial support for prevention/education or services related to HIV/AIDS. While the need for prevention education and services has increased, public sector dollars to local agencies (Allegheny County Health Department, Persad, Pittsburgh AIDS Task Force, for example) have decreased over the past 12-18 months.

> *"Funding [for AIDS-related efforts] in Southwestern Pennsylvania is at best a zero sum situation."* Local provider

The shortage of dollars has been exacerbated by the delays in the state contracting process. Processing of annual contracts by the Pennsylvania Department of Health takes five to six months after the beginning of the fiscal year. This can result in a corresponding gap in some services for people with AIDS/HIV infection and has already resulted in payless paydays for staff of agencies trying to respond.

> *"My insurance premiums were being paid by Ryan White funds. The premium is due. I have no money. I have already borrowed from my family and friends to meet the payments since August. If I lose my insurance, I will lose my house as I spend down to Medical Assistance and I don't know how I will find another place to live that I can get into with my wheelchair or that I can afford. My premium is only $175 each month. Doesn't the state know we're all better off if they get the funds out here."*

In addition to the immediate problems caused by inadequate, delayed funding streams, **agencies in the region lack futuristic dollars.** The demands on them are increasing; their response,s of necessity, are short-term; most have no resources for planning to meet future needs or for evaluating the effectiveness of current programs. Scarce human resources needed to respond to client needs are frequently being diverted to fundraising activities and staff and volunteer burnout are common concerns. While more foundations and corporations are responding financially, each has different interests, different funding cycles, and different forms and reporting requirements that make it difficult for small agencies to respond.

People with HIV/AIDS often have little knowledge of alternative sources of services or of entitlements that may pay for those services and, until recently, have had few incentives to apply for those entitlements for services being provided by AIDS Service Organizations (ASOs). Applying for public sector entitlements is often a burdensome process made more difficult by the exhaustion experienced by many people living with HIV-infection. As a result of this and of fear of breach of confidentiality by other organizations, some ASOs have offered services, particularly case management and supportive services, to people who might have been eligible for other funding for those services such as the Department of Public Welfare's Targeted Case Management or AIDS Waiver programs. As the demand for services has grown, this posture has significantly increased the strain on agency resources.

RECOMMENDED ACTIONS:

The public sector must increase available funding for AIDS prevention and services. Private sector dollars are increasing but they cannot begin to fill the gaps left by inadequate increases in public sector dollars for service programs or direct cuts in monies for testing, counseling, prevention education, and services.

The contracting process used by the Pennsylvania Department of Health, Bureau of HIV/AIDS must be shortened. The Department has been providing funds to community-based providers for five years. They must immediately take steps to reduce lag time, extend contracts over several years to alleviate the service discontinuity caused by their current process, or find other mechanisms to assure funds for continuity of services.

A working capital reserve or system for a loan pool should be developed at the regional coalition level to fill part of the gap caused by the delay in state and federal funds. Encouraging each small agency responding to the epidemic to divert significant staff and volunteer efforts to fundraising only to accommodate public sector delays in contracting and paying is not a productive response. The Southwestern Pennsylvania AIDS Planning Coalition (SWPAPC) and The Forbes Fund, a supporting organization of The Pittsburgh Foundation established to assist agencies in responding to public sector funding disruptions, should collaborate to help fill the need for a working capital reserve.

Technical assistance should be provided to assist agencies in developing resource plans that broaden their base of funding in a systematic way. More specific suggestions about this are made in the section on Agency/Staff Capacity.

More private sector funders should respond to AIDS-related requests. AIDS cuts across a broad spectrum of funding areas--housing and education, for example, as well as the traditional health and human services. Funders who give priority to low income housing, for example, might consider supporting the low income handicapped housing project being developed that will serve people with AIDS or the personal care facility for younger people including PWAs currently being developed by Verona House.

Private sector funders should consider support for planning. The nature of the epidemic is not static.

> *"Organizations in the region need to have planning dollars to work to stem the tide and to determine how best to meet the increased complexity of the service responses needed."*
> Former agency director

Foundations, corporations, and the United Way should consider pooling and leveraging their resources and becoming a National Community AIDS Partnership area. In 1988, the Ford Foundation initiated a challenge grant program, the National Community AIDS Partnership (NCAP), in conjunction with nine national foundations and corporations. In each of the cities selected for this initiative, an advisory group was convened, a needs assessment conducted, and local funds were raised according to the match requirements of the challenge grant, pooled with the national match, and distributed to local groups in response to a local request for proposals. NCAP staff have indicated that the Ford Foundation is considering opening this program to a new round of cities/areas. If this occurs, staff at the Jewish Healthcare Foundation will be notified of this and have agreed to convene other local funders around this project.

If a new round of applications for NCAP are not considered, local foundations interested in funding AIDS related programs or projects, may wish to collaborate in developing either a pool of funds or a combined application form. Either step would significantly reduce the burden on small agencies.

The Coalition members agencies should work together to scan the Pennsylvania Bulletin, The Federal Register, and AIDS-related RFPs on a systematic basis and cooperate in responding to appropriate opportunities for funds for the region. Most individual agencies do not have the time nor the resources to access these documents regularly and many do not have the capacity to develop the proposals themselves although they may be the best-positioned agencies to respond to the service need addressed in the proposal.

Case managers and other persons working with people with HIV/AIDS must learn to maximize use of entitlements. The pool of funds for AIDS-specific services is limited. Many people living with AIDS/HIV infection are eligible for other public-sector-funded services. Case managers and other social service staff working with people with HIV/AIDS need to direct their eligible clients to programs that can support services, including case management. Community-based AIDS money and Ryan White

funds should be used only as a last resort. Additional recommendations related to this issue are described in the section on services later in this report.

Agencies and organizations must develop the norm of providing resources for their own training. In order to encourage providers to serve people with HIV/AIDS, community-based AIDS service organizations (ASOs) have been using their own staff and financial resources to train other types of providers. Public and private sector funders can encourage all health and human service providers to develop appropriate policies and assure adequate staff training by asking their grantees or contractors about HIV-related policies and about staff HIV-training as a part of their application or review process. They can further assist by providing technical assistance or mini-grants when necessary to assist in such training or policy development so that those agencies don't drain the limited resources of the ASOs. Agencies whose staff is eligible for training through the Pennsylvania AIDS Education and Training Center should be encouraged to use that resource for staff training.

Agency/Staff Capacity

Issue:

Many of the agencies responding to the HIV-epidemic in the region are new, have limited staff capacity, limited financial stability, and have both boards and staffs with limited experience in running a nonprofit organization. Business expertise is generally lacking. Strategic plans are few and the luxury of time or resources to develop plans is rare. Hospitals and other well-established agencies frequently need technical assistance in developing appropriate internal policies that enable them to respond to the epidemic. This need is particularly acute outside Allegheny County in areas where the hospital or other organization has not yet had a HIV-infected employee or a request for service from a person known to be HIV-infected.

Areas particularly mentioned as areas where help is needed by newly emerging agencies include:

1. **Management and Administration**
   - a. Budgeting and financial reporting
   - b. Policy develop and systems
   - c. Staff supervision
   - d. Strategic planning

2. **Volunteer use**
   - a. Recruiting
   - b. Interviewing and "Hiring"
   - c. Training and supervising
   - d. "Firing"
   - e. Rewarding--use of psychic paychecks

3. **Resource development**
   - a. Writing a multi-year resource development plan
   - b. Techniques/how to--grants, annual funds, special events
   - c. Capturing and maintaining public sector funds
   - d. Planning human resources for resource development

4. **Board development**
   - a. Strategic Planning

b. Board/Staff roles and responsibilities
c. Assessing board skills & recruiting skilled members

5. **Relationships to other systems and agencies**
   a. Understanding what other systems provide so I don't duplicate.
   b. Collaboration--how to
   c. Working with mainstream funding sources

Areas where help and technical assistance is needed by hospitals, long term care facilities, personal care boarding homes and other larger agencies include:

1. **Policy development and implementation.** Many of these organizations indicate that they have received information such as OSHA guidelines but have not actually developed and disseminated policies for their facility.

2. **Staff training** in AIDS including the technical aspects of universal precautions, OSHA guidelines, Act 148, etc. in their particular setting; in utilizing community resources particularly when planning discharges; and in working with staff attitudes about AIDS. The need for staff training is particularly acute in agencies providing mental health services--services that have been in consistently short supply for people with AIDS/HIV infection in most of the region. A new grant to the University of Pittsburgh staff involved in the Pennsylvania AIDS Training and Education Center may be a resource.

RECOMMENDATIONS

Training, technical assistance, and mentorship arrangements should be established for the small organizations responding to the epidemic. Such assistance could help them grow when necessary, help them stay small and focused when that is more appropriate to their community needs, and in both cases maximize their ability to function in a continuing environment of scarce resources.

Information about existing training and technical assistance resources should be disseminated. Linkages could be facilitated by the Coalition. A number of resources are already available to assist both the smaller or newly-emerging and the larger well-established organizations. The Forbes Fund Management Assistance Program, the Nonprofit Management Institute at Carnegie Mellon University, and the area's community colleges all have the capacity to provide this type of training particularly to smaller institutions. The Southwestern Pennsylvania AIDS Planning Coalition should take a leadership role in working with those training institutions and local funders to disseminate information about existing opportunities and, when necessary, develop seminars and mentorships for agencies that need that help.

More experienced agency executives and volunteers from the for-profit sector may also be available to act as mentors for agency staff and volunteers at smaller agencies. The Forbes Fund and the United Way's Volunteer Action Center may be able to take a leadership role here. Leadership Pittsburgh alumni members might also be approached to share their skills as volunteer mentors.

The Pennsylvania AIDS Education and Training Center offers numerous programs that can provide technical assistance to hospitals and other medical facilities/providers. The Jewish Healthcare Foundation and the Hospital Council of Western Pennsylvania are also currently exploring some direct assistance to hospitals working on policy issues related to the HIV epidemic.

SERVICES

General Issues

Parallel service systems have developed for people with HIV/AIDS. Interviews and focus show a series of related reasons for this. First, neither the professional provider community nor people with AIDS/HIV infection have adequate knowledge of existing resources for services.

> *"I just found out this week that I could get emergency housing assistance through [source].* Experienced case manager specializing in AIDS services

Second, people with HIV/AIDS living outside Pittsburgh continue to fear breaches of confidentiality with consequent discrimination and continue to experience reluctance on the part of providers to serve them.

> *"If I'm in the hospital in [hometown], everyone will know what's wrong. It's a small town. There are no secrets."* PWA

> *"Our hospital sends people to [Pittsburgh] because they'll get better care there is they have AIDS. We're just not trained."* Hospital CEO

Finally, referral patterns--professional and PWA-PWA--developed through the course of the epidemic support continuing to refer people to AIDS-specific services in Pittsburgh.

> *"If I find someone who tests [HIV] positive, the first thing I do is get them an appointment [in Pittsburgh]."* Uniontown provider

Many facilities still do not have adequate policies in place nor have they trained their staff members.

Recommendations:

Increase case management training. Case managers themselves have seen this as a need but have had few resources to devote to regular training sessions on the full extent of basic benefits such as Medical Assistance, existing systems of service, streamlining access to services, or new services and benefits being developed. Development of a Case Management Roundtable with regularly scheduled sessions could address this need. A coordinator and some funding from local private sector sources would be necessary to maintain this type of effort.

The Coalition should work to compile a manual of state, county and local programs with eligibility requirements for each. Many individual member agencies have already developed portions of such a manual but the information is not complete nor widely disseminated. Consultation with Helpline and with the Living at Home Program at Montefiore (BOSS program) might suggest ways to computerize such information for easy screening and updating. Funds or in-kind printing support for such an effort could be provided by local foundations and corporations.

Focused training for discharge planning staff at all hospitals in the region is needed. Training is needed about rules on information flow between the hospitals and post-acute care settings as well as on services for people with AIDS and their families/significant others, eligibility requirements for those services, access mechanisms, and appropriate transition to community-based case management. Case

managers need training on these linkages as well. The Case Management Roundtable discussed above and the Pennsylvania AIDS Education and Training Center might be resources for this effort.

Develop a system of access to a panel of experts. People with AIDS need a wide variety of services from a wide variety of service systems. It's difficult for the best trained case manager or discharge planner to know everything about each of those options. The Coalition could develop a panel of people expert in the fields where help or information is most often needed, print the topic, expert's name and phone number on a wallet-sized card and a pre-printed rolodex card, and distribute this to case managers and discharge planners in the region. This expert panel might also be called upon for training on a periodic basis.

Work with the PA Department of Health to develop the 800 number for physicians that was called for in the Governor's budget for 1992-93. All physicians interviewed have indicated that they want to get information from other physicians. Informal networks have filled some of this need but more is needed. **The Coalition (and at the state level the HIV Planning Council) should also continue attempts to work with the Pennsylvania Medical Society, Pennsylvania Psychiatric Physicians, and the county medical societies in the region as means of reaching physicians.**

Encourage use of the PAETC's mini-residency program. A common complaint among professionals has been that attending a workshop does not give them enough experience to actually provide care to a person with HIV/AIDS. The PAETC has developed a multi-day, intensive mini-residency to meet this need particularly for physicians.

Upgrade hotline(s). Hotlines can be an important source of information about services if the persons answering the telephone are well-trained. The Pittsburgh AIDS Task Force has recently made a decision to use the AIDS Factline, Helpline, and Contact Pittsburgh as general hotline numbers rather than incur the cost of a separate hotline through their offices. The Pennsylvania Department of Health, the United Way, and local funders must provide some support to assure that the necessary training, information resources, and means of publicizing these numbers are in place.

Develop a norm of serving people with AIDS/HIV infection. Public and private sector funders should ask organizations that they fund if they have AIDS policies in place, what training their staff has had around HIV/AIDS, and what training they have planned for the upcoming year. This practice is particularly important in dealing with health and human service agencies but could also be applied to educational institutions. Trustees/board members should question their agencies to assure that they are in compliance with the Americans with Disabilities ACT, OSHA, and Act 148 if applicable.

> *"It is unconscionable in 1992 that [agencies and organizations] should discriminate on the basis of AIDS, but I know that they do."*
> Community leader

Colleges and Universities should assure that HIV/AIDS education is including in the curriculum of all programs training health and human service professionals.
This recommendation has been made repeatedly both in the region and at the state and national levels. While some progress is being made, much remains to be done. Attitudes among some faculty members limit that progress.

> *"I went to speak to a group of nursing students. [Key faculty member] was talking to the students before I came into the room. I heard her tell them, 'I still don't think nurses should be required to risk their lives to work with those people'. What could I say to overcome that attitude?"*
> AIDS educator

The Coalition should continue to urge the Pennsylvania HIV Planning Council to work for inclusion of HIV/AIDS training as a part of licensure requirements for health and human service professionals. Other states have instituted HIV/AIDS training as part of licensure or continuing education requirements. Pennsylvania's professional association need to move forward on this.

SPECIFIC SERVICE NEEDS

The specific service needs of people living with HIV/AIDS and the resources they have to meet those needs are as individualistic as the people themselves.

The greatest single need mentioned in the interviews and focus groups by both PWAs and their families or significant others **was information.** The specific information needed was varied but most often had to do with benefits and services. Both families and people living with AIDS reported that case managers and other providers with whom they were working often missed key pieces in the benefits puzzle.

> *"My insurance company had a program that allowed flexibility if I worked with their staff. When I told my case manager that I had [insurance coverage], she said, 'Well they won't pay for these things.' In fact, I found out quite by accident that they would."*
> Person with AIDS

Several persons living with AIDS said they did not want case managers, however. They wanted a person to call to get information when they needed it and to straighten out confusions. This seems to point out some misperceptions about the role of case managers, not surprising since several systems have staff positions called "case manager" but those staff have slightly different roles in each of the systems.

> *"I don't need nobody to tell me what to do. I just want to know where to call to get [service].*
> Person with AIDS

Lack of choice in case managers was another issue mentioned by people with AIDS. African Americans mentioned this most as an absence of African American case managers and a lack of cultural sensitivity on the part of some white case managers.

> *" If I'm going to get the services, I have to talk to this person but she don't know what it's like. She don't know my life. She don't know where I'm comin' from. She kinda talks around me like I'm not there."*

Despite these comments, the vast majority of persons interviewed (over 70%) indicated that they benefitted from the help of their case managers and relied on their assistance.

Persons outside the Pittsburgh area reported significantly less access to case management services. The Health Department staff were most often the ones pressed into such service in counties where there are no indigenous case managers. In those counties, health department staff also noted that they get frequent call from Pittsburgh-based case managers asking for help in arranging services. Both PWAs and Health Department staff indicated a need for case managers outside Pittsburgh.

Housing

A need for affordable, handicapped accessible housing and a need for personal care facilities were the two housing needs most frequently mentioned. The need for a personal care facility was often expressed as a need for a place where someone would be around all the time.

> *"He is becoming so forgetful and gets so confused. I'm afraid to leave him at home while I go to work. He has a visiting nurse but that's only for a short time."* Caregiver

Providers see this as a need that is growing as people are living longer with the disease. People with

AIDS themselves, often expressed the need differently.

> *"I just need someone to be there. I forget things. Sometimes I'm not sure how to do the stove to fix lunch. I just need someone else in the house with me."*

The handicapped housing project with an AIDS service component that is being developed on the Northside of Pittsburgh will meet some of this need as will the Verona House personal care home. Verona House will not, however, address the desire of people living with AIDS to stay in their own homes while more services are brought in. Neither project will address the needs of people outside of Pittsburgh who wish to remain in their own communities.

Case managers and others should work with mainstream programs that provide volunteer in-home services and should encourage existing volunteer programs within ASOs to provide in home services in addition to friendly visiting.

Mental Health

Mental health services were mentioned as a need across the region. Even in Pittsburgh, where Persad Center has taken a leadership role in developing such services specifically for people with HIV/AIDS, counseling and particularly support groups were mentioned frequently as needs. Individual, couple, and family counseling were particularly difficult for people to find unless they had resources to pay a private therapist. Community mental health centers, with the exception of Irene Stacy Center in Butler County and the mental health center in Altoona which serves some Cambria County residents, were not considered to be an option for service by people with AIDS or their families.

Outside Pittsburgh, support groups are almost non-existent and where they are emerging, appropriately trained facilitators are difficult to find. Professionals mentioned that support and supervision for facilitators outside the greater Pittsburgh area is difficult to arrange as well. In addition to lack of trained facilitators, concerns about confidentiality were frequently mentioned as barriers to adequate support services outside Pittsburgh.

> *"I couldn't go to a support group in [location]. Everybody would see me and know I had AIDS."* PWA from Westmoreland County

Many people indicated, however, that they would like to go to support groups in their local community if they could find a location where they did not feel compromised. Some suggested that people's living rooms might be the best place if the group was small.

Women noted that they find it difficult to talk about some of the things that concern them when they are in a support group comprised primarily of men. The small numbers of infected women have made it difficult to develop women's programs until very recently.

Bereavement groups were another frequently expressed need. The nature of the epidemic and the service systems that have been built around it has resulted in an environment where families and significant others are mourning not only the loss of their family members but also the repeated loss of others they have gotten to know through volunteer programs and social support programs such as the Shepherd Wellness Community. Again, this need appeared greater in rural counties but was frequently mentioned in Pittsburgh as well.

Finally, some people living with AIDS expressed a desire for peer-peer support groups. They indicated that those groups met a different need for them than professionally-supported groups.

Respite care, particularly in home respite, was mentioned. One woman living with AIDS mentioned a need for child care on an emergency basis when a parent is hospitalized as a need that she recently had to face and another woman, one whose child had recently died from an AIDS-related illness, said that her greatest need had been for someone to stay with the child while she did errands, saw her own doctor, or just had an hour or two for herself. **A related option, day programs, do not exist in our community for people with AIDS.** The need for such programs is expected to grow as people live longer with HIV infection and more dementia is seen. Some PWAs mentioned this as a need for themselves.

> *"I feel like I exist in no man's land--too sick to work, too well to die, no place to go all day so I just lie there."*
> Person with AIDS

Transportation has been a long-standing problem mentioned by both providers and people with HIV/AIDS and their families. The problem is a complicated one. Transportation is often needed because services are available only in Pittsburgh. Providing transportation eases the pressure on providers in outlying counties to develop services. Some existing transportation options are poorly designed for people experiencing dementia or the extreme fatigue that often accompanies AIDS. Others require that one's diagnosis be given to the transportation company as part of qualifying for services, a significant barrier to use in a climate where people living with AIDS continue to feel discrimination. Most transportation options are available based on means testing, another barrier for people struggling to maintain as much of their financial independence as possible.

Help with activities of daily living (bathing, grooming, washing clothes, meal preparation,etc.) was mentioned as another need. The absence of appropriate personal care home options and the limited supply of these services on an in-home basis--essentially nonexistent in large parts of the region--make this a particularly large gap in the current service continuum.

Lack of access to nursing home beds is a need still noted by providers trying to find post-acute care for AIDS patients in the hospital. Home nursing services seem to be widely available and used frequently as a resource for persons whose home situation allows this solution to meeting post-acute care needs. The lack of access to nursing home beds seems to have two components--some continuing reluctance on the part of providers to take people with AIDS and a reluctance to take people on Medical Assistance because of the low rates paid by that program. The fact that most of the PWAs are younger men while most nursing home residents are older women also causes a problem in finding beds.

Food is another frequently-mentioned problem that is multi-faceted. PWAs on food stamps indicated that they often run out of food before the end of the month. Food bank access is limited by the problems of arranging transportation to coincide with the food bank hours as well as the exhaustion experienced by many. Meals-on-wheels are often difficult to arrange because many of the programs limit their services to older adults. Weight loss is a frequent problem among PWAs and confusion about nutritional supplements--when they are appropriate, how to get them, and how to pay for them--is another commonly mentioned problem.

Dental services, an oft-cited service lack in prior studies, was not mentioned as a significant problem by any PWAs interviewed. Some case managers, however, noted that while they were able to arrange dental services, there were limited options. They also noted that finding dentists who will accept Medical Assistance is a continuing problem, again particularly outside Pittsburgh.

Lack of timely access to drug and alcohol services and lack of sensitivity among staff at inpatient drug and alcohol programs were noted by providers as a problem.

Medical services, as noted earlier in this report, are limited outside of Pittsburgh. Within Pittsburgh, the expense of T-cell testing, a test done to assess immune system function, was the only problem consistently mentioned by men. Women noted that few doctors are knowledgeable about AIDS in women and that since research to date has not focused so extensively on women with AIDS, their doctors (and they) don't always know if a particular problem is AIDS related.

Testing and counseling services vary widely. Some people who had been tested indicated that they were counseled by phone. Another said that his medical provider has a telephone tape that you call for pre and post-test information. Professional opinion on how best to provide pre- and post-test counseling, how and where it should take place, and what should be covered is varied. Counseling about how to deal with sexual partners--how to tell them, what to say, finding someone else to tell them--were things PWAs wished were covered in the counseling. On several occasions, PWAs indicated that the best thing that had been done for them in post-test counseling was to establish their next appointment with the doctor.

> *"When my doctor told me I was positive, it was part of my regular physical. He told me to come back in a week. Then he had me come back a week later, 'to be checked'. Then a week later. He kept me coming every week until I got a grip on myself. I really wasn't getting medical treatment on those visits but I thought I was doing something. It was the best thing he could have done for me."*
> Person with HIV infection

Recommendations:

Within the AIDS Planning Coalition, committees should be assigned to develop plans to respond to service needs noted above and those reported in HIVPLAN reports. Those committees should work with the full Board of the Coalition and, when appropriate, bring in outside experts to help develop responses. The Coalition Board should provide linkages when service gaps or problems seem to be related and the Board, rather than service specific committees, should take the leadership in convening with outside groups when such convening is necessary. The Community Advisory Committee to the AIDS Action Plan project should offer help in linkages and convening when necessary.

Medical Assistance reimbursement rates continue to be a service barrier. The Department of Public Welfare should take responsibility for assuring that people on Medical Assistance can access appropriate services. Capitated contracts in counties where services are limited and greater use of managed care might be considered.

Volunteer services need to be maximized. Volunteer transportation programs can be encouraged through a variety of means including insurance riders; volunteer in-home respite, chore, and activities of daily living help can be encouraged through volunteer training and coordination with other existing volunteer programs. This will require additional staffing, most likely initially at the Pittsburgh AIDS Task Force, to coordinate and train those volunteers and to act as a liaison to other volunteer programs. Appropriate volunteer roles for family members and significant other need to be developed and supported.

Training for case managers and other staff are discussed in the agency/staff capacity section.

Other suggestions related to information on services are noted in a separate section.

PLANNING AND DIALOGUE

Issue:

There has been limited data available with which to plan and a serious coordinated planning mechanism does not exist. Despite the fact that a regional AIDS planning coalition exists, that organization has been mired in internal issues for the past 18 months and has not maintained a serious role in developing information and using it to plan appropriate responses. In addition, the information that is available from the Allegheny County Health Department and from the Pennsylvania Department of Health that would be useful in planning is not routinely shared at the Coalition table. Finally, although the Coalition providers have agreed to a service data collection system ("HIVPLAN") that will help develop unduplicated numbers of clients being served and accurate service data, it is only in the earliest stages of use and information is not yet available from that system.

Recommendation:

The Coalition should set data sharing and planning as one of its highest priorities for the upcoming year. As information becomes available from HIVPLAN, members should urge the ACHD and the Pennsylvania Department of Health to add their information to that from HIVPLAN in order to have the best possible picture of the epidemic. The Coalition will need to assure that appropriate, responsible use is made of data, that trends are tracked, and that anecdotal reports are tested against trends when planning responses to problems. Care must also be taken in this process to assure that all segments of the community impacted by the epidemic are represented in planning activities.

Issue:

New ethical issues are emerging and the region currently has no mechanism to debate them. Providers, families, employers, and people living with HIV infection all raised ethical dilemmas in the course of their interviews for this report. Questions ranged from the role of significant others in considering "do not resuscitate" orders to the duty to warn the sexual partner of a person with AIDS when the person refuses to tell his partner or give permission for someone else to tell.

Recommendation:

Develop a forum for dialogue building on either the Center for Medical Ethics at the University of Pittsburgh or the Hospital Ethics Consortium. Discussion of AIDS-related issues in the Ethics for Lunch series at the University or a series of small workshops could be developed. Private funding should be available to cover the costs of such an effort.

The Coalition members agencies and the religious community should receive information about whatever programs are developed.

INFORMATION EXCHANGE

Issues:

The most commonly cited need of people with AIDS/HIV infection, their families or significant others, and providers was for reliable information.

> *"How do I find out about the new treatments I read about in the paper?...I thought I should be taking nutritional supplements but I read they're bad for some people? Should I take them?...Well, Dr. [X] told me one thing, then I went to Dr. [Y] and he told me to do something different."*

Professionals, including physicians and case managers do not always have the most up-to-date information about treatments, services, and benefits and how best to access them for their patients/clients. Eligibility criteria change. Options for treatment and community-based services change. The benefit systems are complex under the best of circumstances.

Hotlines and agency-developed brochures were frequently noted to be sources of misleading information. Use of jargon familiar to people working in the epidemic was cited by both people with AIDS and their families/significant others as confusing. Another source of confusion stems from the ways in which responses to the callers are phrased. What may seem to the hotline volunteers to be the same response may be perceived by the callers as two different responses to the question posed.

Brochures may not get to the intended audience. Despite the fact that numerous brochures delineating community-based service options have been developed and distributed to hospital social work staff and to sites doing HIV testing and counseling, many families and HIV-infected people indicate that they never got such information.

> *"Our son was in [hospital] in Pittsburgh for 3 weeks. No one ever talked to us about the care he would need when he got out even though he was coming home with us. They arranged for a visiting nurse service but that couldn't provide someone just to stay with him while we were out. He died before we found out that there were volunteers that could have helped give us a break and a support group for families only a few blocks from our home. Why didn't anyone tell us?"* Mother

Other families and PWAs who were given information found it was presented in terms they did not understand.

> *"We desperately need AIDS 101 for parents, especially those of us over 55."*
> Father of PWA

People using/providing information are not the only ones who need consistent accurate information. **Community and political leaders need information** as well.

> *"Sometimes, I hear from the people who want money but I really don't know what's going on in AIDS--who gets services and who doesn't and what they really need."*
> Local legislator

Employers, particularly from small and mid-sized businesses, need training and assistance in developing appropriate policies to deal with HIV-infected workers. Despite our being in the second decade of this epidemic, most employers have not developed policies to respond in the case of an HIV-infected

workers. While the need for such policies is most acute in healthcare settings, other employers are beginning to acknowledge the need for such documents and back-up as well as training for the supervisors of those employees.

> *"AIDS demands much more of managers than any seminar suggests....issue is how to achieve a balance between organizational needs and the fair and compassionate treatment of [an] employee."*
> *First Person,* Harvard Business Review, July-August 1992

Recommendations:

The Southwestern Pennsylvania AIDS Planning Coalition and those organizations that do print newsletters should collaborate on distributing accurate service and benefit information in both lay and professional terms (depending on the audience for their mailing) through their existing channels. Particular efforts need to be made to broaden the distribution of that information. While confidentiality concerns make it impractical for organizations to share mailing lists, extra copies could be made available to other groups to include in their own mailings or handed out to clients. Another alternative would be for coalition members to work together to develop a monthly or quarterly services and benefits column that could be used by the many newsletters in the region or could be distributed as a flyer by organizations that do not have newsletters. The printing of such a flyer might be done by a corporation as in-kind support to the effort. Information should also be shared with other planning coalitions since some agencies and clients cross coalition lines.

The 800 number for physicians to use for AIDS information and technical assistance (described earlier) should be encouraged.

The Coalition should also send this information to *Out* magazine, an information source widely cited by gay men in the region.

The Coalition, perhaps working with the Community Advisory Committee to this project, should collaborate with the United Way,the Smaller Manufacturer's Council, the Pittsburgh Business Group on Health, and the Allegheny Conference on Community Development or other groups of employers and other groups to provider information and training to employers.

The Coalition agencies need to work cooperatively in getting timely, factual information to community and political leaders on a regular basis. Prior to the Coalition's incorporation, the group did little advocacy or information sharing of this type, instead referring issues to its members for action. As an incorporated entity, it is better positioned to be an advocate on behalf of the entire group.

In order to develop a broader constituency of concern about the epidemic, the Coalition needs to share data and decisions with the broader community and with news media on a regular basis.

Individual Coalition members can act as liaisons to professional organizations, newsletters and journals that may inform other providers in their fields. Providers, particularly those in the medical field, have repeatedly indicated that their own professional organizations and newsletters represent the best mechanisms for educating their fellow professionals. The Coalition should assign members to be informational liaisons with other professions

Another '92
AIDS project

—

Jewish Healthcare Foundation of Pittsburgh
Pennsylvania Department of Public Welfare
Southwestern Pennsylvania AIDS Planning Coalition
Visiting Nurse Association of Allegheny County
present

CASE MANAGEMENT: WORKING WITH THE SYSTEM

Thursday, April 2, 1992
10:00 am to 3:00 pm

10:00	**WELCOME AND INTRODUCTIONS**	**Dana M. Phillips** Chairman, SWPAPC Director, AIDS Action Plan Jewish Healthcare Foundation
10:15	**CASE MANAGEMENT--AN INTEGRATED MODEL**	**Elaine Crider** Director Bureau of Special MA Programs, Office of Medical Assistance Programs, Dept. of Public Welfare **Susan Gingrich, M.H.S.** Director Home and Community Program Section, Office of Medical Assistance Programs, Dept. of Public Welfare
11:15	**BEING CASE MANAGED: A CONSUMER PERSPECTIVE**	
11:30	**WORKING SUCCESSFULLY WITH TCM**	**Jeff Ware** Executive Director New Beginnings Counseling Services, Williamsport, PA
12:00	**WORKING WITH DISCHARGE PLANNERS**	**Carla Sivic, MSW** Social Work/HIV Coordinator VA Medical Center
12:15	**LUNCH AND DISCUSSION**	
1:15	**QUALITY IN CASE MANAGEMENT-A CONSENSUS**	**R. Helen Ference, Ph. D.** Training & Development Coordinator, VNA of Allegheny County
2:45	**CLOSING COMMENTS**	**Dana Phillips**

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The Jewish Healthcare Foundation of Pittsburgh

BRANCHES

Agenda: Government Relations
Inventive "alchemy" between foundations and governments promises new elixirs.

Agenda: Children's Health
What's threatening the kids of Pittsburgh? Probably not what you think.

Agenda: Women's Health
Women may be the largest demographic group to be neglected by U.S. health care. Here's what the JHF is doing about that.

Agenda: Continuum of Care
They cared for us. Now it's our turn to do right by them.

Project Update
Fall 1992

Agenda: Government Relations

FOUNDATIONS AND GOVERNMENTS IN SEARCH OF GOLD

"Just recently, foundations and governments are seeking to discover the secret of alchemy," states Karen Wolk Feinstein, PhD, president of the Jewish Healthcare Foundation. "Together we are combining our unique talents, ingenuity, resources and operating styles to produce gold—new solutions to health and social problems that really make a difference."

"Healthcare problems are too broad and intractable for either group to solve alone," observes David M. Eisenberg, PhD, senior program officer. "A few foundations have now begun to see that we can play a powerful, complementary role with government. Together, we can pull off seemingly impossible projects. It's an exciting time for philanthropy."

Mixing the Elements

In its emergence as a new convener, for instance, the Jewish Healthcare Foundation organized western Pennsylvania's first "Conference on Policy and Program Development Collaboration Between Regional Private Funders and State Government." Joining the foundation in planning the two-day March event were the United Way of Allegheny County and the United Jewish Federation. Participants included General Assembly members and Administration officials as well as other government and foundation policymakers.

This conference was an example of the foundation's ability to "mix the elements," in this case the talents and resources of public and private leadership.

The conference focused on two initiatives, the prevention of chemical dependency among youth and the development of a continuum of care for Jewish seniors. "However," observes David Eisenberg, "the meetings have already catalyzed significant other activity. Officials from the Department of Public Welfare, the Governor's office, the Department of Aging and the Health Department have been in regular contact with the foundation, exploring a variety of projects of mutual interest such as immunization and primary health care for children, long-term care insurance for the elderly, and women's health care."

Children and Lead: Fixing Bad Chemistry

The Jewish Healthcare Foundation is also out in front on a collaborative solution to end lead poisoning...a health condition so critical that the August issues of *Good Housekeeping* and *Family Circle* magazines told 50 million readers it poses "the number-one environmental threat to children."

Lead can rob a child of lifelong potential. Senior program officer N. Mark Richards, MD, MS, MPH explains that "exposure to lead in even minute amounts can cause permanent learning

CONTINUED ON PAGE 2

The Jewish Healthcare Foundation was created in 1990 to reach out to the elderly, underprivileged, indigent, and underserved people of western Pennsylvania...to provide new perspectives on their health problems, and leadership to advance their health care.

Agenda: Children's Health

THE TOPIC IS KIDS AT RISK

What is the number-one health threat to the children of Pittsburgh?

Not cancer. Not rare disease.

The health of children is at risk because of illnesses and health problems that adults can help prevent.

The highest percentage of deaths—34.5 percent—among all young people between the ages of five and 24 is attributable to unintentional injuries...many of them preventable.

An example? Shootings. Murder is a leading cause of young deaths, especially among kids who join gangs. In fact, the United States is first among all industrialized nations for deaths caused by firearms.

Suicide accounts for more than one-fifth of all deaths among young people over the age of five. Suicide is the third leading cause of death in this age group...and many suicides may be preventable.

HIV infection is increasing among children. Preventable.

Contagious diseases such as measles are on the rise. In 1983, there were 1,497 reported cases of measles in the United States. In 1989 this number shot up to more than 18,000—and by 1990 reached almost 30,000. Sixty children died from measles, six of them in Philadelphia. Others suffered permanent brain damage. And measles can be prevented with a simple inoculation.

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