

A SURVEY OF AIDS PREVENTION FUNDERS: WHICH PROGRAMS ARE FUNDED, AND WHY?

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CONTENTS

EXECUTIVE SUMMARY	3
WHY DO THIS STUDY?	4
WHAT DID WE ASK?	5
WHO DID WE ASK?	5
SOME DEFINITIONS...	6
WHAT DID WE FIND ?	
Demographics and Amount of Funding	6
WHAT GETS FUNDED?	8
who GETS FUNDED?	9
HOW DO FUNDERS LEARN ABOUT AIDS?	10
RESULTS OF TELEPHONE INTERVIEWS	11
LESSONS LEARNED...	13

EXECUTIVE SUMMARY

Because of threats to government funding, community based organizations that provide HIV prevention programs diversify their sources of income by seeking non-governmental funding, including funding from foundations.

This survey of foundations across the United States asked questions about the amount of money they spend on AIDS and HIV prevention, the types of prevention projects and populations their grants served, and the sources of AIDS information used by the foundation staff. The results were then compared to the types of projects known to be effective and to the populations most at risk for HIV infection.

These organizations funded a diverse range of HIV prevention programs, with a total of 583 grants worth over \$8.1 million. *This represents almost a quarter of all AIDS-related funding by foundations in the United States.*

- HIV prevention grants represented 52% of all AIDS-related grants
- The average HIV prevention grant was for almost \$14,000, ranging from \$750 to \$1.4 million.
- Public policy, capacity building, outreach and technical assistance were among the most frequently funded HIV prevention programs.
- Some useful HIV prevention programs, such as condom distribution and needle exchange, were rarely funded.
- Women and youth received 25% of the funding for HIV prevention.
- More grants targeted the general population than drug users, gay men or ethnic minorities, although these groups contain more people at risk for HIV infection.
- Print media, site visits and colleagues were the main sources of AIDS related information for funders.
- Better sources of information are available to help funders gauge the effectiveness of proposed programs.
- Several factors (such as using culturally relevant language, providing creative rewards for participants, designing flexible programs and creating a forum for open discussion) that make HIV prevention programs more effective are provided for use when evaluating programs.

WHY DO THIS STUDY?

Government funding for HIV prevention is shaped, and limited, by the often contentious social, moral, and political context of the AIDS epidemic in the United States. Because of this, and because of the uncertain future of federal funding from year to year, AIDS service organizations diversify their sources of income by seeking non-governmental funding. Non-governmental funding includes donations from individuals and corporations, contributions through special events and promotions, and grants from independent, community and corporate foundations.

Non-governmental foundations are an important source of funding for many HIV prevention programs. In 1994, over 38,000 foundations and corporate giving programs contributed \$11.3 billion of the \$130 billion given to charities by the American public.¹ Private foundations gave about \$32 million for AIDS-related causes in 1994, and now give more than \$35 million a year to various AIDS-related organizations.^{1,2}

Proposed changes, that threaten to reduce federal sources of money for *AIDS care and services* (programs for people with AIDS or HIV infection), have increased pressure on private funders to choose between funding AIDS care and services or *HIV prevention* (programs to prevent new HIV infections). Private philanthropies already experience pressure to take on tasks in diverse areas, such as housing, job training, and public health, that some would consider responsibilities of the government. Thus these organizations must define their role with regard to public sector versus private sector responsibilities, as well as the priority AIDS holds within each organization.

As prevention funds become a scarcer commodity, it is important that funds are applied to programs known to be effective.² The current state of prevention knowledge has shown that education about AIDS alone is less effective than education combined with skills building and establishment of peer and community norms; sustained, intense interventions are more effective than short-term, weak interventions; and HIV counseling and testing alone is not sufficient for HIV risk reduction.³ Culturally relevant programs, especially small group discussion, outreach programs, and peer/volunteer training, designed with input from the targeted community, are among the most effective programs.⁴

This study examined the support for HIV prevention services provided by foundations and corporate giving programs. Patterns of funding are compared to the epidemiological trends for HIV/AIDS in the US. The data include the types of prevention programs funded, populations

served by these programs, and the percentage of HIV–related funding devoted to prevention. This information provides a snapshot of HIV prevention funding in the US for private foundations deciding how to direct their HIV/AIDS spending.

WHAT DID WE ASK?

1. What is the total annual amount of HIV prevention funding provided by a representative sample of foundations that fund AIDS–related programs?
2. What types of prevention projects are supported, and what populations do they serve?
3. What information is used by foundation representatives (boards, program officers, etc.) to determine the amount of AIDS–related funding they will supply and the types of programs they will fund?
4. Is the funding provided by these foundations appropriate relative to the epidemiology of the HIV/AIDS epidemic, prevention needs, and the current state of prevention knowledge?

WHO DID WE ASK?

We identified a representative, national sample of non-governmental organizations that fund AIDS–related programs using the 1995 edition of *AIDS Funding: a Guide to Giving by Foundations & Charitable Organizations*.⁵ In order to provide a representative sample of HIV/AIDS program funders, a survey was sent to all of the funders listed in the directory that were located in California, Florida, Georgia, Illinois, Maryland, Michigan, Minnesota, New Jersey, New York, Texas, Washington and the District of Columbia. These states/districts were selected to get a sampling of funders from areas with high, medium and low numbers of AIDS case reports.⁶ States were excluded only if they did not contain any funders in the directory. Funders must have funded at least one HIV/AIDS program during their most recently completed fiscal year in order to be included in the study.

We designed a 5-page survey with three categories of questions: the amount of funding given in AIDS-related grants, the types of programs these grants funded, and the populations served by the grants. Funders reported on grants distributed during the most recently completed fiscal year. Additional information was gathered about the funders, such as first year of AIDS funding, use of affiliation group funding or challenge grants, and sources of information about AIDS. Information on the type of foundation and annual budget were obtained from the 1995 edition of *AIDS Funding: a Guide to Giving by Foundations & Charitable Organizations* published by The Foundation Center. Responses were analyzed using STATA 4.0 software (STATA corporation, 1995).

A subset of funders was contacted by telephone for a short follow-up telephone survey. They were selected from those who indicated that they would be willing to participate in a telephone interview. These funders were asked more detailed questions concerning how they identify potential projects, the types of projects they fund, and any consequences as a result of their funding of AIDS-related projects. Responses were tabulated and presented as frequency distributions.

SOME DEFINITIONS...

As defined in the survey, *HIV prevention* funding includes all funds provided for primary HIV prevention (the prevention of new HIV infections). These funds may be in discrete programs or encompassed in larger projects that include other HIV services, such as early care for infected individuals. *AIDS care and services* refers to programs that are primarily for those already infected with HIV or diagnosed with AIDS.

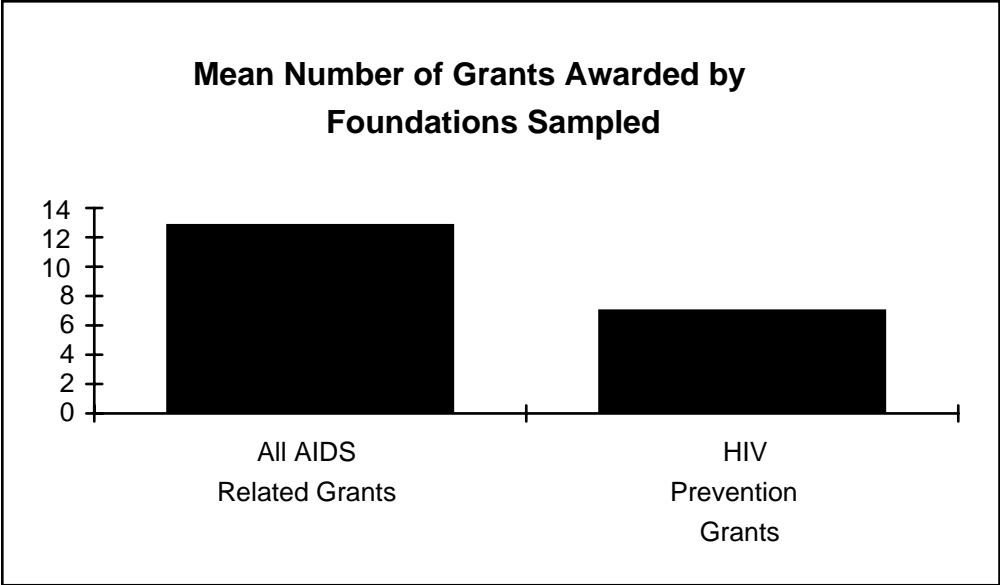
WHAT DID WE FIND ?

Demographics and Amount of Funding

Four hundred and thirty two (432) surveys were mailed to non-governmental funders of HIV/AIDS programs in twelve states and territories (see appendix A). A total of 113 surveys was returned. After removing those not eligible for inclusion, 86 responses were analyzed (see appendix B), for a response rate of 20%. This is similar to other mail surveys of AIDS funders.⁷ All but four of the responding funders had completed their most recent fiscal year within seven months prior to receiving the survey.

The respondents had an average total annual budget of \$99,500,000. A total of 1,115 AIDS-related grants was given by 86 funders, with 583 of these grants being for HIV prevention. Eighty-four of these were challenge or matching grants. Respondents gave an average of 13 AIDS-related grants, including an average of 7 HIV prevention grants (figure 1). The average HIV prevention grant was slightly less than \$14,000.00 (see appendices C & D).

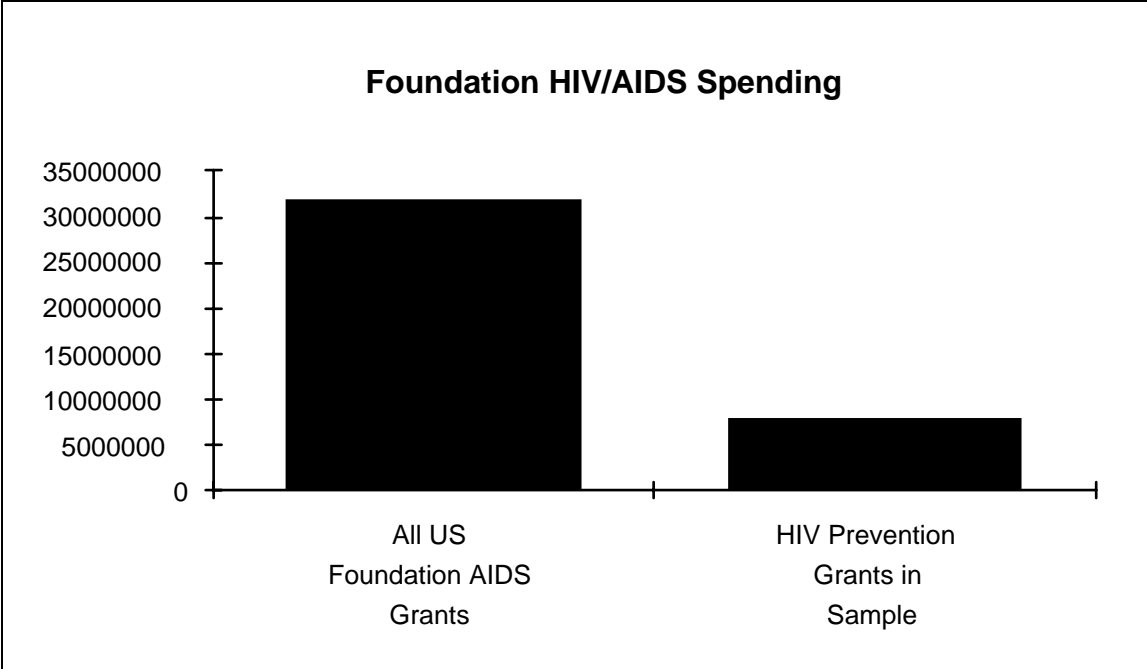
Figure 1.



This group of organizations funded a diverse range of HIV prevention programs, with a total of 583 grants worth over \$8.1 million, in one fiscal year. *This number represents almost a quarter of all AIDS-related funding by foundations in the United States.* (figure 2).

When asked about the value of all health-related grants during the last fiscal year, the median response was \$200,000-\$299,000, while the median value of all AIDS-related grants was \$51,000-\$99,000. Thus, these funders spent a sizable percentage of their health-related funding on AIDS-related grants. However, the median value of HIV prevention grants was less than \$50,000. Of note, half of the funders began their AIDS-related funding prior to 1989, within five years of the discovery of HIV as the cause of AIDS.

Figure 2.



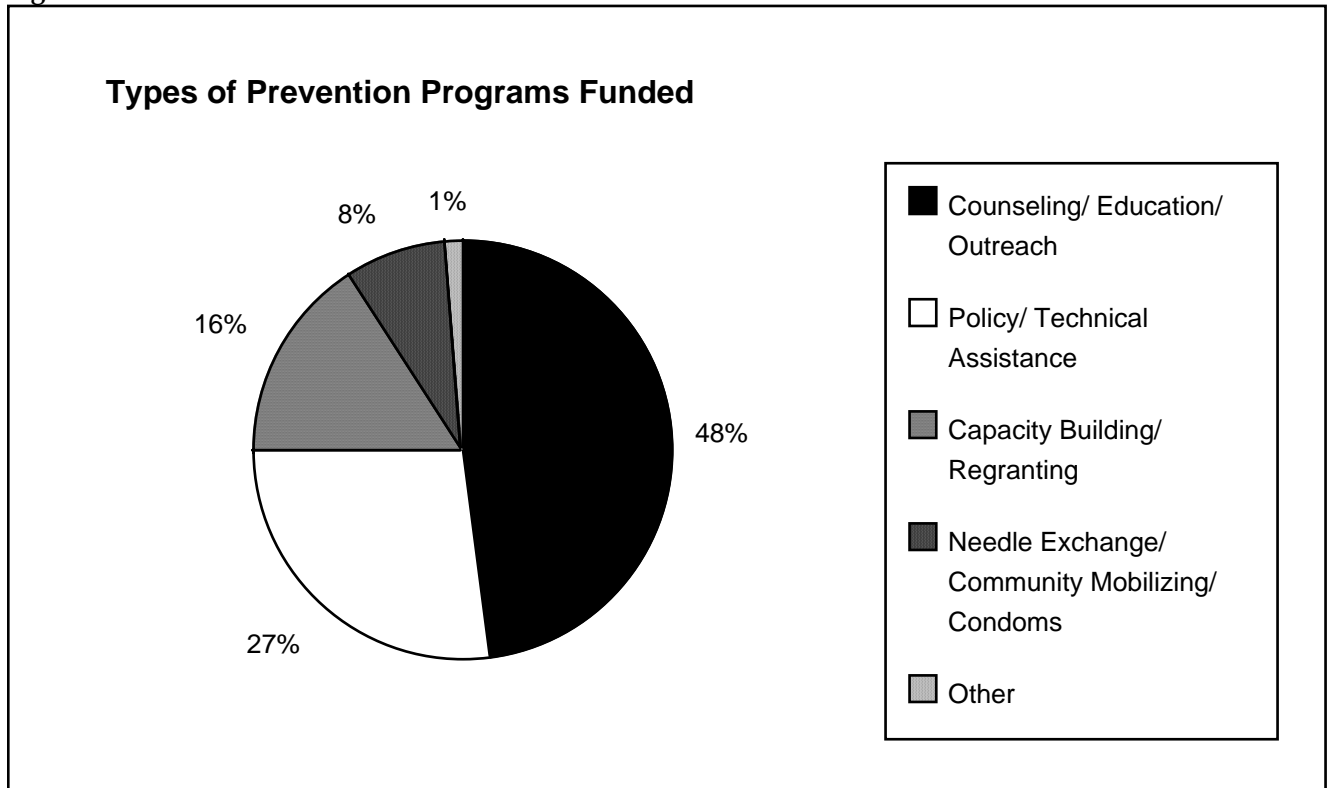
WHAT GETS FUNDED?

It is rewarding to note that the types of programs funded are largely those that have been shown to be effective in preventing new HIV infections (figure 3 and appendices E & F). Public policy, outreach, workshops, and community mobilization all were popular programs for funding. Programs that have been shown to be less successful, such as media campaigns and HIV testing, were less frequently funded.

Unfortunately, needle exchange, a program that has been shown to be successful in preventing HIV infection, was supported by few funders. **This is especially tragic in that these programs are denied federal funding as well.** Needle exchange presents a situation where private funding could offset a lack of government funding for an effective program.

Several respondents included hospice, construction, medical services, housing and nutritional services in their HIV prevention funding. Some of these programs, such as hospice and nutritional services, are clearly for AIDS care and services, not HIV prevention as defined above. The other programs are impossible to classify without more detailed information. These programs are included in the funding totals because they were considered to be HIV prevention programs by the responding funders.

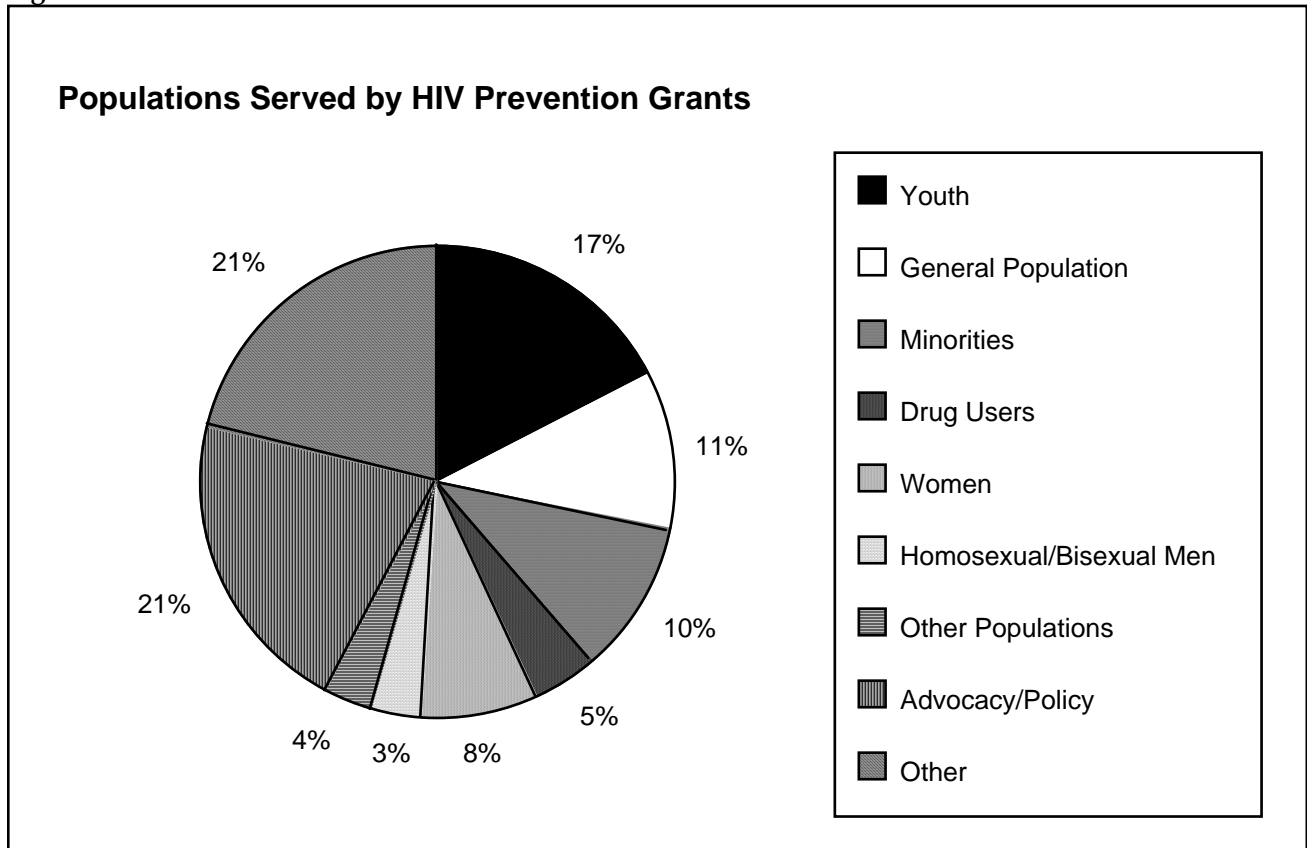
Figure 3.



who GETS FUNDED?

Some of the populations served by the HIV prevention funding in this study are similar to those where the epidemic is having the greatest impact (figure 4 and appendix G). Youth and women, two groups with rapidly increasing rates of HIV infection, are served by 25% of all funding. However, homosexual/bisexual men, injection drug users, and people of all ethnic minorities (all higher risk groups) each receive less funding than the general population, which includes many people at low risk for HIV infection. The nature of this study does not permit any explanation for this finding.

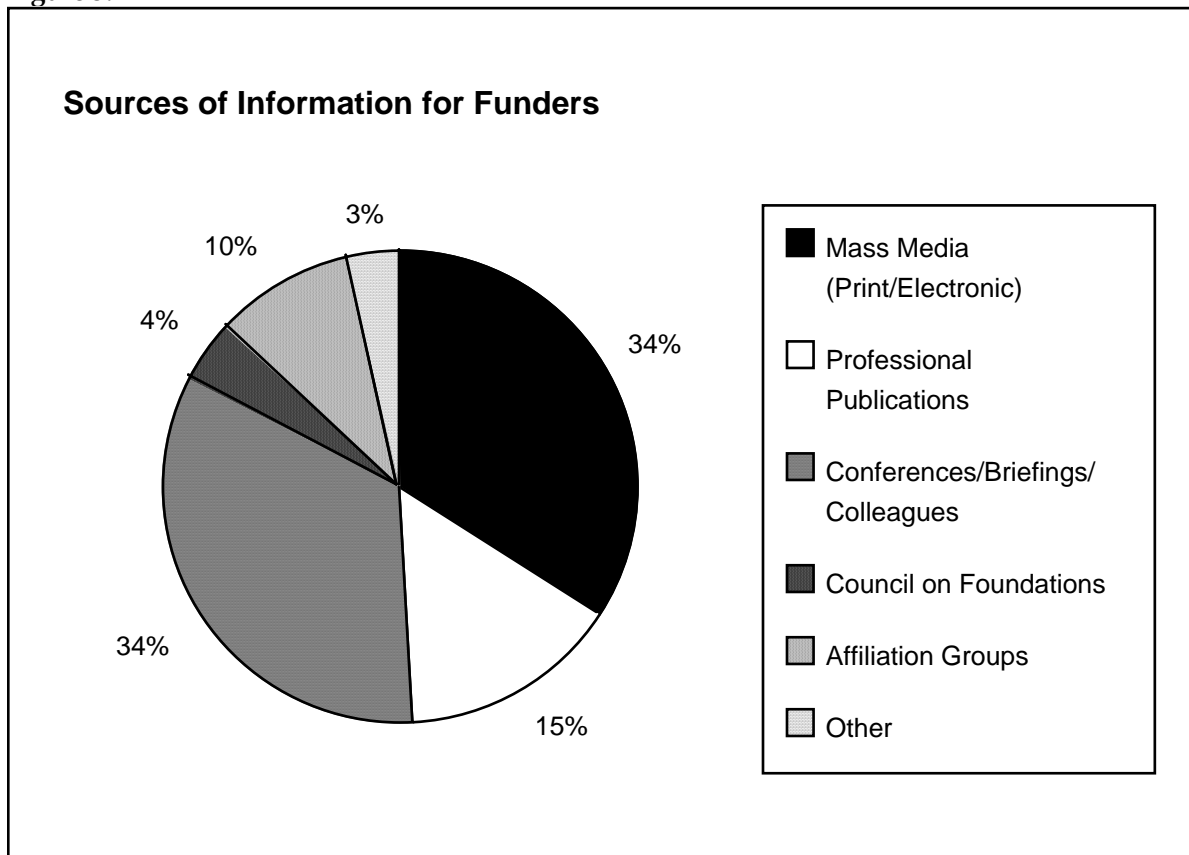
Figure 4.



HOW DO FUNDERS LEARN ABOUT AIDS?

Many sources of AIDS information are used by funders (figure 5 and appendices H & I). Print media were the only source of information rated as useful by more than half of respondents. Site visits with grantees, informal dialogues with colleagues and friends, and professional publications were also popular sources of information. Interestingly, only 29% of respondents rated regional affiliation groups as useful sources of AIDS information, and only 13% of respondents rated other affiliation groups as useful sources of information, despite the fact that 46% of funders gave AIDS-related funding through an affiliation group. Electronic information sources, such as the Internet and electronic bulletin boards, are rarely used as sources of AIDS information.

Figure 5.



RESULTS OF TELEPHONE INTERVIEWS

Telephone interviews were conducted with 32 of the funders who completed the survey. Each funder was asked five questions regarding the reasons why their organization funds AIDS related projects, how they identify projects to fund, whether or not they have funded policy or advocacy projects, and if there were any unanticipated consequences of their AIDS funding (see appendix J).

Reasons for Funding AIDS-related Programs

Overall, the funders expressed high enthusiasm for their organizations' commitment to AIDS funding. In fact, several found the question, "Why does your organization fund AIDS related projects?" difficult to answer, as AIDS funding is such an integral part of their overall program funding. Most funders stated that AIDS belonged in the area of health care within their

mission statement or the trustees of the organization felt that it was an issue deserving funding. Responses included the following :

“... Our funding decisions are made with regard to public health importance, and the AIDS data for our county show an increasing severity of the problem.”

“... We originally got involved because we like to fund emerging issues, but we continued our [AIDS] funding because of the importance. We now fund newly emerging populations that are affected [by AIDS], such as women and children.”

“... AIDS is an important social issue, and was originally part of our civil rights work, helping stigmatized people...”

“AIDS is a part of our health education and community services programs.”

Identifying Projects for Funding

Almost one third of funders stated that their organization funds both solicited and unsolicited projects. A small minority of organizations rely on donor directed or staff directed funding of projects.

Funding for Advocacy and Policy Development

Over half of funders stated that their organization funds policy development or advocacy for AIDS related issues. Policy and advocacy programs that were funded include a harm reduction study group and needle exchange advocacy group, custody issues for children of HIV infected parents, treatment of HIV infected prisoners, and a county survey on attitudes towards AIDS education in schools. Advocacy groups supported by funders include Funders Concerned About AIDS, NY City AIDS Fund, AIDS Action Council, Gay Mens Health Crisis advocacy programs, National AIDS Council, and Washington AIDS Partnership.

Unanticipated Consequences of AIDS-related Funding

Three funders felt that there had been some unanticipated negative consequences as a result of their organizations' AIDS related funding. These included staff members feeling pigeonholed as HIV funders within the organization, unhappy community members, and criticism of a funded program on a national conservative radio show.

Almost two thirds of funders felt that there had been some unanticipated positive consequences as a result of their organizations' AIDS related funding. These included more visibility for the foundation, acting as a catalyst and giving credibility for further funding of

projects, many compliments from other funders, staff feeling good about this work, bringing new donors to the foundation, bringing service providers together to coordinate services, and increasing the awareness about AIDS in the community.

Several funders were aware that their funding acted as ‘seed money’ or a ‘stamp of approval’ that encouraged other funders to support worthwhile causes. Funders also took pride in helping to initiate small projects, often ignored by traditional funding sources, that were successful and grew into much larger programs. Although these programs later received funding from other sources, funders were pleased to know that their foresight early in the process had multiplied into sustainable programs. As one funder stated, *“The rewards of funding new projects that aren’t funded by the government are immense.”*

LESSONS LEARNED...

As detailed in a recent Wall Street Journal article, **generic AIDS messages aimed at a general audience are not effective AIDS prevention programs.** Funders must support targeted prevention programs— often targeting disenfranchised or marginalized populations, such as gay men, drug users, and sex workers.²

This study shows that this group of funders have learned about HIV and AIDS through several channels. They have applied this knowledge to their HIV prevention grantmaking by funding effective programs that often, but not always, target those at highest risk for HIV infection. Importantly, these funders feel that their support for these programs has had positive effects on their own organizations.

Unfortunately, national and local print media are the most commonly used sources of AIDS information. **Better sources of information are available to help funders gauge the effectiveness of proposed programs.**^{8,9} Intervention studies and outcome evaluations are good sources of information about many types of prevention programs, and are often available from local health departments or HIV Prevention Planning Councils. This information can be used to identify those programs with the best chances of success.

Several factors that facilitate the effectiveness of HIV prevention programs have been identified.⁴ These include:

- Designing programs that are culturally relevant and language appropriate
- Embedding AIDS information into broader social contexts

- Providing creative rewards and enticements for participants
- Designing programs that are flexible, to meet clients' needs
- Promoting integration into and acceptance by the community
- Repeating essential prevention messages
- Creating a forum for open discussion
- Soliciting participant involvement

Funders can determine if proposed programs include any of these effectiveness 'enhancers' in their designs prior to supporting them.

Some populations at low risk for HIV infection received more funding than higher risk populations. Funders need to consider not only the effectiveness of the *type* of prevention program, but also the *specific* population the program will serve. Local health departments and HIV Prevention Planning Councils can provide information on the HIV risks for specific populations.

This study has several limitations. The response rate of 20%, while common for a survey of this type, is quite low. Because of the difficulty in retrieving information, detailed knowledge of the exact program type or number of grants was not always available. Nevertheless, the funders in this study recognize that HIV prevention programs remain central to ending this epidemic, and have contributed to the success of these programs across the nation. The commitment shown by the funders in this study must continue throughout the philanthropic community in order to sustain successful HIV prevention programs.

Appendix A. Location of Funders Surveyed

State/Territory	Surveys mailed	# of Responses	Response Rate
California	113	29	26%
District of Columbia	17	7	41%
Florida	19	3	16%
Georgia	11	2	18%
Illinois	28	8	29%
Maryland	8	4	50%
Michigan	11	6	55%
Minnesota	11	4	36%
New Jersey	15	5	33%
New York	160	33	21%
Texas	26	8	31%
Washington	13	4	31%
TOTAL	432	113	26%

Appendix B. Responses to Survey N=113

Type of Response	Number	Percent
Completed survey	54	48%
Completed survey and telephone interview	32	28%
Returned by US Post Office	8	7%
Does not give AIDS grants	16	14%
Policy prohibits responding to surveys	3	3%
Total response rate	86/432	20%

Appendix C. Foundations Reporting AIDS Funding N= 86

Total annual budget	mean=\$99,500,000 median=\$11,500,000 range=\$976-\$3,100,000,000
Number of HIV/AIDS grants awarded	mean= 13 median= 6 range= 1-300
Number of HIV prevention grants awarded	mean= 7 median=2 range= 0-153
Total number of HIV/AIDS-related grants awarded	1115
Total number of HIV prevention grants awarded	583

Appendix D. Selected Characteristics of HIV Prevention Grants Given by Funders N=86

Total number of grants	583
Total dollars disbursed	\$8,155,117.00
Mean size of grants	\$13,988.00 range=\$750.- \$1,418,096.00
Number of challenge grants	84*

* Denotes that this is a minimum number because some funders did not specify the total number of grants in this category.

Appendix E. Types of Prevention Programs Funded

Program Type	Number of Grants	Number of Funders
Public Policy	88*	20
Capacity Building	78	16
Group Outreach	71*	29
Individual Outreach	50*	22
Multisession Workshop	36*	17
Community Mobilization	33*	18
Prevention Case Management	23*	15
Media Campaign	21*	10
Single Session Workshop	19*	10
HIV Counseling/testing with another program	17*	12
Speakers Bureau	13*	9
Regranting	13*	13
Hotline	11*	9
Needle Exchange	5*	5
HIV Counseling/testing	4*	4
Other Programs (see next table)	101	9

* Denotes that this is a minimum number because some funders did not specify the total number of grants in this category.

Appendix F. "Other" Programs Funded N=101

Program Type	Number of Grants
Technical Assistance	37
Evaluation Research	32
Peer Education	14
Condom Distribution	8
Hospice	4
Improve/Build Facilities	2
AIDSWalk Sponsor	1
Educational Theater	1
Food Program	1
Dental Services	1

Appendix G. Populations Served by HIV/AIDS Prevention Funding

Population	Value of Grants	Range	# of Funders
Youth- Total	1,424,395		
Youth	906,518	6,000-288,000	22
High Risk Youth	233,127	13,127-125,000	5
Homeless Youth	120,000*	50,000-70,000	3
Gay/Lesbian Youth	77,750	3,750-30,000	5
African American Youth	61,000*	-	2
Hispanic Youth	26,000*	4,000-22,000	3
General Population	907,610*	1,500-794,000	12
Ethnic Minorities-Total	821,333*		
Latinos	293,000*	4,000-135,000	9
African Americans	209,500	20,000-80,000	4
People of Color	138,333	8,333-110,000	3
Asian/Pacific Islanders	82,000*	10,000-45,000	5
Puerto Ricans	50,000	-	1
Native Americans	31,500	-	1
Haitians	17,000	-	1
Women-Total	657,500		
Women	575,000	3,150-390,000	7
Hispanic Women	45,500	5,500-40,000	2
Arab Women	32,000	-	1
Drug using Moms	5,000	-	1
Drug Users-Total	379,377		
Substance Users	349,377*	9,377-265,000	4
Gay/bi Needle Users	25,000	-	1
Needle Exchange	5,000	-	1
Homosexual/ Bisexual Men	250,710*	1,000-86,000	10
Other Populations-Total	293,429*		
Rwandan refugees	80,000	-	1

Appendix G. con't.

South African women & children	50,000	-	1
Rural population & Policy Makers	40,000	-	1
Homeless	30,000		1
PWA's	25,000	-	1
Sex Workers	22,404	10,000-12,404	2
Farm workers	20,000		1
Mentally Ill	19,000	-	1
Hearing Impaired	4,750	750-4,000	2
Mexican physicians	2,275	-	1
Babies & Young Children	1 grant	-	1
Hospice Residents	1 grant	-	1
Advocacy/Public Policy- Total	1,717,096		
Advocacy	284,000	131,500-152,500	2
Public Policy	1,433,096	15,000-1,418,096	2
Other Prevention- Total	399,490		
Capacity Building	196,990	10,880-110,000	4
AIDS Service Organizations	130,000*	10,000-100,000	5
Regranting	70,000	20,000-50,000	2
Focus Groups	2,500	-	1
Other	1,304,177		
Construction	845,000	-	1
Housing	215,000	20,000-195,000	2
Medical Research	205,000	5,000-200,000	2
Medical/Dental Services	17,500	-	1
Nutritional Counseling	14,677	-	1
Hospice	7,000*	2,000-5,000	3
TOTAL	8,155,117*		

* Denotes that this is a minimum number because some funders did not specify the total dollar amount of a grant in this category.

Appendix H. Sources of AIDS Information for Funders N=86

Source	Total (%)	Most important source (%)
National Print Media	49 (57)	15 (31)
Local Print Media	44 (51)	8 (18)
Site Visits with Grantees	41 (48)	13 (32)
Colleagues/Friends	40 (47)	5 (13)
Professional Publications	39 (45)	2 (5)
Television or Radio	27 (31)	-
Regional Affiliation Group materials	25 (29)	6 (24)
HIV/AIDS Conferences	21 (24)	4 (19)
Board/Staff Briefings	16 (19)	4 (25)
Public Health/Medical Journals	16 (19)	5 (31)
Council of Foundations meetings	15 (17)	2 (13)
Regional Grantmaker Association meetings	15 (17)	1 (7)
Other information sources (see below)	14 (21)	8 (57)
Other affiliation group materials	11 (13)	5 (45)
Internet/Electronic BBS	9 (10)	-
Other Professional Conferences	9 (10)	-

Appendix I.

"Other" Sources of Information # of Responses

AIDS Service Organizations	4
Department of Public Health	3
Needs Assessment Studies	3
People Living With AIDS	2
Program Director	1
Other Funders	1

Appendix J. Results of Telephone Survey of HIV/AIDS Funders N=32

Why does your organization fund AIDS related projects?

AIDS is within our mission statement	16
Trustee decision to fund AIDS programs	10
Other reasons	6

How do you identify projects that you may fund?

Fund solicited and unsolicited projects	11
Fund unsolicited projects	9
Fund solicited projects	8
Funding is donor directed	2
Funding is staff directed	2

Has your organization provided any funding for policy development or advocacy for AIDS related issues?

Yes	18
No, but we do fund policy and advocacy	9
No, we don't fund in these areas at all	5

Have there been any unanticipated negative consequences as a result of your AIDS grantmaking?

No unanticipated negative consequences	29
Some unanticipated negative consequences	3

"...Staff members feel pigeonholed as HIV funders within the organization..."

"...We've had a few unhappy community members..."

"...One of our funded programs was criticized on a national conservative radio show..."

Have there been any unanticipated positive consequences as a result of your AIDS grantmaking?

Some unanticipated positive consequences	21
No unanticipated positive consequences	11

"...More visibility for our foundation..."

"...Brought new donors to our foundation..."

"...We got many compliments from other funders..."

"...Our funding gave credibility for further funding of projects..."

"...Our staff feel good about this work..."

"...We have brought service providers together to coordinate services..."

"...We have increased the awareness about AIDS in our community..."

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