Objective: The paper provides an overview of the National Library of Medicine’s (NLM’s) AIDS Community Information Outreach Program during the years 1994 to 2005, discusses the impact of previously funded projects, and explores future implications for HIV/AIDS information outreach to communities in need.

Methods: A qualitative assessment was conducted to provide information on the impact of projects funded by the AIDS Community Information Outreach Program during fiscal year 2002. Interviews were conducted and final reports were analyzed, resulting in themes based on roles and responsibilities of participants and the impact of the projects in the communities.

Results: Results from the assessment suggest that access to HIV/AIDS information led to improved communication between patients and their health care providers and encouraged better health care decision making. Feedback from reports and interviews included examples of impact such as an increase in services provided to communities, national and global recognition of HIV/AIDS services, sustainability of projects, and improved communication.

Conclusion: Community-based health information outreach projects may empower the HIV/AIDS community to become more involved in health care and improve communication with providers. NLM will continue to promote the AIDS Community Information Outreach Program to encourage community organizations to design local projects for their specific communities.

INTRODUCTION

The National Library of Medicine (NLM) recognizes the importance of establishing relationships with organizations that encourage and foster communication and information access. A major effort to enhance understanding of the HIV/AIDS community’s information needs, resources, and services began in June of 1993 when NLM and the National Institutes of Health (NIH) Office of AIDS Research cosponsored the NIH HIV/AIDS Information Conference. The purpose of the conference was to review the various HIV/AIDS information services, assess NIH’s current efforts in providing information services, and identify additional needs. The conference brought together representatives of five of the major constituencies using or needing HIV/AIDS information: clinical researchers; medical, dental, and nursing providers; allied health care providers; news media and the general public; and patients and the affected community [1]. The need to access current and technically accurate HIV/AIDS information was one of the emerging themes of all the groups, especially those in the affected community. The groups also expressed the importance of caregivers having the most up-to-date health information. Unfortunately, a large proportion of the HIV/AIDS community did not have access to electronic information resources, despite the tremendous potential of the resources [1].

As a result of the recommendations from the conference, NLM issued a request for proposals (RFP) for access to HIV/AIDS information led to improved communication between patients and their health care providers and encouraged better health care decision making. Feedback from reports and interviews included examples of impact such as an increase in services provided to communities, national and global recognition of HIV/AIDS services, sustainability of projects, and improved communication.

Conclusion: Community-based health information outreach projects may empower the HIV/AIDS community to become more involved in health care and improve communication with providers. NLM will continue to promote the AIDS Community Information Outreach Program to encourage community organizations to design local projects for their specific communities.

Highlights

- The AIDS Community Information Outreach Program encourages organizations to design local programs for improving information access for the affected community.
- Most community organizations serve as “gatekeepers” and possess the expertise needed to provide access and information in meaningful ways.
- Project impact was seen through sustainability of projects, communication and collaboration with other community-based organizations, increasing requests for information and services, implementation of new services, access to reliable resources, and tailoring or translation of materials in different languages.

Implications

- HIV/AIDS information access has been improved via organizations funded through the program.
- Interdisciplinary partnerships encourage sustainability of projects, expansion and access to HIV/AIDS resources, and skill sharing among groups that can lead to developing new and improved outreach.
- There is a continuing need for funding and training community organizations so they can effectively meet the needs of their clients and those in the HIV/AIDS community.

Supplemental Tables 3, 4, and 5 and Appendixes A and B are available with the online version of this journal.
AIDS Community Information Outreach Projects funded in May of 1994. NLM has continued to issue this solicitation into the year 2006 and has awarded over 190 organizations with funding in an effort to eliminate disparity of information access in the HIV/AIDS community (Table 1).

The program serves as a funding mechanism to promote improved access to HIV/AIDS information for health professionals, patients, the affected community, caregivers, and the general public; encourage partnerships and community-focused activities; and promote awareness and use of technology applications for improved information access. Projects involve one or more of the following information access categories:

- providing or improving access to electronic HIV/AIDS-related information resources by organizations or by the clients they serve, including the purchase of equipment and telecommunications services
- providing or obtaining training to develop skills to access or use HIV/AIDS-related information, including using the Internet
- developing specific educational or information materials, such as culturally appropriate or language specific tools
- providing access to HIV/AIDS-related documents, for example, developing connections with local health sciences libraries to obtain use of their collections

Emphasis is placed on supporting community-based organizations (CBOs), libraries, faith-based organizations, and health departments to design and implement these projects. NLM initially made awards of up to $25,000 but now offers funding levels to include express awards up to $10,000 for a simplified application and standard awards up to $50,000.

This paper reviews the need for supporting information access to the HIV/AIDS community, outlines NLM’s funding efforts in this area, and examines results from a qualitative evaluation of AIDS Community Information Outreach Projects funded in 2002 to assess the program’s impact.

BACKGROUND

Disparities in disease prevalence and information access

The Centers for Disease Control and Prevention (CDC) recently reported that, through the year 2005, the estimated cumulative number of diagnoses of AIDS in the United States and dependent areas was 988,376, and the estimated cumulative number of deaths of persons with AIDS was 550,394 [2]. These statistics reflect the overall devastation of this disease but do not address the fact that HIV/AIDS continues to disproportionately affect certain groups in this country such as African American and Hispanic populations and minority women and children [3]. Since the beginning of the epidemic, information has been determined as a critical resource for health professionals, educators, physicians, scientists, librarians, and consumers in an effort to understand and manage the complications of HIV/AIDS [4, 5].

Digital disparity, however, exists in access to and use of computer technology among populations who differ in socioeconomic status, educational background, gender, minority status, and age [6]. Even when socioeconomic status is accounted for, race, language, age, and disabilities are significant predictors of familiarity with and access to technology [7]. To bridge the gap of health information access disparity, consumers must begin to have access to vital information that can encourage and promote healthy behavior choices and improve health status [4].

Empowering consumers with information

The quality and quantity of health information now available on the Internet is helping to shift medicine toward patient-centered care and is fostering better communication between consumers and their health care providers [8]. Knowing how to find Internet resources has enabled HIV/AIDS patients to access critical information such as AIDS clinical trials, social support groups, legal advice, advocacy, and information about alternative treatments and the HIV/AIDS disease process. The Internet provides an avenue for consumers to remain current on the latest health information and motivates participation in decision making and improving health behaviors [8]. Research has shown that health-related use of the Internet among people living with HIV/AIDS has had a direct effect on health behaviors including HIV treatment and adherence to medication. Internet use is also associated with indicators for better health and conceptualized as an active coping strategy [9].

THE NATIONAL LIBRARY OF MEDICINE’S (NLM’S) AIDS COMMUNITY INFORMATION OUTREACH PROJECTS FUNDING

To begin to address these kinds of information-related issues, NLM has funded a series of HIV/AIDS-focused projects to overcome access barriers and bring information to affected communities. Figure 1 highlights the types of organizations funded through the AIDS Community Information Outreach Projects between the years of 1994 and 2005. The projects were led by five main types of organizations: CBOs, public libraries, health sciences libraries, health care organizations, and other. The “other” category represents those organizations such as an academic institution, a

Table 1
AIDS Community Information Outreach Projects funded 1994–2005

| Year | Number of awards |
|------|------------------|
| 1994 | 19               |
| 1995 | 16               |
| 1996 | 22               |
| 1997 | 19               |
| 1998 | 19               |
| 1999 | 14               |
| 2000 | 16               |
| 2001 | 16               |
| 2002 | 14               |
| 2003 | 16               |
| 2004 | 20               |
| 2005 | 18               |
correctional facility, and so on that do not fall in the above-mentioned categories.

Most projects led by CBOs were primarily concerned with obtaining computer equipment and Internet connections and providing access and training for their staff and clients. Public libraries were generally concerned with enhancing both their print and video collections and in establishing a technology base. Public libraries also purchased equipment and telecommunications (Internet connections) and provided user services. The projects led by health sciences libraries mainly emphasized collaborating with CBOs and sometimes public libraries. Partnership often involved helping these kinds of organizations procure equipment, obtain Internet access, and conduct training in the use of electronic resources. Final reports submitted by completed projects noted that interdisciplinary partnerships enabled organizations to take advantage of expertise areas from health professionals, community stakeholders, and advocacy leaders.

Projects engaged in a number of activities to accomplish the goal of improving access to HIV/AIDS information (Figure 2). All of the projects included multiple activities, but the majority of projects over the past eleven years have continued to improve on resource development and access. Many awardees created Web pages describing their projects and providing links to relevant HIV/AIDS resources. Sites often included materials tailored for specific populations.

As organizations improved their resources, it be-
comes even more important to train individuals in how use these resources. Most projects involved some form of training, whether of staff, clients, or the general public.

Table 2 highlights the target populations identified and served by the AIDS Community Information Outreach Projects. Most of the projects focused on people with AIDS as the primary target population and further tailored the projects to identify with specific racial and ethnic groups. CBO staff and volunteers were also noted as primary target populations in most projects, and some incorporated the train-the-trainer approach, which involved several CBO staff and volunteers.

**EVALUATING THE IMPACT OF THE AIDS COMMUNITY INFORMATION OUTREACH PROGRAM**

**Methods**

To understand the impact of previously funded projects, NLM conducted a qualitative assessment based on feedback from representatives of organizations funded by the AIDS Community Information Outreach Program during fiscal year 2002 [10]. The projects generally took place for eighteen to twenty-four months beginning in 2002 and ending in 2004. The purpose of the assessment was to define “impact” as it related to each project and determine the extent to which the projects impacted the target communities. A qualitative research approach based on an exploratory-descriptive design, grounded theory using semi-structured interview questions with a representative from each of the fourteen organizations awarded funding in 2002, and data from the final reports were the primary methods of data collection.

The interview process focused on understanding the roles of the participants and a typical day as it related to each project. Questions were also posed regarding the project representatives’ personal definitions of impact in relation to the project and examples of how they knew that there was an impact. The semi-structured questionnaire (Appendix A), consisting of six questions, guided the direction of the interview and allowed the participants to share their experiences in working with the HIV/AIDS population. The interview questions were developed according to Windsor’s classification and included grand tour, mini-tour, example, experience, and native language questions [11]. This interview process is often used in professional settings and assured the interviewees that NLM was not exercising excessive control over the flow of the interview. The interviews were conducted over the telephone, audiotaped to ensure accuracy of transcription, and coded by NLM staff.

**Data analysis**

Qualitative data from final reports submitted by each organization and the interviews conducted with the representatives were thematically analyzed. The interviewer read all transcripts and final reports. NLM staff independently coded transcripts with themes, and consensus on the themes was reached through discussion.

**RESULTS**

Themes arising from the data analysis generally dealt with the roles and responsibilities of project participants as well the perceived impact of the projects. The participants were directly involved in the organization and funded project. The title and experience of the representatives from each organization—such as health educator, resource and reference librarian, executive director, director of teen services, director of development, project coordinator, network administrator, professor, and case manager—suggested the array of representation from each organization. The target populations the organizations served also varied (see Table 3 and Appendix B for brief project narratives).

**Roles and responsibilities**

Participants were asked to describe a typical project day to illuminate relationships between the participants and the target community. Participants were also asked to describe their specific roles in the project. Overall, many of the participants stated they served as “gatekeepers” for their communities, bridging the gap.
between finding and accessing information. Some of the participants spent their time in constant correspondence with clients and/or community members via email and updating Website information. The representative of the AEGiS project, which provides a state-of-the-art database of HIV/AIDS information, stated, “E-mail correspondence is necessary to communicate with our readers.” Another participant agreed, noting, “I review HIV/AIDS news, and a lot of times that’s checking emails, reviewing clinical education Websites . . . going back and forth to see which fact sheets ought to be revised to reflect advances.”

Many of the projects involved purchasing computers and providing training to the community. Daily activities included demonstrating resources and interacting with computer users. Participants repeatedly expressed direct communication with the communities as a major role in a typical day. Participants further validated this theme through comments such as, “Our librarian served as a gatekeeper working with individuals regarding different situations. She was responsible for all tasks and made sure the information was put into the right hands.” Others stated their days consisted of “getting feedback from adolescents in the community”; “referring clients to our resource center”; “assisting staff, case managers, and clients with information access needs”; and “receiving help desk calls, overseeing the server, and communicating with our clients.”

Others mentioned the technical aspects of their roles such as “morning systems check, content acquisition, meeting with staff”; “supervising the development of the computer lab”; and “developing a manual for teens.” Some other roles consisted of translating information for a Website, developing and maintaining the Website, and attending meetings to keep up with the latest changes in HIV/AIDS information.

Defining project impact

Participants were asked to define “impact” as the word relates to AIDS information access (Table 4). Several participants noted that impact could be defined as increasing patients’ involvement in their care. An increase in requests for information and clients and/or community members asking questions about their health showed that they became more involved in making decisions involving their health. Because clients and community members were able to ask knowledgeable questions, communication was improved between health care providers and patients. Similarly, a participant noted that “being able to openly communicate with readers about the scientific facts about HIV/AIDS eliminates mystery and opens a door to reducing stigma, and has a major effect on this fight.”

Philadelphia FIGHT’s representative also defined impact through communication, noting that “Critical Path [a suite of low cost Internet services] has become the backbone of the AIDS community in terms of communication,” while the representative from the Asian Association of Utah indicated that “Impact means to have the community appreciate materials on HIV by training both individuals and community groups and being able to explain the information . . . it’s a better understood dialogue.”

The theme of communication and collaboration with other organizations and agencies also played a major part in defining the impact of some projects. One organization’s representative remarked, “In terms of communicating with other AIDS organizations, we are able to create listservs and plan programs to get out to the different communities . . . our summit was successful just because of communication!” Another participant felt that, because of collaboration with other technical agencies, “There was an impact in regards to broadening our ideas as to how we could use the electronic media as a way of communicating in education and information.”

Participants also stated that being able to provide a new service made a major impact in communities. Most of the communities served would not normally have had access to computers and free Internet services as offered through the funded projects. AID Atlanta’s representative stated, “Impact is being able to provide a resource room where a lot of clients have been able to learn more about HIV and other STDs and caring for themselves and gathering the information from the computer as well as getting access to IT services [to which] they might not have normally had access.” The Columbus AIDS Taskforce representative also felt that service to community members was important: “impact means being able to reach the communities and give them resources . . . we are able to offer resources that may not be available anywhere else.”

Feedback from participants noting growing requests for services and information substantiated that impact was also defined as an increase in services and the demand for services provided through the AIDS outreach projects. For example, the University of Texas Health Science Center at San Antonio made an impact on the national and global level, developing a Website that originally received HIV/AIDS-related questions from local adolescents but now receives questions from Latin America! Organizations providing computer training received requests for more classes. The participant from Project REACH Youth, which developed a manual for teens, described the overwhelming requests for the manual: “students, teachers, and parents are asking for it . . . organizations want to use the manual for their projects . . . this manual made a definite impact on different levels.”

Examples of project impact

In addition to defining the impact of projects, participants were asked to describe an example of how they knew their projects had an impact. Participants provided many examples including testimonials and community and/or client comments and improvements in services (Table 5). The examples validated the definitions of “impact” expressed by the participants.

The theme of sustainability as an example of impact was shared by many of the participants. The represen-
tative from Hope House Day Care indicated that “the greatest testimonial to the program is that it hasn’t ended and it wasn’t for naught. It’s going forward and moving on and reaching [in] ways that we thought weren’t possible when we first proposed it!” Magnolia Coastlands’ representative expressed this theme also: “caretakers are seeking information, and we are a continual resource . . . there was nothing and now there’s something.”

Many of the organizations received testimonials and feedback from users: for example, “Thanks so much for keeping this invaluable site up and running! I sincerely believe what I had learned from AEGiS has played a significant role in keeping me alive and fairly healthy for 15 years! And that allows me to be of use to others as well.” The InfoNet project received letters from clinics saying how much they appreciated having information, how much they rely on it, and how frequently they use it. In several instances, letters specifically stated that providers were able to spend more time with their clients.

Access to information was another frequent example of impact. The translation of materials in different languages encouraged communication between health care providers and community members. The Asian Association of Utah, for example, found that when information was given in the native language, people tended to have more questions. “In English, some people didn’t comprehend the facts and apply it to their cultural life. Prior to the information being available, the community was more closed and not wanting to talk about it.”

Promotion of the AIDS Community Information Outreach Projects request for proposal and NLM products and services

The assessment also asked about how participants learned of NLM funding. Participants frequently noted the NLM Website or NLM mailings, mailing lists, newsletters, and word of mouth. Some participants also found out about the funding via librarians.

Participants recommended targeting community-based and nonprofit organizations and minority-focused conferences and mailing lists as vehicles to publicize the availability of funding. Participants also suggested partnering with organizations closely associated with the HIV/AIDS community (e.g., CDC, National Prevention Information Network, Health Resources and Services Administration, etc.) to spread the word.

Challenges

Organizations faced different challenges in trying to implement their proposed projects, and it became clear that a strong project leader was an essential component for success. Without an effective and committed leader devoting significant attention to implementing the programs, projects could be doomed to mediocrity or failure. The staff turnover in the smaller CBOs and public libraries was also a problem for effectively running some projects. The loss of a single individual can remove the entire institutional knowledge of a project and result in serious delays in implementation. Some organizations also needed more than eighteen to twenty-four months to successfully complete projects due to personnel issues and delays in purchasing computer equipment.

Establishing partnerships could also be a challenge. Even though collaboration and partnerships took time and energy to accomplish, most situations resulted in established relationships. Community groups looked to other CBOs for assistance in enhancing and promoting services, thereby creating a network for improved dissemination of information. Also, most of the projects enabled libraries to play a significant role in providing HIV/AIDS information and resources. All projects collaborated in some way with other agencies to reach their goals and expand access to HIV/AIDS information beyond what was accomplished prior to their projects.

DISCUSSION

Some limitations should be considered regarding this assessment. The interview questionnaire consisted of open-ended questions to elicit maximum feedback, and self-reported responses were interpreted and cataloged by the interviewer. Though the interviewer made a conscious effort not to demean or express critical comments to prevent negative perceptions of the assessment, representatives may have withheld pertinent information that they might perceive as unacceptable to the agency, as NLM was conducting the evaluation. During the period of interviewing the project’s representatives, NLM posted the 2005 RFP for the AIDS Community Information Outreach Program. This situation may have led representatives to hold back experiences that they felt might affect their awarding status in the 2005 round of the program.

Despite its limitations, the assessment of the 2002 AIDS Community Information Outreach Projects provides a snapshot of how communities have benefited from improved access to HIV/AIDS information. One overwhelming result of projects funded between the years of 1994 to 2002 has been a new or enhanced awareness of the importance of information and the ways this information is available to staff and clients. The projects also underscore the importance of understanding the community’s specific needs for information and respecting the community’s desire to identify its specific needs. The “ownership” of designing local programs encourages sustainability and the likelihood of significant impact on the target population. In a study conducted to understand how information can better assist people living with HIV/AIDS, Hogan et al. similarly suggest that it is necessary to have a better understanding of specific groups so that information can be tailored to meet their specific situations [12].

NLM continues to encourage partnerships among community organizations and other agencies involved in HIV/AIDS services. Through previous projects and relationships, NLM has found that an effective means of reaching minority consumers for information out-
reach involves working with organizations who are already involved in the health issues of the community of interest [13]. These collaborations are beneficial because they encourage the expansion of access to HIV/AIDS resources, sharing and enhancement of skills among groups, and potential for new projects to develop as a continuation of previously funded projects.

CONCLUSION

Overall, the 2002 AIDS Community Information Outreach Projects were successful and made a significant impact in their communities. Project leaders were able to see impact through an increase in services provided to their communities, testimonials and feedback from patrons and clients, and the sustainability of programs and services due to collaboration with other agencies. Community organizations and those on the HIV/AIDS frontline need up-to-date health information to make informed decisions about health. NLM is committed to improving access to HIV/AIDS information for the affected community, their caregivers, and the public and will continue to support community-based outreach efforts in the fight against the HIV/AIDS epidemic.

REFERENCES

1. National Library of Medicine. Information services for HIV/AIDS: recommendations to the NIH. report of a conference co-sponsored by the National Library of Medicine and NIH office of AIDS research, June 28–30, 1993. [Web document]. NIH publication no. 94–3730, 1994. [cited Aug 2006]. <http://sis.nlm.nih.gov/hiv/nihrpt.pdf>.

2. Centers for Disease Control and Prevention. HIV/AIDS surveillance report: HIV infection and AIDS in the United States and dependent areas, 2005, v. 17. [Web document]. Atlanta, GA: US Department of Health and Human Services; 2006. [cited Jan 2007]. <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/pdf/2005SurveillanceReport.pdf>.

3. Centers for Disease Control and Prevention. Eliminate disparities in HIV and AIDS. [Web document]. Atlanta, GA: US Department of Health and Human Services. [cited Jan 2007]. <http://www.cdc.gov/omh/AMH/factsheets/hiv.htm>.

4. National Library of Medicine. Strategic plan for addressing health disparities 2004–2008. [Web document]. Bethesda, MD: The Library, 2004. [cited Aug 2006]. <http://www.nlm.nih.gov/pubs/plan/nlm_health_disp_2004_2008.html>.

5. Huber JT, Gillaspy ML. Social constructs and disease: implications for a controlled vocabulary for HIV/AIDS. Libr Trends 1998;47(2):190–208.

6. Wilson K, Wallin J, Reiser C. Social stratification and the digital divide. Soc Sci Computer Rev 2003;2(2):133–43.

7. Cooper MN. Disconnected, disadvantaged, and disfavored: explorations in the digital divide. [Web document]. Consumers Union, 2000. [cited Aug 2006]. <http://www.consumersunion.org/pdf/disconnect.pdf>.

8. Kalichman SC, Weinhardt L, Benotsch E, Cherry C. Closing the digital divide in HIV/AIDS care: development of a theory-based intervention to increase Internet access. AIDS Care 2002;14(4):523–37.

9. Kalichman SC, Cain D, Cherry C, Pope H, Eaton L, Kalichman MO. Internet use among people living with HIV/AIDS: coping and health-related correlates. AIDS Patient Care STDS 2005;19(7):439–48.

10. National Library of Medicine. Fiscal year 2002 AIDS Community Information Outreach projects. [Web document]. The Library. [cited Aug 2006]. <http://www.nlm.nih.gov/news/aidsprojs02.html>.

11. Windsor R, Clark N, Boyd N, Goodman R. Evaluation of health promotion, health education, and disease prevention programs. McGraw-Hill, 2003:175–214.

12. Hogan TP, Palmer CL. Information preferences and practices among people living with HIV/AIDS: results from a nationwide survey. J Med Libr Assoc 2005;93(4):431–9.

13. Dutcher G. Collaborating with community organizations: consumer health information projects sponsored by the National Library of Medicine. Health Care on the Internet 2002; 6(4):3–20.

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Received December 2006; accepted March 2007