

Ghosh, M., & Bhatt, J. (2006). The challenging and critical role of information professionals in combating aids in India. In C. Khoo, D. Singh & A.S. Chaudhry (Eds.), *Proceedings of the Asia-Pacific Conference on Library & Information Education & Practice 2006 (A-LIEP 2006), Singapore, 3-6 April 2006* (pp. 517-525). Singapore: School of Communication & Information, Nanyang Technological University.

## THE CHALLENGING AND CRITICAL ROLE OF INFORMATION PROFESSIONALS IN COMBATING AIDS IN INDIA

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**Abstract.** The nature of work for librarians/information professionals is undergoing a profound transformation, due to the arrival of deadly diseases like AIDS (Acquired Immunodeficiency Syndrome) and the change in information needs of the local community. This change necessitates much more professional expertise, updated knowledge, critical thinking and involvement in developing effective AIDS literacy programs. Information professionals serving in different libraries or potential information dissemination centers can provide dedicated services to society by helping to access AIDS information not only in urban settings but also in rural environments. This paper outlines strategies for effective collaboration in the context of AIDS literacy promotion efforts. It identifies a number of obstacles in the process of empowering the community and suitable measures essential for success.

### Background and Context

India has a large population, low literacy levels and consequently low levels of awareness; and AIDS is one of the most challenging public health problems ever faced by the country. A study carried out by scientists at the All India Institute of Medical Sciences (AIIMS), New Delhi, reveals that Indians are more vulnerable to AIDS, and infected with HIV (Human Immunodeficiency Virus) and are more likely to contract the disease than people in other countries. The study claims that Indians have a lower immunity to the virus because they have genes that hasten the disease. There are possibilities that all our lives will be touched in the near future, in one way or another by the epidemic, unless timely preventive measures are used. Information is the first step in HIV prevention; ignorance about the disease and how the virus is transmitted can generate fear and prejudice towards those who are infected. The majority of the HIV positive population is not well informed about managing the various aspects of AIDS and unpredictable illnesses; often not provided with useful or accurate information by their physicians. We, the information professionals, need to care about and act on this the situation. Information officers serving in different libraries/ potential information dissemination centers ought to take a leading role in educating and transforming knowledge of and attitudes towards HIV/AIDS through extensive library programs. Many researchers believe that India has become home to the largest number of HIV-infected people in the world. There would be nothing more tragic than seeing a country as rich in culture and history, and with as much potential, being destroyed by an epidemic that could be avoided with relatively easy and inexpensive interventions. Many infected people live in rural areas and do not know that they carry the virus. Many millions more, know nothing or too little about HIV to protect themselves against it. Educating people about HIV/AIDS and prevention is not a simple but rather a complicated task, as India has many major languages and hundreds of different dialects. But with the use of convergence technologies it is possible to overcome these barriers. Access to information can empower people and help them to face health and medical challenges effectively. The spread of the epidemic in rural areas presents a need to disseminate AIDS related information for health protection rather than waiting for information to follow the appearance of the disease in communities. Approaches to health promotion that do not consider differing contextual factors are unlikely to succeed. In particular, innovative strategies to disseminate AIDS information amongst disadvantaged population groups are needed. It has been observed that awareness is greater amongst the literate. Public libraries in rural areas should provide tailor-made education programs for those at the lower education levels. Community empowerment can lead to advocacy, political action, policy changes or legislation in favor of disenfranchised groups.

## **HIV/AIDS Information and Libraries: A Review of Related Literature**

There is only a modest body of literature addressing the role of libraries in disseminating HIV/AIDS information. Although a large number of articles on health information needs is available, online searches and the study of the literature for the last few years yielded very few results that linked libraries and HIV/AIDS as descriptors. Chikonzo (2005) in her article discussed the role of librarians in collecting, repackaging and disseminating information on HIV/AIDS to different sectors in their respective countries as a means of reducing the impact of the disease in developing countries. She also discussed the challenges to the provision of HIV/AIDS information by librarians in developing countries. Ghosh (2005) proposes a model of ICT-driven public libraries for India and suggests that public libraries could offer a single integrated environment for dissemination of HIV/AIDS information. Press & Digs- Hobson (2005) opined that “librarians can play an important role in the provision of health information if they listen carefully to community needs, develop cultural competence, and work with community partners”. *Library Trends* devoted two issues to consumer health (Fall 2004 & Winter 2005). A total of 17 articles in these issues referred to HIV/AIDS Information resources and services. Campbell (2004) suggested ‘partnerships’ or ‘alliances’ as a strategy in the prevention of AIDS. She further stated, “HIV is too complex and too multifaceted for any one stakeholder constituency to deal with”. Margaret (2004) in her 70<sup>th</sup> IFLA conference paper explored the possibilities of using fiction collections as tools to fight the HIV/AIDS battle. Alpi and Bibel (2004) opined that meeting the health information needs of diverse communities, is a challenge for librarians.

An issue of *Aslib Proceedings* (2003) devoted a special double issue of 12 articles to health informatics. These articles covered a wide range of issues. In their study of the use of the Internet for health information, Williams et al (2003) identified a range of reasons that different groups of people used the Internet for accessing health care information. The different groups included patients, intermediary professionals and general interest users.

Jones (2003) provides an overview of his research project on the efficacy of providing patient information via touch-screen information systems. McWhirter (2003) looks at the potential of using television sets at hospital bedsides to provide patients with access to health information.

Gunter et al (2003) explore the effectiveness of digital interactive television (DiTV) in providing health information services and stated that the Department of Health in the UK has made a major investment in testing the potential of DiTV as a health information platform. Lankaster (2003) identified various problems and barriers to the effective use of the NeLH in public libraries such as level of information, appearance, search tools, need for staff intervention, staff training, etc.

Charles (2003) discusses HIV/AIDS in Uganda and recommends library intervention to control the epidemic. He identifies various programs and activities of the National Library of Uganda and the Kenya National Library Service to delivering integrated HIV/AIDS services and programs to the people. O'Brien (2003) elaborated on the role of libraries, especially school libraries, in preventing an AIDS epidemic. Nicholas et al (2002) provide an exploratory analysis of the use of NHS touch Screen Health Kiosks in various public locations and libraries in the UK and observe a significant consumption of health information by the general public.

Muswazi (2000) conducted a survey of 14 public libraries in Swaziland on the availability of HIV/AIDS resources and found out that information resources are limited in terms of relevance, currency and volume. Wald (2000) reviews the poor availability of white literature on AIDS, for use by both health workers and the general public in Ethiopia, as a case for using gray literature to raise awareness.

A poster by this author at IATUL 2005 entitled “AIDS challenge: preventive health care information and women in India” displayed health related projects and initiatives undertaken by the government of India to disseminate health care information to the rural masses with special reference to women in India.

In 2005, the U.S. National Commission on Libraries and Information Science (NCLIS) published a book entitled “The Role of Libraries in HIV/AIDS Information Dissemination in Sub-Saharan Africa. The report is available on the NCLIS website.

## **Health Literacy in the Context of HIV/AIDS**

India needs to accelerate the spread of information on HIV/AIDS and remove the stigma associated with the disease. Alarmingly heavily populated states like Bihar, Gujarat, UP have low awareness; nearly 75% women in rural areas have never heard about HIV/AIDS. Emphasis should be given to disseminate information at the local level particularly at the hard hit states viz. Maharashtra, Tamil Nadu;

and to the policy makers, health professionals and donors. There are many stakeholders in health literacy; patients, content developers and designers, printers and distributors. In this context librarians need to identify and coordinate the activity of the team for dynamic development of education materials suitable for local needs (Siddamallaiah). A working definition of health information literacy is " the set of knowledge and skills needed to recognize a health information need; identify likely information sources in all formats, and use them to retrieve relevant information; analyze, understand and synthesize the quality and content of information and its appropriateness to a specific situation; and to apply the information in making health decisions- with an aim toward improved health outcomes" (MLA Task Force). The United Nations program on HIV/AIDS (UNAIDS) report has pointed out that women are the most vulnerable sections and almost 50% of the 37.2 million HIV positive persons in the world are women. Although Information & Communication Technologies (ICTs) were introduced in rural development in 1986, rural libraries largely remained forgotten assets in the dissemination of information to the rural population.

Health literacy in combination with self-efficacy results in health empowerment, a process that incorporates affective, communicative and cognitive skills relative to health development. There are three different types of health literacy: Functional health literacy, represents the cognitive and social skills which determine the motivation and ability of individuals and communities to gain access to, understand, and use information in ways which promote and maintain good health". The next level, interactive health literacy, focuses on personal and social skills development, such as self-confidence, negotiation, and assertiveness, and the resulting individual health-related behaviors associated with these attributes. Lastly, critical health literacy refers to the development of specific higher level cognitive and communication skills, such as accurately interpreting and evaluating media reports, navigating health care systems, and the capacity to effectively access and use health information (Kickbusch et.al.). Information professionals can easily assist in the acquisition of the first two levels of health literacy, which will enable the achievement of the third level.

Articulating the role that health literacy plays in reducing HIV/AIDS will require a combination of quantitative and qualitative research methods with attention to processes, in addition to outcomes. Ideally, baseline evaluations should be conducted prior to implementation of new programs, followed by periodic evaluations at regular intervals on a long-term basis. Evaluation results should be analyzed and disseminated in a timely manner to facilitate program changes, and use of best practices. Project planning and monitoring should be conducted with direct involvement of the local population in determining needs, establishing goals, and developing culturally-sensitive strategies. By using participatory approaches, a more comprehensive picture of changes that occur on individual, family, community and societal levels may be ascertained. The added benefits will be the strengthening of technical skills, fostering local ownership and building community capacity (UNAIDS).

Health literacy initiatives aimed at HIV/AIDS need to be carefully evaluated relative to the degree to which they address human rights and empower individuals, civil society, and communities. Indeed, societal change and empowerment, rather than knowledge or behavioral change, may be the most important outcomes of such initiatives. Using a human rights perspective that incorporates social, cultural and political contributions to the HIV/AIDS epidemic can be one of the most successful means of empowering and mobilizing people (NGO Networks for Health). The lack of knowledge of AIDS, its modes of transmission and ways to avoid infection is a major challenge to efforts to avoid the spread of AIDS, and many of those who have heard of AIDS, do not know even one way to avoid infection. It is clear that public libraries and AIDS prevention organizations need to strengthen the educational components of their programs, since even basic information about AIDS is seriously deficient.

Traditional oral communication channels, including songs, proverbs, riddles and storytelling, have been undervalued and underutilized. These methods of learning are rich in visual imagery, one of the foundations for learning. HIV/AIDS usually affects those who are hardest to reach through conventional print and broadcast media channels – the poor, the uneducated, and those living in rural areas. Culturally familiar media channels can be used to inform and inspire the more vulnerable and marginalized groups within societies. In order for such groups to gain more control over the external conditions of their lives, the positive attributes of each culture must be harnessed to prevent the further spread of HIV/AIDS and to provide care and support for those who are already living with the conditions (UNAIDS). It is a recognized fact that the new technologies make information services directly available to the end user. Indeed the increasing range of electronic information is based on the willingness of individuals and organizations to attempt to market their information products directly to the end user. In such a situation future library and information professionals are expected to assist the users:

- with carefully and well organized information particularly electronic information.

- by providing information which has been evaluated and repackaged to meet their needs precisely, and
- by facilitating their use of both the technology and information.

According to Warner & Procaccino, interactive online services are suitable for those who prefer privacy, but human interaction of the librarian could become an even more essential piece in the health information seeking process. They also recommended personal outreach in community settings by librarians to establish themselves more with their communities so that they are viewed less formally.

Technology provides the opportunity and the spur for rethinking a great number of traditional paradigms. Different health resources can be searched through one common index using a single tool. Today networking of computers plays an important role in communication and dissemination of information. Public libraries in India should implement a variety of programs which are aimed at encouraging more effective participation of women. They should organize seminars, workshops on education and career options, Information Kiosks, etc. The public library is an ideal location for such info cafés.

ICTs, including traditional media, mass media, and digital technologies can have a powerful influence, but are not sufficient to prevent HIV transmission. They can, however, be viewed as tools to facilitate empowerment and the realization of human rights by creating economic, educational, social and political opportunities. Print and broadcast media, including newspapers, magazines, radio and television, are becoming less expensive and more accessible in underdeveloped areas and have the potential to reach those who are illiterate and for whom formal educational opportunities are limited, as well as more vulnerable and high-risk groups hidden within populations. Another reported advantage of such techniques relates to the stimulation of dialogue around HIV/AIDS, bringing it to the forefront of the public's consciousness and thus, inspiring community action and policy changes. Media campaigns incorporating popular arts, entertainment and social marketing techniques have proven particularly useful in achieving some of the goals of health promotion, such as changing attitudes toward what is considered acceptable behavior.

India's diversity poses a great challenge in adopting strategies which are socially and culturally appropriate. A series of measures may be initiated for promoting public awareness and community support in response to the outbreak of the disease. These include Information, education and communication (IEC), which is considered as one of the important strategies in the fight against HIV/AIDS. The IEC strategy in India is operational at two levels. At national level advocacy is being promulgated to create a supportive environment. On the regional level control societies are undertaking IEC strategies in the local language in cultural nuances of the states. The basic thrust is to use IEC in a manner so as to effect behavioural changes that would contribute to the reduction of HIV transmission.

Following are the examples of few collaborative initiatives to promote AIDS literacy:

- New York Online Access to Health (NAOH <http://www.noah-health.org/>) is a collaboration of a number of New York libraries, including the New York Public Library, provides full-text HIV/AIDS related information for consumers.
- Consumer Health information network (CHIN) project at Massachusetts- a collaboration of a hospital and six public libraries in the surrounding community. National Library of Medicine, the University of Illinois at Chicago's library of the health Sciences collaborated with a variety of community-based organizations to extend access to HIV/AIDS information.
- Philadelphia's AIDS Information Network have staff training program and cooperating with local AIDS service agencies, also acting as referral points and play an important role in the fight against AIDS.
- Visual AIDS is a project working very closely with New York public libraries <http://www.thebody.com/visualaids/about.html> increasing public awareness of AIDS through visual arts. It raises money to provide direct services to artists living with AIDS.
- Detroit Community AIDS Library (DCAL) is a partnership of Academic health sciences, medical hospital and public libraries. The goal is to provide a gateway to local and worldwide HIV/AIDS information resources for Detroit and Southeastern Michigan. Funding for this project coming from the National Library of Medicine and have been utilized to strengthen participating library collections on HIV/AIDS and educating librarians to better meet the HIV/AIDS information needs of the community, and to provide a computer-based networked resource on HIV/AIDS.
- Kenya National Library Service (KNLS) introduced HIV/AIDS awareness program in response to the Government's appeal for multi-sect oral approach to combat HIV/AIDS. The Kenya National Library Service is associated with an AIDS awareness project that repackages and translates information from foreign sources ( Sturges, 2001).

### **Emerging Role of Information Professionals in Disseminating AIDS Information**

Information professionals can play dual roles as both advocates and educators in the process of AIDS information dissemination. Fourie, while commenting on new roles of librarians stated "...they require empathy, tireless dedication to a cause, commitment, and a service-for-free orientation...for the benefit of society at large" Ready availability of up-to-date information enables timely and informed decision-making, as well as efficient allocation and mobilization of resources. The professionals in India have to play a decisive role through the process of educating their society, because they are generally the people who have the responsibility of collecting and organizing the resources commensurate with the needs of the local community. Information professionals working in public and medical libraries can play an active role in developing Open Archive collections. They need to help researchers to expose their output on HIV/AIDS for the benefit of the local community. Regular user awareness programs can be conducted for this purpose. Services to archive work on HIV/AIDS of Indian authors can be offered on their behalf. Therefore it is important that they constantly update their knowledge and make themselves knowledgeable about HIV/AIDS. They must be committed to educating people about the disease, have an understanding of different cultural values and constantly reacquaint themselves with current developments in the treatment of HIV/AIDS and governmental policies dealing with it. As a consequence of becoming HIV/AIDS educators, librarians must, engage in a form of social marketing. The main activity of this marketing is promotion of HIV/AIDS information from NGOs, Health centers, social workers and clinical professionals working in this area. Librarians need to expand their roles as educators to that of health educators as well and target local groups within the community who might require the attention of information specialists. In order to combat the disease, professionals serving in various libraries need to

- empower adolescents to protect themselves from HIV infection
- create documentation of the AIDS epidemic using convergence technologies
- make information relevant, realistic and acceptable to the local community
- reduce the stigma of HIV/AIDS increases infection
- form partnerships with marginalized community groups, such as Aids orphans, widows and the aged.

Library services for HIV/AIDS education may range from very basic to full-fledged support and information services. The most basic service that may be offered is the provision of community, group and organization contact details. More sophisticated services offer wider contacts with outside agencies, provision of referrals to these agencies, a wide collection of specific types of information (e.g. diet and lifestyle), availability and use of anti HIV drugs (it is very important that HIV patients take these drugs exactly as prescribed) and established links to non-mainstream sources of information. It is understood that libraries with vigorous HIV/AIDS literacy programs can and do make a difference to the people and communities who use those services. Information professionals should take keen interest in the acquisition of special collections that will help to get the message across to those people, and to keep them informed of new developments in the prevention and treatment of HIV/AIDS.

A study carried out by NCLIS on new roles for libraries in HIV/AIDS information dissemination in Africa, makes three main recommendations:

1. Libraries' role in disseminating HIV/AIDS information is strongest when they establish partnerships with other organizations already involved in dissemination and education activities.
2. Libraries in Africa should expand the scope of information resources they collect and distribute to include sources outside the role of traditional libraries, including taking a leadership role in using Information and Communication Technologies (ICTs) for sharing digital materials, and providing information in formats that are accessible and interesting to children and young adults who are making decisions about their own sexual behavior.
3. An opportunity for African librarians now exists to redefine their traditional roles and take a strong lead in the dissemination of HIV/AIDS information.

Information professionals in India should undertake following activities to promote AIDS literacy:

- organize seminars, exhibitions and other related forum such as World AIDS Day celebrations-Distribution of publications on HIV/AIDS freely among public during exhibitions and weekly lectures.
- Arrange conversations with the community on impact of HIV/AIDS
- organize gatherings among peer groups to discuss various issues related to the disease

- create alternative ways of delivering information to young adults who are unable to attend school because they or a family member has the disease, or because they have been orphaned as a result of parents dying of AIDS
- translate documents on HIV/AIDS from English to regional languages in order to reach a wider audience.
- deliver information and referral services which can refer to local HIV-related services.
- provide interactive access to HIV/AIDS databases already available on the internet
- provide assistance to the NGOS and health associations working on HIV/AIDS in the creation and distribution of information materials for public access.

### **Challenges to AIDS Information Access, Management and Control**

In order to control the epidemic's expansion, health communications and education programs must not limit their operations to prevention messages, but rather address the interrelated components of the HIV/AIDS continuum prevention, care and support (UNAIDS, 2001)

However there are challenges to the provision of HIV/AIDS information for librarians in India posed by both the epidemic and the socio-economic environment:

- The dynamics of the epidemic raise the need to keep abreast with new developments thus the need to actively collect, synthesize and disseminate information. This is however constrained by lack of adequate resources (human, financial and material) to initiate and sustain efforts.
- Low levels of penetration of the infrastructure and supporting environment necessary to effectively use ICTs
- Lack of ICT related training for staff working in libraries
- The multiplicity of demand for consistent, relevant and timely information for HIV/AIDS, and existence of factors at various level, and in different settings also poses the challenge of processing and packaging the same information for different level of users.
- Low literacy levels and a poor information culture. Limited information literacy increases demands for more information processing to add value to information and services to promote information awareness, accessibility and usability. There is limited capacity (human, financial and structural) at organizational level to promote knowledge sharing within the community. In addition, there is lack of appropriate forum for sharing knowledge on HIV/AIDS. There are shortage of researched information about the various categories of information users, their specific HIV/AIDS information needs and desired delivery mechanisms.
- Lack of organizational capacity and initiative for information management  
There are fragmentation of information management efforts that creates potential for duplication of efforts and wastage of scarce resources. Limited capacity at local level particularly constrains information dissemination efforts to communities; Inadequate structural and physical information delivery system at all levels that could be exploited for information access and sharing. Consequently, many potential users are not aware of the existence of needed information and/or sources of such information and the appropriate channels for access.
- Inadequate funding of libraries by their governments might make it difficult for libraries in developing countries to effectively harness ICTs in the provision of HIV/AIDS information.

### **Recommendations**

Some recommendations on how some of these challenges can be met are outlined below:

- There are insufficient libraries and information institutions to meet the needs of culturally and linguistically diverse people. The Health Resource Center to be created to provide medical library and health information resources to the general public.
- Governments in India should take libraries and provision of HIV/AIDS information seriously; hence governments should allocate reasonable financial resources to libraries, especially, public libraries in order for them to do a good job.
- Librarians in public libraries procuring information resources on AIDS must train library users and the general public on maximizing access to HIV/AIDS information. Prevention should be a key area of focus and prime concern that can be brought about by awareness.
- Librarians should take up pre and post HIV test counseling. The importance of counseling is brought home by the fact that who has been counseled took precautions to protect their partner/child from getting infected. At a time when infection rates among women are rising be-

cause they are powerless, ordinary female population must be sensitized to change their behavior. Reducing the risks through awareness with the help of modern technologies and mass media should be priority if India is not to face an AIDS epidemic.

- Need for Enhancing Competencies to disseminate health information if information professionals are to play a significant role in "AIDS Literacy". Hence they must have well developed training and facilitating skills, to help people to use not only libraries but also information sources in different forms and formats. This is to say that training of professionals be considered as the training for 'Information Empowerment Specialists' rather than 'Bibliographic Instructions Advocates'. The public libraries must be under the control of a full time library professional and they should get allowances and service conditions comparable to the counterparts in academic, research and special libraries. Only by ensuring a level playing field, we can attract talents in the profession to this field.
- Developing community networks and AIDS information portal accessible through libraries. Internet has brought people together, even from remote regions, to a "virtual conference table" and a "virtual consultative process." Some of the most marginalized communities of the world are actively involved in dialogue and in policymaking on HIV. People living with HIV/AIDS who are not confident enough to speak up for themselves would join the network, because it would mean that other people would get know about each other. Librarians should have well planned approach to ICT issues to capture funding from either, internal and external sources. They should develop good strategy to bring ICTs into libraries, get politicians and funding agencies to listen to the needs of libraries. Critical to planning any adoption of convergence technologies is ensuring trained staffs are available to maintain the network. Staff working in public libraries must be encouraged to attend continuing education programs and skill.
- Collaboration with NGOs & other libraries/networks:  
Health related information seekers often prefer to talk with some one with the same condition, public libraries may consider collaborating with medical librarians in approaching support groups for those with medical conditions (Dorothy & Procaccino, 2004). Further collaboration with organizations that focus on HIV/AIDS could be considered. An example of such collaboration is Digital libraries network (Dlnet) established during summer 2003 by National Electronic Library for Health (NeLH), UK. DLnet aims to become a community of practice providing marketing and training and facilitating the sharing of ideas, materials and experience. Librarians have been invited to sign up as 'representatives' to join Dlnet. NeLH is working in partnership with other library services to unify and maximize communication efforts. Librarians should establish cooperation and links with external partners and international organizations for funding of programmes like and should aim to have vibrant organizations concerned with HIV/AIDS.
- Creating the Virtual opportunities for disadvantaged  
As ICT infrastructures improve, location independence increases. On the one hand it lets people access to distant resources and information and on the other hand outsiders can more easily be contacted. Library Network itself is a virtual library. It can support the growth of virtual libraries especially those offering to users in remote areas of the country. There are abundant opportunities, driven by the users' demand, to create new applications and services for unprivileged.
- Inclusion of Medical Informatics in LIS Syllabus  
The introduction of Online Master's of Library and Information Studies (MLIS) Distance Education (DE) Program with Health Science emphasis option at The School of Library and Information Studies at The University of Alabama, started in Fall 2005 with Medical Informatics, Medical Librarianship as Elective subject. Initiatives of these kinds can be taken as examples for the Indian Library Schools.

## **Conclusions**

To combat the AIDS pandemic it is necessary to deliver timely, credible, and multi-sectoral information about HIV/AIDS. It has to reach not just clinicians and scientists, but a huge array of others, such as behavioural specialists, policymakers, donors, social activists, industry <sup>leaders</sup> as well as common people. India has an emergency in terms of treatment but if it ignores the preventive aspects it will face a crisis in coming years, which will use up its resources. There is a need for strong advocacy and political support at the national level. Educating the users in libraries how to access health information on the internet has the potential to give them knowledge to maintain more healthy life styles, provide them

with reliable information about their problems and make them aware of possible treatment options. One of the keys to successfully combating the HIV/AIDS epidemic is the creation of an infrastructure that concurrently develops healthcare networks, education programs, and community participation.

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