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First 3 Years of the National AIDS Clearinghouse

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Synopsis

The National AIDS Clearinghouse is an information service provided by the Centers for Disease Control. The Clearinghouse was established in 1987 to respond to increasing numbers of public and pro-

fessional inquiries, to disseminate accurate information, and to make referrals to local sources of information and assistance. Four data bases—Resources and Services Database containing information about more than 16,000 organizations that provide counseling and testing for human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) and other education and prevention services; Educational Materials Database containing more than 8,000 individual, hard-to-find educational materials; Funding Database; and the AIDS Clinical Trial Information Service (ACTIS) Database—are searched by information specialists to respond to more than 45,000 requests annually for information from a variety of health professionals, organizations, and the general public.

Between 1987 and 1991, the Clearinghouse disseminated more than 60 million copies of publications related to HIV and AIDS. Information and education remain the most critical tools for the prevention of HIV infection, and the National AIDS Clearinghouse provides an essential element for the dissemination of education and prevention information.

SINCE THE FIRST REPORTS that documented the beginning of the human immunodeficiency virus (HIV) epidemic in 1981 (1,2), thousands of news stories and scientific articles about HIV and acquired immunodeficiency syndrome (AIDS) have been printed in newspapers, popular magazines, and journals and aired on radio and television.

Background

Although much has been learned about the virus, HIV infection, and the disease of AIDS as the epidemic has spread in the last 10 years, a gap remains between the growing body of HIV and AIDS information and what the public knows, understands, and believes (3). An even wider gap

exists between what is known about HIV infection and AIDS and the public's acting upon that knowledge to reduce or change behaviors that place persons at risk.

In the fall of 1986, the Centers for Disease Control (CDC) was assigned the lead responsibility in the Public Health Service (PHS) for informing and educating Americans about AIDS. Following the development of a comprehensive plan (4) in 1987, CDC established the National AIDS Information and Education Program and charged it with creating a national media campaign and an organized response to the public's interest, concerns, and needs generated by the campaign. The national media campaign brought together the tools of advertising and marketing to raise public awareness

of HIV and AIDS—radio and television public service announcements, print ads, brochures, and press attention delivering credible, accurate health messages about HIV and the way it is transmitted. The CDC National AIDS Clearinghouse was established along with the National AIDS Hotline to respond to increasing numbers of public and professional inquiries for accurate information and referrals to local sources of information and assistance (5).

The initial planning for a clearinghouse occurred in early 1987, and it was established in the fall of that year. The core elements of the Clearinghouse were to develop (a) a data base of resources and services offered by public, private, profit, and nonprofit agencies, organizations, coalitions, businesses, clearinghouses, hotlines, facilities, institutions, and other sources of AIDS information and services; (b) a data base of hard-to-find educational materials, including pamphlets, curriculums and teaching guides, audiovisuals, public service announcements, and other items; (c) an access system for references and referral to the Clearinghouse information; and (d) a system for distributing, on demand, an inventory of selected government-approved publications.

The Clearinghouse's services were aimed primarily at professionals, including health care workers, educators, social service workers, clergy, employers, human resource managers, and others working in a variety of settings such as State AIDS programs, community-based organizations, AIDS service organizations, businesses, and associations.

Shortly after the Clearinghouse was established, the Presidential Commission on the Human Immunodeficiency Virus Epidemic (6) acknowledged that information and education are essential in the prevention of HIV infection and AIDS and recommended that the documents pertaining to the HIV epidemic produced by the Federal Government should be made available free of charge through the Clearinghouse to the general public, public health officials, and health care providers.

The Health Omnibus Programs Extension Act of 1988 (Public Law 100-607) authorized the Secretary of Health and Human Services, through the Director of CDC, to "establish a clearinghouse to make information concerning acquired immune deficiency syndrome available to Federal agencies, states, public and private entities, and the general public" (7). It also mandated the creation of a data bank on HIV infection and AIDS clinical trials and treatments and mandated that information be collected, catalogued, stored, and disseminated—all

the core activities of a clearinghouse. The authority for the data bank was given to the National Institutes of Health (NIH) and the Food and Drug Administration (FDA).

Recognizing the need to avoid duplication, maximize resources, and use existing infrastructures to implement the legislation as quickly as possible, the already functioning Clearinghouse provided a mechanism to meet this mandate. As a consequence, interagency agreements were arranged by CDC with the National Institute of Allergy and Infectious Diseases (NIAID, NIH), the National Library of Medicine (NLM, NIH) and the FDA to create the AIDS Clinical Trials Information Service (ACTIS), which began operating as an extension of the Clearinghouse.

Clearinghouse Mission and Framework

The mission of CDC's National AIDS Clearinghouse is to make timely, accurate, relevant, and effective HIV infection and AIDS education and prevention information accessible and available to health and other professionals, organizations, and the general public. This mission entails a comprehensive effort to collect, catalog, process, inventory, maintain, and disseminate information on HIV infection and AIDS. Access to the information data bases is provided through trained staff at the Clearinghouse, as well as through existing information service mechanisms (for example, Combined Health Information Database (CHID) available through the commercial vendor Maxwell Online, formerly BRS Information Technologies, and DIRLINE, AIDS DRUGS, AIDSTRIAL of NLM). The access system also allows direct on-line access for selected Federal, State, and local officials.

The Clearinghouse avoids duplicating existing bibliographic data bases of published literature, for example, those of MEDLINE, AIDSLINE, AIDS Knowledge Base, or CHID. Rather, it focuses on HIV and AIDS services and resources and on hard-to-find literature or other unpublished educational materials. Similarly, the Clearinghouse does not duplicate, but rather complements, other HIV and AIDS information services. For example, the CDC National Center for Chronic Disease Prevention and Health Promotion's (NCCDPHP) AIDS School Health Education Database (ASHED) maintains HIV and AIDS information for educators of school-aged children. The Clearinghouse works closely with NCCDPHP to identify and acquire material for inclusion in ASHED, and in turn has

Table 1. Category of persons calling the AIDS Clinical Trials Information Service, October 1989–September 1990

Category	Percent
Patients	43
Family and friends	13
Physicians	9
Representatives of organizations.....	15
Pharmacists	1
Other health professions	10
Unknown	9

Table 2. National AIDS Clearinghouse users making reference requests, October 1989–September 1990

Category	Percent
Administrators	34
Information providers	4
Students	9
Special constituents	3
Educators	7
Health professionals.....	13
Legal professionals.....	1
General public	16
Unspecified.....	13

on-line access to the data base to help answer requests for information relating to school-aged children.

The Clearinghouse is the PHS's major distribution source for information about HIV infection and AIDS. An inventory of government-produced educational materials and other selected educational materials is maintained, and copies are distributed free of charge. The inventory contains brochures, posters, print ads, and other materials produced by the "America Responds to AIDS" campaign, as well as Morbidity and Mortality Weekly Report (MMWR) articles, current surveillance reports and guidelines, videotapes, and other PHS educational materials, such as the FDA brochure, "Condoms and Sexually Transmitted Diseases, Especially AIDS."

An important consideration in the development of the overall information system was to ensure the coordination of the Clearinghouse systems with the information and referral needs of CDC's National AIDS Hotline. The National AIDS Hotline has 24-hour, on-line access to the Resources and Services Database. The National AIDS Hotline information specialists use this data base to make referrals to local HIV infection and AIDS resources and services. The data base is maintained and updated by the Clearinghouse. Clearinghouse inventory items

are accessed through its on-line publication ordering system for the Hotline. This cooperative system fulfills an important dissemination function for the Hotline. The Hotline, in direct contact with the public, provides feedback to the Clearinghouse in identifying new, as well as updating existing, resource and service organization records.

The core functions of CDC's National AIDS Clearinghouse are to provide information contained in the data bases through reference and referral services to health and other professionals and organizations, particularly those at the community level. Although distribution of publications is a major activity of the Clearinghouse and will continue to be an integral component, the uniqueness of the data bases and the reference and referral services make the Clearinghouse a valuable resource for its constituents. This concept is consistent with other Department of Health and Human Services information clearinghouses (unpublished report by the Assistant Secretary for Planning and Evaluation, "Human Services Information Clearinghouses: A Discussion of Policy Issues." September 1981).

Although many State and local service organizations produce HIV and AIDS education and prevention materials and use existing materials, these front line organizations frequently lack the resources to provide the education and prevention services needed to prevent the spread of HIV infection. The Clearinghouse must establish partnerships and cooperative relationships with these organizations to build an infrastructure that (a) provides effective use of limited resources; (b) identifies information and service needs of special target populations at the State and local level; and (c) assures dissemination of timely, accurate, and relevant education and prevention information.

Major Accomplishments

The Clearinghouse has responded to increasing demands for services and has reached into every State as well as many foreign countries. Through four data bases, information is now available on resources and services for persons with HIV infection or AIDS, HIV infection and AIDS educational and prevention materials, funding for education and prevention programs, and drug and clinical trials. The Resources and Services Database contains information on more than 16,000 organizations providing counseling and testing; education, referral, and information dissemination; and medical, legal, and other services to persons with HIV

infection or AIDS. More than 5,000 new organizations were added to the data base in 1990. A system for the ongoing verification of information has been designed and implemented. The types of organizations included in the Resources and Services Database are presented in figure 1.

The Educational Materials Database describes more than 8,000 individual, hard-to-find educational materials. New materials are being identified and added to the data base at the rate of 3,000 per year, and information about materials in the data base is updated regularly. The types of documents in the Educational Materials Database are presented in figure 2.

A Funding Database was established in 1990 to provide information on available HIV infection and AIDS education and prevention funding opportunities for national, State, and local organizations. This data base includes information on Federal grants, cooperative agreements, and contracts, as well as private foundation and other funding sources.

The ACTIS Database provides current information on federally and privately sponsored clinical trials for AIDS patients, those infected with HIV, and health care providers. The data base has more than 300 records on specific clinical trials for AIDS- and HIV-related conditions and more than 100 records on specific drugs being studied in the clinical trials. More than 2,500 calls are received monthly. The distribution of 23,645 calls to the AIDS clinical trials information service, by type of caller, is presented in table 1. Specially trained staff at the Clearinghouse (reference specialists) respond to nearly 16,000 requests for information annually from many different health care workers and other persons (table 2).

Materials in the inventory range from the original "Surgeon General's Report on Acquired Immune Deficiency Syndrome" to brochures and posters from all phases of the "America Responds to AIDS" campaign. More than 100 different titles are included in the inventory. Between 1987 and 1991, more than 60 million copies of publications and other materials have been distributed. Table 3 lists the top 10 inventory items (all brochures) distributed since the Clearinghouse became operational, as well as those distributed in the fiscal year 1990.

In support of the national mailout in 1988 of "Understanding AIDS" to all households in the United States, the Clearinghouse distributed nearly 5 million copies of the brochure to homeless people, health care professionals, residents of pris-

Figure 1. Distribution by type of organization in Resources and Services Database, FY 1990

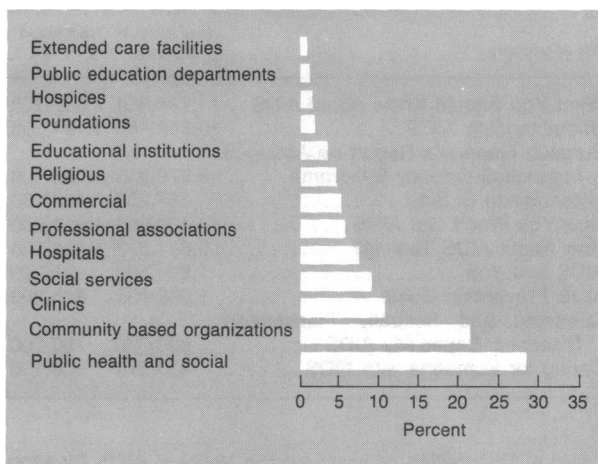
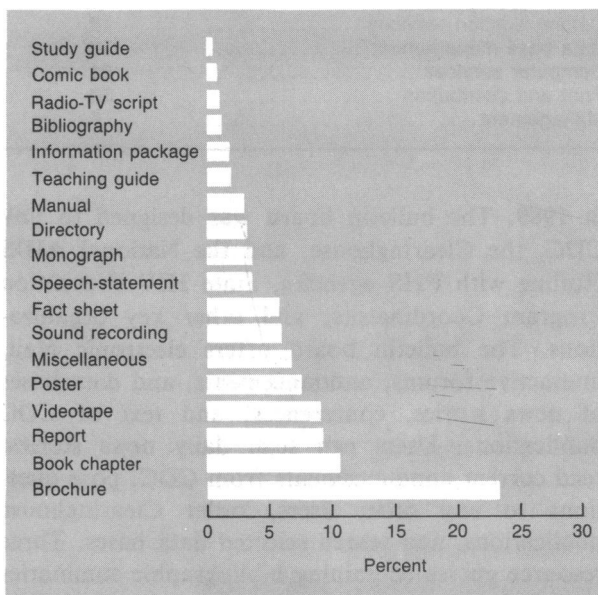


Figure 2. Type of documents included in the Educational Materials Database, FY 1990



ons, military personnel, government employees, and Peace Corps volunteers. The Clearinghouse processed more than 80,000 orders for copies of "Understanding AIDS" and the "Surgeon General's Report on Acquired Immune Deficiency Syndrome" that came from callers seeking more information as a result of the national mailout.

The Clearinghouse has enhanced access to its services and activities. In 1989, toll-free 800 access and toll-free 800 TTY/TDD access for the deaf were added to reference and inventory distribution services. An electronic bulletin board was initiated

Table 3. Top 10 items distributed through the National AIDS Clearinghouse inventory

Title of brochure	Total number 1987-90	Distributed FY '90
What You Should Know About AIDS ..	14,124,864	357,700
Understanding AIDS.....	10,052,185	1,454,100
Surgeon General's Report on Acquired Immune Deficiency Syndrome.....	8,979,913	1,286,400
Entendiendo El Sida.....	4,867,233	466,100
How You Won't Get AIDS.....	4,409,865	1,917,200
How About AIDS Testing?	3,057,217	1,393,100
AIDS and You	1,981,503	998,200
AIDS Prevention Guide	1,255,835	844,200
Condoms and Sexually Transmitted Diseases, Especially AIDS	503,040	180,500
Caring for Someone with AIDS	433,374	106,100

Table 4. Distribution of costs for the National AIDS Clearinghouse, FY 1990

Category	Percent
Exhibit and outreach	6
Reference, referral	9
Communication services	10
Data base management.....	19
Computer services	21
Print and distribution	30
Management.....	5

in 1989. The bulletin board was designed to link CDC, the Clearinghouse, and the National AIDS Hotline with PHS agencies, State HIV Prevention Program Coordinators, and other key organizations. The bulletin board offers electronic mail, interactive forums, announcements, and data bases of news stories, conferences, and text of CDC publications. Users can scan daily news stories, read current announcements from CDC, pose questions to any other users, order Clearinghouse publications, and search selected data bases. Three resource guides containing bibliographic summaries of information on selected topics have been produced and disseminated. These guides include a "Directory of AIDS-Related Databases and Bulletin Boards," "AIDS and Deafness Resource Directory" produced in conjunction with the National AIDS Hotline and Gallaudet University, and "AIDS and the Workplace Resources for Workers, Managers, and Employers" produced jointly with the National Leadership Coalition on AIDS.

Evaluation, Quality Control

To ensure that the information contained in the Resources and Services Database and the Educa-

tional Materials Database is accurate, quality control measures have been initiated. A questionnaire has been designed and is being mailed to all organizations listed in the Resources and Services Database. The results of the survey will be used to update available information on organizations providing resources and services to persons with HIV infection or AIDS.

The pamphlets, brochures, and posters in the Educational Materials Database are being evaluated by a panel of experts for content (accuracy), instructional design (appropriateness for target audience), and technical production. Two additional areas of non-English language materials were assessed—cultural appropriateness and translation (idiomatically correct and appropriately translated). Of the more than 1,600 educational materials that have been evaluated, 23 percent were rated as below average, 54 percent average, and 23 percent above average. Preliminary analysis indicates that the items rated as below average (*a*) were generally inaccurate, outdated, incomplete, or misleading; (*b*) used inappropriate terminology, such as "high-risk groups," or undesirable terms, such as AIDS "victim"; (*c*) had a negative tone that seemed judgmental, moralistic, or authoritative; or (*d*) contained inappropriate language or content for the target audience, that is, were culturally insensitive.

In addition to the evaluation just described, the Clearinghouse regularly solicits user feedback on its services and products, and changes are incorporated as appropriate.

The Future

The Clearinghouse must continue to be creative and innovative and use resources effectively to meet an increasing demand for services. Costs of Clearinghouse operations must be clearly documented and opportunities for cost savings identified. The majority of costs for the current operation of CDC's National AIDS Clearinghouse are in printing and distribution, computer services, and data base development and management (table 4). As we look to the future, innovative use of telecommunication and computer technology may lead to improved effectiveness. Although the Clearinghouse has disseminated materials free of charge, limited future resources may make cost recovery an essential component of Clearinghouse operations.

The Clearinghouse must continue to develop and initiate new strategies to communicate information on HIV infection and AIDS to the public and especially to specific target audiences, and to in-

form professional audiences about the services and products of the National AIDS Clearinghouse. New technologies such as CD-ROM should be evaluated for their application to Clearinghouse services.

Over the last 30 years, the Federal Government has established clearinghouses or information resource centers to meet information demands. At least 43 other PHS clearinghouses, ranging from the Alzheimer's Disease Education and Referral Center to the National Worksite Health Promotion Center, are currently in existence. Clearinghouses provide an information resource for the American public and remain essential resources in our effort to control disease. In the absence of a vaccine or a cure for AIDS, information and education remain the critical tools for HIV-AIDS prevention, and the Clearinghouse is a critical component of this prevention program.

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A System for Evaluating the Use of Media in CDC's National AIDS Information and Education Program

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Synopsis.....

The National AIDS Information and Education Program (NAIEP) commissioned the National Academy of Sciences to design a prototypical system of research for use in the evaluation of the agency's media campaign. It consists of four types of evaluation: formative, efficacy, process, and outcome. These types of evaluations are used to answer such questions as the following: What message strategies will work best? Can a campaign under optimal conditions be expected to make a difference? What interventions are actually delivered during the campaign? Has the campaign actually had an impact?

How NAIEP has used the system and adapted it during 1 year of research activities is outlined, and examples from a variety of other social marketing programs are described.

IN 1989, THE CENTERS FOR DISEASE CONTROL (CDC) commissioned the National Academy of Sciences (NAS) to provide recommendations concerning the evaluation of its AIDS prevention programs. NAS responded with "Evaluating AIDS Prevention Programs" (1), which provided guidelines specifically for the evaluation of the media

campaigns of the National AIDS Information and Education Program (NAIEP), but the guidelines also can be viewed as a research exemplar that is widely applicable to virtually any social marketing program.

We begin with a broad discussion of issues that commonly arise in the evaluation of social market-