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ABSTRACT

This handbook is designed to help information providers in the area of Acquired Immune Deficiency Syndrome (AIDS) to become aware of the information barriers which confront persons with disabilities, adapt conventional information resources about AIDS, and locate specialized AIDS information resources. Although the handbook is intended primarily for AIDS information providers in Suffolk County, New York, it is applicable throughout the United States. The handbook begins with an introductory section about access to AIDS information resources for people with disabilities. It is followed by separate sections on resources for people with hearing, visual, developmental, and other disabilities. Each section has three parts. The first part familiarizes AIDS information providers with some of the special needs of people with that disability and ways the providers can adapt information they already provide so that it will be accessible to clients. The second part describes resources that have been specifically developed for consumers with specific disabilities. The third part describes resources that have been specifically developed for professionals who are working with consumers with each disability. The addresses and telephone numbers of the resources' publishers and producers are listed in a directory in the back of the handbook. Appendices list AIDS hotlines, tape library offerings, additional sources of information, and a checklist for material selection. (JDD)

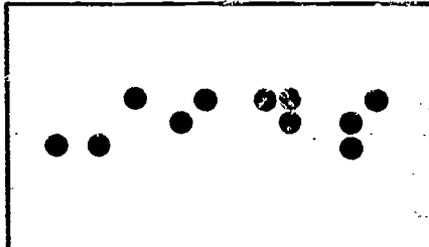
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# AIDS INFORMATION RESOURCES FOR PEOPLE WITH DISABILITIES

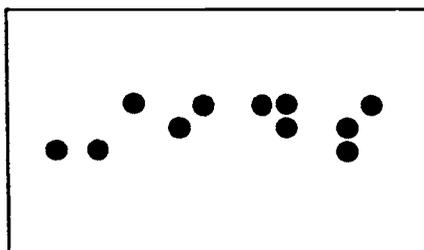
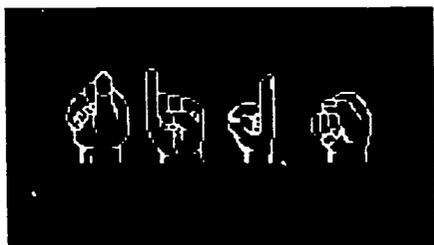


A Handbook for Information Providers in Libraries,  
AIDS Organizations, and Disability Organizations

**TALKING BOOKS PLUS**  
Suffolk Cooperative Library System  
627 North Sunrise Service Road  
Bellport, New York 11713

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# AIDS INFORMATION RESOURCES FOR PEOPLE WITH DISABILITIES



A Handbook for Information Providers in Libraries,  
AIDS Organizations, and Disability Organizations

by Julie Klauber

**TALKING BOOKS PLUS**  
Suffolk Cooperative Library System  
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August 1993

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## FOREWORD

In his report to the nation on Acquired Immune Deficiency Syndrome, Surgeon General C. Everett Koop said, "Information and education [are] the only weapons against AIDS."<sup>1</sup> Information about AIDS and its prevention has increased dramatically during the past decade. Schools, libraries, bookstores, television, radio, newspapers, magazines, and pamphlets are filled with information to make people aware of AIDS and how to prevent it.

Yet, 18.1 million Americans aged 15 or older (about one in ten) cannot see words and letters in newsprint because they are blind or visually impaired, and 7.7 million (about one in 25) cannot hear a normal conversation or a television program about AIDS, or call a conventional AIDS hotline, because they are deaf or hard of hearing.<sup>2</sup> Millions of others cannot understand traditional media because of a developmental disability, or visit an AIDS information center because of a physical disability.

The purpose of this handbook is to help AIDS information providers in libraries, AIDS organizations, disability organizations, and other settings:

- become aware of the information barriers which confront persons with disabilities;
- adapt conventional information resources about AIDS for these individuals;
- locate specialized AIDS information resources which address their needs.

Although this handbook is intended primarily for AIDS information providers in Suffolk County, New York, it is applicable throughout the United States. We hope other organizations will add to it, adapt it, share it, and use it.

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<sup>1</sup>Koop, C. Everett, Surgeon General's Report on Acquired Immune Deficiency Syndrome (Washington, DC: U.S. Department of Health and Human Services, 1986), p.28.

<sup>2</sup>U.S. Bureau of the Census, Current Population Reports, Series P-70, No. 8, "Disability, Functional Limitation, and Health Insurance Coverage: 1984/85" (Washington, DC: U.S. Department of Commerce, December 1986).

## ACKNOWLEDGMENTS

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Most of all, thanks are due to the staff of Talking Books Plus -- Janet, Ruth, Margarita, Juanita, Carol and especially Marge -- and to the following members of our community who contributed their time and expertise to review this publication:

- Peter Carroll, Librarian, Shoreham-Wading River Library; Representative, People with AIDS Coalition of Long Island
- Jodi Dee, Administrative Aide, Suffolk County Office of Handicapped Services
- Annette Landi, Counselor, New York State Commission for the Blind and Visually Handicapped
- Arlene Leventhal, Librarian, Half Hollow Hills Community Library
- Margaret Petersen, Librarian, Mastic-Moriches-Shirley Community Library
- Dina Reilly, Director, Deer Park Public Library; Volunteer, Long Island Association for AIDS Care
- Sally Rein, Librarian, Patchogue-Medford Library
- June Roberts, Executive Director, Self-Initiated Living Options, Inc.
- Jean Wright, Coordinator, AIDS Services, Suffolk County Department of Health.

Last, but never least, thanks to all the patrons of Talking Books Plus who give us understanding, insights, and impetus to bring the world of information to people with disabilities in our community.

## HOW TO USE THIS HANDBOOK

**The addresses and telephone numbers of all organizations, publishers, and producers referred to in the handbook are listed separately in the "Directory" at the end of the handbook.**

**The designation "SCLS" indicates that the item has been acquired by the Suffolk Cooperative Library System and is available on interlibrary loan through any public library in Suffolk County.**

The handbook begins with an introductory section about access to AIDS information resources for people with disabilities. It is followed by separate sections on AIDS information resources for people with hearing, visual, developmental, and other disabilities.

Each of these sections has three parts. The first part is intended to familiarize AIDS information providers with some of the special needs of people with that disability, and how they can adapt information they already provide so that it will be accessible to them. The second part describes resources that have been specifically developed for consumers with that disability. The third part describes resources that have been specifically developed for professionals who are working with consumers with that disability.

Consumer and professional resources are listed alphabetically by title. The type of resource (e.g., article, book, organization) is noted next to the title, and is followed by the author, place of publication, publisher or producer, date, length, and price, when applicable.

The addresses and telephone numbers of the publishers and producers are listed in the directory in the back of the handbook. Since availability and prices often change, it is suggested that individuals interested in purchasing any of the resources listed contact the publisher or producer prior to sending payment.

The appendices include several additional resource lists and informational materials of particular interest to organizations and professionals who provide AIDS information to people with disabilities.



I.

# INTRODUCTION

# INTRODUCTION

## ACCESS TO AIDS INFORMATION FOR PEOPLE WITH DISABILITIES

Organizations that provide information about AIDS to people with disabilities must remove the barriers which impede access to their resources and services. These barriers include:

- (1) Attitudinal barriers
- (2) Architectural barriers
- (3) Communications barriers

Although the focus of this publication is on specialized AIDS information resources for people who have communications barriers due to impaired vision, hearing, or developmental disabilities, it is equally important to recognize and eliminate attitudinal and architectural barriers.

### Attitudinal Barriers

Attitudinal barriers often result from ignorance and lack of understanding, and can cause misconceptions, stereotypes, and fears. Ignorance about disabilities can result in false assumptions which are especially dangerous in the provision of information about AIDS, such as the assumption that people with disabilities do not have active sex lives.

Some people have difficulty communicating with people with disabilities because they are inexperienced or uncomfortable. They are unsure of the right thing to say or do, how to act, or what kind of assistance to provide. These difficulties can interfere with the effective flow of essential information.

AIDS information providers must be able to provide the same kind of information to people with disabilities as they do to others, whether it is demonstrating the use of a condom to someone who is quadriplegic or explaining what is involved in an AIDS test to a person who is deaf. They must receive appropriate training in

disability awareness and communications, and be familiar with the specialized organizations and resources available to assist them. When difficulties are encountered, they must be able to provide appropriate referrals.

### **Architectural Barriers**

Architectural barriers are the physical components of a building which make it difficult or impossible for people with disabilities to enter or use its facilities. Such barriers include lack of accessible parking, lack of ramps, narrow doorways, inaccessible rest rooms, and many others.

The Americans with Disabilities Act *requires* that all public services and public accommodations remove these barriers. When the removal of barriers is not readily achievable or creates an undue hardship, reasonable accommodations must be provided so that individuals with disabilities have equal access to the organization's goods or services. For example, if a particular office or meeting room in which information is provided cannot be used by a person who uses a wheelchair, the service should be provided in another room which is accessible.

Organizations that provide AIDS information should assure that their facilities meet the requirements of the Americans with Disabilities Act and other state and local regulations.

### **Communications Barriers**

Barriers which prevent people with disabilities from access to normal communications may include printed material that can not be read by people with visual or learning disabilities, or spoken information which can not be heard by people with hearing impairments.

Organizations that provide AIDS information must take steps to assure that people with disabilities have access to their printed and spoken resources. They can adapt conventional materials by providing auxiliary aids such as sign language interpreters or devices which enlarge print or amplify sound. They can also take advantage of the special resources developed specifically for these individuals which are described in this publication.

### **COMMUNICATIONS TIPS**

**See the person who has a disability as a person, not as a disability.**

**Don't "talk down."**  
**Avoid responding to persons with disabilities out of "gratefulness" for not having a disability yourself.**

**Speak directly to the person who has a disability, not to a companion or interpreter.**

**Treat adults as adults.**  
**Don't use first names unless that familiarity is extended to everyone present.**

**Be considerate. It might take extra time for the person with a disability to say or do things.**

## Selected Resources

**Relax. Don't worry about using common expressions like "See you later" or "I've got to be running along" when talking to persons with disabilities.**

**When talking to a person who uses a wheelchair, don't lean or hang on it. It is part of that person's body space. If the conversation continues for more than a few minutes, sit, squat or kneel.**

**Always ask before you push a wheelchair or provide other personal assistance.**

*(Adapted from the Mid-Hudson Library System's "Now That We've Met, What Do I Say?")*

There are many useful sources of information to help AIDS information providers eliminate attitudinal and architectural barriers, and meet the requirements of the Americans with Disabilities Act. Local disability organizations and public libraries can help you find them. The following resources are especially recommended. In Suffolk County, they are available through any public library.

*Access; State and Local Governments.* Pamphlet. Eastern Paralyzed Veterans Association, n.d. 14 pp. Free. SCLS.

*Accessibility.* Videotape. Eastern Paralyzed Veterans Association, 1988. 30 min. \$19.95. SCLS.

*The ADA: Removing Barriers in Places of Public Accommodation.* Pamphlet. Eastern Paralyzed Veterans Association, n.d. 27 pp. Free. SCLS.

*The Americans with Disabilities Act; Questions and Answers.* Pamphlet. U.S. Equal Employment Opportunities and U.S. Department of Justice, Civil Rights Division, rev. Sept. 1992. 32 pp. Free. SCLS.

*Awareness Is The First Step Towards Change: Tips for Disability Awareness.* Pamphlet. National Easter Seal Society, n.d. Fold-out. 25¢. SCLS.

*Nobody Is Burning Wheelchairs.* Videotape. National Easter Seal Society, 1991. 15 min. \$35.00. SCLS.

## Organizations

- Eastern Paralyzed Veterans Association
- New York State Office of the Advocate for the Disabled
- New York State Education Department, Office of Vocational and Educational Services for Individuals with Disabilities (VESID)
- Northeast Disability and Business Technical Assistance Center
- Self-Initiated Living Options, Inc. (SILO)
- Suffolk County Office of Handicapped Services
- U.S. Department of Justice, Office of Americans with Disabilities Act

## **II.**

# **AIDS Information for People with HEARING IMPAIRMENTS**

## ADAPTING CONVENTIONAL INFORMATION

Organizations that provide information about AIDS will want to make it accessible to individuals with hearing impairments. In addition to the specialized materials listed in the next section, conventional materials can be adapted to meet their needs.

### Printed Materials

**Written materials should be clear, concise, and well illustrated.**

Most people with hearing impairments can read conventional printed publications about AIDS. However, some people who are deaf or severely hearing impaired have limited reading skills, especially those who lost their hearing at birth or early in life, who use a non-verbal modality such as American Sign Language as a primary means of communication, or who experienced particular educational difficulties. Therefore, a special effort should be made to assure that printed materials are clearly written and well illustrated. Many of the pamphlets listed in the next section reflect this need.

### Videotapes and Television Programs

**Television programs and videotapes should be captioned for the hearing impaired.**

Organizations that produce, show or lend videotapes about AIDS should use materials that have signed narration and/or captions. Captions are printed subtitles that appear at the bottom of the picture. Captions may be "open" (visible to any viewer), or "closed" (visible only with specially equipped televisions or VCR's).

Videotapes and television programs with signed narration or captions that are produced especially for people who are deaf or hard of hearing are described in the next section. However, some conventional videotapes and television programs which are used with general audiences are also closed captioned. Conventional videotapes and television programs which are closed captioned are too numerous to list here. They can usually be identified by the letters "cc" or a special symbol on the videotape label or in the television listings.

(Some examples of videotapes which are closed captioned are: "A.I.D.S.: Profile of an Epidemic," "AIDS: A Healing Ministry," "The AIDS Movie," "The AIDS Quarterly," "Born in Africa," "A Common Thread - The AIDS Quilt," "Doubledutch - Double Jeopardy," "An Early Frost," "Frontline," "The HIV Test," "Life After Diagnosis,"

"Other Faces of AIDS," "Saving a Generation - Successful Teaching Strategies for HIV Education in Grades 4-12," "Sex, Drugs & Aids - What You Need to Know," "Suzi's Story," "Teen AIDS in Focus," "Till Death Do Us Part," "What You Can Do To Avoid AIDS," and "Who Pays for AIDS?")

Organizations that show closed captioned videotapes or television programs can make the captions visible by using a new model television set (all 13" or larger television sets which are made in the U.S. on or after July 1, 1993 must be equipped with a built-in decoding circuitry chip) or by attaching a device called a television decoder to an older model television set.

**Additional information about captioning and captioning equipment is available from the National Captioning Institute. In Suffolk County, closed caption decoders may be borrowed through any public library.**

### **Programs and Presentations**

Organizations that offer programs or presentations about AIDS should make sure that they are accessible to individuals who are deaf and hard of hearing. Sign language interpreters, Assistive Listening Devices, and printed copies of the presenters' speeches should be provided.

**Have printed text of presentations available.**

#### Sign Language Interpreters

If an individual who uses sign language will be attending the program, a certified sign language interpreter should be available. For information about locating a certified sign language interpreter, contact the National Information Center on Deafness or the Registry of Interpreters for the Deaf, Inc. In Suffolk County, certified sign language interpreters can be located through the New York Society for the Deaf, Long Island Service Center.

**Use certified sign language interpreters.**

#### Assistive Listening Devices (ALDs)

Assistive Listening Devices (ALDs) should be available for people who are hard of hearing. ALDs are devices which amplify sound and/or block external noises. They can be used with or without a hearing aid. There are many different kinds of ALDs available. The organizations listed at the end of this section can provide additional information about ALD's.

**Have an Assistive Listening Device available.**

### **Telephone Information**

Many individuals who are deaf or hard of hearing use a Telecommunications Device for the Deaf (TDD), also known as a teletypewriter (TTY) or text telephone (TT), to communicate by telephone. The conversations are typed on a small keyboard, and appear as visual displays or paper printouts.

**Install a Telecommunications Device for the Deaf.**

In order to communicate directly, both the caller and the individual or organization being called need to have a TDD. In New York and most other states, people who have TDDs can call those who do not (or vice-versa) by using a special relay service as an intermediary. Although relay service operators are required to maintain confidentiality, people may feel uncomfortable using them for highly personal conversations. Therefore, it is suggested that organizations that operate AIDS hotlines or provide information about AIDS by telephone should have a TDD.

The organizations listed above can provide additional information about purchasing and using a TDD. Once the TDD is installed, all staff who answer the telephone should become familiar with general TDD operations and etiquette.

### **Selected Resources**

Cagle, Sharon J. and Keith M. Cagle. *GA and SK Etiquette; Guidelines for Telecommunications in the Deaf Community*. Booklet. Bowling Green Press, 1991. 53 pp. \$8.95. Available from Gallaudet University Bookstore. SCLS.

Compton, Cynthia L. "Why Use Assistive Listening Devices?" *SHHH Journal*, January-February 1993, 14-17. SCLS.

*Communicating with Deaf People: An Introduction*. Pamphlet. National Information Center on Deafness, 1987. 20 pp. \$20.00. SCLS.

*Hear's to the ADA*. Videotape. Self Help for Hard of Hearing People Inc., 1992. 23 min. \$40.00. SCLS.

Moore, Matthew S. and Linda Levitan. *For Hearing People Only; Answers to Some of the Most Commonly Asked Questions About the Deaf Community, Its Culture, and the "Deaf Reality."* Book. Deaf Life, 1992. \$14.95. SCLS.

*Tips You Can Use When Communicating with Deaf People*. Pamphlet. National Technical Institute for the Deaf, n.d. Free. SCLS.

*Using Your TTY/TDD*. Videotape. Sign Media, 1989. 30 min. \$34.95. SCLS. Available from Gallaudet University Bookstore. SCLS.



## **Organizations**

- American Speech-Language-Hearing Association
- National Information Center on Deafness
- National Technical Institute for the Deaf
- Self Help for Hard of Hearing People

## CONSUMER RESOURCES

The following materials about AIDS prevention were published or produced specifically for individuals with hearing impairments. Additional materials for consumers are listed in "AIDS Pamphlets Designed for Deaf People" and "HIV/AIDS Videotapes Accessible to Deaf People" (see next section).

### **AIDS and the Deaf. [PAMPHLET.]**

AIDS Education Services for the Deaf, n.d. Fold-out. 35 cents. SCLS.

This concise brochure provides basic information about what AIDS is; how the virus is and is not transmitted; how to prevent AIDS; and what to do if you are worried about having AIDS. It is intended for deaf individuals who possess a good command of the English language, and is more detailed and less explicit than "AIDS: What Deaf Should Know" (below).

### **AIDS Education Services for the Deaf. [ORGANIZATION.]**

AIDS Education for the Deaf is an organization developed to "bridge the new public awareness of AIDS to deaf people, and relax the anxieties caused by misinformation that accompanies this disease. In addition, the program helps prevent further spread of the virus by education, which is the best defense at this time." The program is a project of the Greater Los Angeles Council on Deafness, and is funded by the California Office of AIDS.

### **AIDS Kills Women Men and Babies. [PAMPHLET.]**

Dallas County Health Department, 1988. Fold-out. Free. SCLS.

This brochure features simple cartoon illustrations depicting safe and unsafe practices. Also available in Spanish.

### **AIDS.Net. [COMPUTER BULLETIN BOARD.]**

International Deaf/Tek, Inc. \$50 annual fee plus connect time.

AIDS.Net is a computer bulletin board on DEAFTEK.USA, an electronic mail network dedicated to people who are deaf or hard of hearing. Information is provided by the National Information Clearinghouse on AIDS, along with agencies and professionals serving deaf people. Subscribers can also ask questions of experts.

**AIDS: What Deaf Should Know.** [PAMPHLET.]

AIDS Education Services for the Deaf, 1992. Fold-out. 50 cents. SCLS.

This is a brief, illustrated brochure that is geared to deaf individuals with minimal language skills. It describes how you can and can't get AIDS and what to do to prevent it. Some of the illustrations are explicit. A sample TDD conversation between a counselor and a deaf individual is included.

**AIDS -- What Mean? AIDS -- How Stop? Learn About AIDS!**  
[PAMPHLET.]

Travis County Council for the Deaf, AIDS Services of Austin. 1989, rev. 1990. Fold-out. Free. Available from the Dallas County Health Department. SCLS.

This simple, illustrated brochure is intended specifically for people who use a language other than English. Includes sexually explicit material.

**AIDS; What the Deaf Community Needs to Know.** [VIDEOTAPE, SIGNED AND CLOSED CAPTIONED.]

Gallaudet Media Distributors, 1988; 1990 release. 41 min. \$15.00. SCLS.

Aimed at deaf people who use sign language, this video presents a great deal of information about HIV and AIDS, including transmission, safe sex, and the importance of educating other deaf people. It is staged as a conversation by a married couple on a television talk show, with periodic summaries by an observer.

**Deaf Mosaic.** [TELEVISION PROGRAM; CAPTIONED, SIGNED, AND VOICE.]

Gallaudet University, Department of Television, Film, and Photography. Weekly. 30 min. Broadcast on cable and PBS affiliated stations throughout the United States, Canada and Japan. Broadcast locally on the Discovery Channel on Saturdays from 9:00 to 9:30 a.m.

Deaf Mosaic is a nationally broadcast television program, in a magazine format, developed for and about people in the deaf community. The program often includes stories relating to AIDS and the deaf community. Some of the programs can be purchased as videotapes (see below).

**Deaf Mosaic #312: "Living with AIDS."** [VIDEOTAPE; CAPTIONED, SIGNED, AND VOICE.]

Gallaudet University, Department of Television, Film, and Photography, n.d. 30 min. \$35.00.

This "special edition" includes interviews with National Institute of Health officials and U.S. Surgeon General Everett Koop; and a visit with a deaf man coping with AIDS.

**Deaf Mosaic #509.** [VIDEOTAPE; CAPTIONED, SIGNED, AND VOICE.]

Gallaudet University, Department of Television, Film, and Photography, 1989. 30 min. \$35.00.

This edition of Deaf Mosaic features the Deaf Names Project, in which members of the deaf community memorialize deaf people with AIDS as part of the national AIDS quilt project.

**Deaf Mosaic #707: "The Age of AIDS."** [VIDEOTAPE; CAPTIONED, SIGNED, AND VOICE.]

Gallaudet University, Department of Television, Film, and Photography. November 1991. 30 min. \$35.00.

During this "town meeting," experts on deaf health issues and deaf people with AIDS discuss community services and AIDS prevention for the deaf community.

**Deaf Teens and A.I.D.S.** [BROCHURE.]

AIDS Education Services for the Deaf, 1991. Fold-out. 35 cents. SCLS.

This brochure provides basic information about AIDS, AIDS prevention, and AIDS testing in an informal style.

**It's Not Just Hearing Aids** [VIDEOTAPE, SIGNED AND VOICE.]

Deaf Communications Foundation, 1988. 60 min. SCLS.

This video provides important information for deaf people about dealing with AIDS. It includes several humorous vignettes, and an interview with an interpreter who has AIDS. It is narrated in sign language by Bobbie Beth Scoggins, star of "Dallas" and "Children of a Lesser God."

**Lifesaver Kit and Guide.** [PAMPHLET AND KIT.]

AIDS Education for the Deaf, 1992. Various parts. 35 cents. SCLS.

This is a wallet-sized envelope containing a small, simple guide to safer sex and IV drug precautions. It is intended to be distributed with a condom and water based lubricant, and includes directions for using a condom.

**National AIDS Hotline - Deaf Access.** [TELEPHONE HOTLINE.]

The National Aids Hotline is a 24-hour, toll-free service that provides confidential information, referrals, and educational materials to the public. Its special telephone number for deaf individuals who use a TTY/TDD is (800) AIDS-TTY or (800) 249-7889 (TDD). An attractive poster promoting the service is available from the organization.

**A Positive Influence.** [VIDEOTAPE, OPEN CAPTIONED AND SIGNED.]

Greater Los Angeles Council on Deafness, n.d. 47 minutes. \$19.95. Available from AIDS Education Services for the Deaf.

Academy Award winner Louise Fletcher stars in this film on what to do when a deaf person is HIV positive.

**The Silent Network (TSN).** [TELEVISION NETWORK.]

The Silent Network is a cable television network dedicated solely to programming geared toward the deaf community. Most of the shows are broadcast simultaneously with open captions, sign language, and voice/music. TSN's wide range of informational, educational and theatrical programming often includes timely and topical subjects such as AIDS.

**EI SIDA Mata Mujeres Hombres y Ninos.** [BROCHURE.]

Dallas County Health Department, 1988. Fold-out. Free.

Spanish edition of the brochure "AIDS Kills Women Men and Babies."

## PROFESSIONAL RESOURCES

### **AIDS and Deafness; Resource Directory. Second ed. [BOOK.]**

Produced by the National AIDS Information Clearinghouse in conjunction with Gallaudet University and the National AIDS Hotline. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National AIDS Information Clearinghouse, October 1989. 105 pp. SCLS.

A directory of national, state, and local organizations that offer AIDS-related services to people who are deaf and hard-of-hearing. Organizations included in the directory provide TTY/TDD access, sign language interpreters, or educational materials or services geared toward deaf people. (This book is currently out of print; for information about future editions or updated information about specific resources, contact the National AIDS Information Clearinghouse.)

### **AIDS Pamphlets Designed for Deaf People. [FACT SHEET.]**

National AIDS Hotline, n.d. 3 pp. Free. SCLS.

This fact sheet describes pamphlets and brochures which are available from a variety of organizations.

### **HIV/AIDS Videotapes Accessible to Deaf People. [FACT SHEET.]**

National AIDS Hotline TDD Service, n.d. 27 pp. Free. SCLS.

Describes signed, open captioned, closed captioned and conference videotapes about AIDS and HIV that are available from a wide variety of organizations.

### **National Coalition on Deafness and HIV/AIDS (NCDH). [ORGANIZATION.]**

The mission of the National Coalition on Deafness and HIV/AIDS (NCDH) is to serve as a network of agencies, individuals and representatives across the country providing HIV/AIDS prevention, education, and direct and indirect services to deaf and hard of hearing people. The group also promotes assistance, assures accessibility, identifies resources and services, supports, expands and disseminates written and video materials in the deaf community nationwide, and seeks to promote and ensure training, advocacy, and consultation to agencies and professionals to increase the accessibility and sensitivity of their services. Membership dues are \$25 for individuals and \$40 for organizations.

**Special Report: AIDS and the Deaf Community. [MAGAZINE.]**

Gallaudet Today, Vol. 18, No. 3 (Spring 1988). \$3.00. SCLS.

This issue of Gallaudet Today, the quarterly magazine of Gallaudet University, focuses on AIDS and the deaf community. Contents include: "I Call Them Friends," an article about a hearing impaired "buddy"; "Personal Glimpses Into the World of AIDS," a series of profiles of people in the deaf community whose lives have been touched by AIDS; "Spreading the Word," about Gallaudet University's efforts to intensify its AIDS education; and "AIDS: A Growing Epidemic," an article intended to dispel some of the myths and misinformation surrounding AIDS.

**III.**

**AIDS Information for People with  
VISUAL IMPAIRMENTS**



## ADAPTING CONVENTIONAL INFORMATION

Organizations that provide information about AIDS will want to make it accessible to individuals with visual impairments. In addition to the specialized materials listed in the next section, conventional materials can be adapted to meet their needs.

### Print Materials

Print materials should be available in alternative formats for people with visual impairments. These formats may include:

#### Large print

**Some photocopy equipment, typewriters and personal computers can be used to enlarge standard print materials.**

Many people with visual impairments, including many who are legally blind, can read large print. Type should be 16 points or larger. Text should be in upper and lower case rather than all capitals, which are much harder to read. Standard print materials can be enlarged with large type typewriters, word processors, or desktop publishing software. Photocopy machines that have enlargement capabilities can also be used.

#### Braille

**Talking Books Plus has computer equipment that transcribes print to braille available for use by Suffolk County organizations.**

People with visual impairments who read braille often prefer this format. A list of organizations that provide braille transcription services is available from the National Braille Press. A list of volunteer groups that provide transcription services is available from the National Library Service for the Blind and Physically Handicapped.

#### Audiotape

**Talking Books Plus volunteers will record AIDS information resources produced by organizations in Suffolk County.**

Publications can be recorded onto audiotape by commercial facilities or trained volunteers. Recorded publications have the widest accessibility, since most people with visual impairments do not read braille, and many cannot see well enough to read large print.

### Other formats

Many people with visual impairments can read conventional print with the help of low vision devices or computer equipment that scans print and converts it into voice or braille.

Some people with visual impairments have their own computers with large print, voice or braille output. Providing these individuals with a copy of the publication on computer disk will enable them to access it.

Short publications can be provided as recorded telephone messages, or can be read aloud.

**Taped messages are a useful source of information for people with visual impairments. See Appendix B for a list of toll-free taped messages available through the New York State AIDS Hotline.**

### **Audiovisual Materials**

When selecting audiovisual materials about AIDS for audiences which may include people with visual impairments, choose materials which are not heavily dependent upon graphics or which contain good verbal descriptions of graphic presentations.

### **Selected Resources**

*Making Libraries Accessible to Patrons Who Are Blind or Visually Impaired.* Fact sheet. American Foundation for the Blind, 1993. 2 pp. Free. SCLS.

*Toward Equal Access: Providing Information Access Services to Blind and Visually Impaired Persons Under the Americans with Disabilities Act (ADA).* Pamphlet. National Federation of the Blind, Information Access Project for Blind Individuals, n.d. Free. SCLS.

*What Do You Do When You See A Blind Person?* Videotape. American Foundation for the Blind, 1972. 14 min. \$69.95. SCLS.

### **Organizations**

American Foundation for the Blind  
National Association for Visually Handicapped  
National Library Service for the Blind and Physically Handicapped

## CONSUMER RESOURCES

The following materials about AIDS have been produced in alternative formats for people with visual impairments. Many of the materials listed are not available for purchase; rather, they can be borrowed by eligible individuals through the organizations that produced them. Materials produced by the National Library Service for the Blind and Physically Handicapped (NLSBPH) can be borrowed through cooperating libraries nationwide; in Suffolk County, NLSBPH recorded books can be borrowed directly from Talking Books Plus.

**This list includes materials published in 1987 or later. Because of the changing nature of AIDS information, even recent materials may contain dated information.**

### **AIDS and Chemical Dependency. [RECORDED PAMPHLET.]**

Dorothy A. Flynn. 1987. DN0424(01). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

AIDS has become a special threat to recovering people because of the high numbers among intravenous drug users. This pamphlet describes the symptoms of the disease, how to avoid contracting the AIDS virus, and how to use the principles of recovery programs to deal with the effects of the disease.

### **AIDS and Society. [RECORDED BOOK.]**

Mary Bronson Merki. 1989. DM0622 (01). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

Contents include: AIDS, a deadly disease; How AIDS is transmitted; Testing for AIDS; Care of the AIDS patient; Prevention of the spread of AIDS.

### **AIDS and the Law: A Guide for the Public. [BRAILLE BOOK.]**

Marion L. Dalton, Scott Burris, and the Yale AIDS Law Project, editors. 1987. BR 07388. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries.

Twenty readings that emanate from the Yale AIDS Law Project. Three articles provide medical background and historical perspective. Each of the others treats one of the legal aspects of AIDS, citing and explaining relevant cases, laws, and court decisions in nontechnical language.

**The AIDS Book: Creating A Positive Approach. [RECORDED BOOK.]**

Louise L. Hay. 1988. RC 31745. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

A guru of positive thinking as a means of healing offers advice on how to achieve self-love and serenity. The first of three sections offers an explanation of AIDS; section two discusses self-healing exercises involving new age techniques such as mirror work, meditation, and imaging; and section three covers ways of finding help from doctors and medical institutions as well as using alternative therapies.

**Recorded publications are not just for people who are blind or visually impaired! They also provide access to information for many individuals with learning disabilities, and for those who cannot hold regular books or turn pages because of physical disabilities.**

**The AIDS Booklet. [RECORDED PAMPHLET.]**

Frank D. Cox. 1989. DS0625 (01). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

Describes how AIDS and related diseases are commonly spread, so that the readers can protect themselves and their friends against it.

**The AIDS File: What We Need To Know About AIDS Now! [RECORDED BOOK.]**

George Jacobs and Joseph Kerrins. 1987. CC0469 (02). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

Discusses the history of AIDS; the threat it presents to all sexually active persons; the immune system, how it works and how AIDS undermines it; the tests for AIDS; the problems and progress of immunization and therapeutic drugs for the disease; AIDS prevention; and a list of misunderstood or insufficiently known facts about the disease.

**AIDS Prevention Guide: For Parents and Other Adults Concerned About Youth. [RECORDED BOOK; BRAILLE BOOK.]**

U.S. Department of Health and Human Services. 1989. RC 30700; BR 8121. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

AIDS can affect anyone - male or female, old or young, rich or poor, or from any ethnic or racial background. This guide is intended to help adults discuss the virus and its prevention with young people. Topics include "deciding what to say to younger children" and "common questions, accurate answers."

**AIDS: The HIV Myth. [RECORDED BOOK.]**

Jad Adams. 1989. CD0575(04). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

This book marshals the diverse arguments against the now widely accepted theory that the HIV virus is the sole and sufficient cause of AIDS. The author describes the early years of AIDS research and especially the scientific background against which it occurred.

**AIDS, The Spiritual Dilemma. [RECORDED BOOK.]**

John E. Fortunato. 1987. RC 26311. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

A psychotherapist issues a challenge to fellow gays and lesbians to put the roots of their religious faith down deep into their own experience of suffering and to love with compassion "when many would like us to go away." A provocative, highly unorthodox call to Christian caring.

**AIDS: The Ultimate Challenge. [RECORDED BOOK.]**

Elisabeth Kubler-Ross. 1987. RC 28921. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

The author conveys her own feelings and those of her clients and their families as they deal with AIDS. She details the suffering of persons with AIDS; presents case histories; provides dialogue from public meetings regarding care for AIDS patients; and looks at AIDS from the perspective of such groups as mothers, babies, drug addicts, and homosexuals.

**AIDS: The Women. [RECORDED BOOK.]**

Ines Reider and Patricia Ruppelt, editors. 1988. RC 30349. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

Personal accounts from women affected by the disease — wives, mothers, sisters, and lovers of people with AIDS; women who have AIDS; and by the doctors, nurses and counselors who serve people with AIDS. Explicit descriptions of sex.

**And the Band Played On: Politics, People, and the AIDS Epidemic.**  
[RECORDED BOOK.]

Randy Shiits. 1987. FD 26042; RC 26042. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

The author, a reporter for the *San Francisco Chronicle*, has been covering the AIDS epidemic full-time since 1982. He describes the apathy and politics displayed by the government, the media, the medical establishment, and the gay community before they realized the magnitude of the crisis, as well as the tragedy of the disease's human toll.

**Conquering AIDS Now: With Natural Treatment, A Non-Drug Approach.** [RECORDED BOOK.]

Scott J. Gregory and Bianca Leonardo. 1987. DP0902(03). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

Two holistic health experts provide a comprehensive, plain-speaking guide to the numerous alternative therapies now available.

**Coping With AIDS; The Public Response to the Epidemic.**  
[RECORDED PAMPHLET.]

1988. DL0050(01). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

Prepared by the Public Agenda Foundation as part of the "National Issues Forums" series. Contents include: Anatomy of an epidemic; Coping with the crisis; A perilous vice, reasserting moral standards; The public interest, protecting the uninfected; Practical approach, choosing a strategy that works; Epidemic of fear, preventing discrimination, pursuing a cure; Great AIDS debate, responding to the epidemic.

**Entiendo el Sida.** [RECORDED PAMPHLET.]

U.S. Department of Health and Human Services. 1988. CBF913. Produced by the Florida Library for the Blind and Physically Handicapped. Available on free loan through cooperating libraries.

Spanish edition of Understanding AIDS.

**The Essential AIDS Fact Book: What You Need to Know to Protect Yourself, Your Family, All Your Loved Ones.** [RECORDED BOOK; BRAILLE BOOK.]

Paul Harding Douglas and Laura Pinsky. Prepared in cooperation with the Columbia University Health Service. 1987. RC 26933; BR 07254. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. Also available from Recording for the Blind. SCLS.

Dozens of magazines and journals which contain articles about AIDS — ranging from *U.S. News & World Report* to *Journal of Counseling and Development* — are available in braille, cassette, record, and other special media. A list of them can be found in Magazines in Special Media (National Library Service for the Blind and Physically Handicapped, 1990).

A clear, concise introduction to AIDS. The first part, "What You Need to Know About AIDS," addresses causes, transmission, patterns of illness, and treatment. The final part, "What You Can Do About AIDS," includes information on how to avoid the AIDS-associated virus (HIV), on the HIV antibody test, and on discrimination against people with AIDS. Includes listings of national and state organizations, hotline numbers, and HIV antibody testing sites.

**Healing AIDS Naturally.** [RECORDED BOOK.]

Laurence Badgley. 1987. DP0901(05). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

A holistic approach to regaining and maintaining health through natural methods.

**Informe del Jefe del Servicio de Salud Publica de los Immuno-Deficiencia Adquirida (AIDS).** [RECORDED DOCUMENT.]

Servicio de la Salud Publica de los Estados Unidos. 1988. (CBF 912). Produced by the Florida Library for the Blind and Physically Handicapped and available on free loan through cooperating libraries.

Spanish translation of the Surgeon General's Report on Acquired Immune Deficiency Syndrome.

**Living with AIDS on Long Island.** [RECORDED BOOK.]

Long Island Association for AIDS Care. 1989. SUF 00058. Produced by SCLS Talking Books Plus. Available on free loan through cooperating libraries. SCLS.

Prepared by the Long Island Association for AIDS Care (LIAAC) for people who have AIDS. Includes basic information about AIDS; the kind of services which can help; and the stories, experiences, ideas and suggestions of people who have been living with AIDS on Long Island.

**Lynda Madaras Talks To Teens About AIDS: An Essential Guide for Parents, Teachers, and Young People.** [BRAILLE BOOK.]

Lynda Madaras. 1988. BR 08193. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries.

A candid and detailed discussion, aimed specifically at young adults, about AIDS. Chapters include "AIDS: The Rumors and Real Facts," "Preventing Sexual Transmissions: Abstinence and Safer Sex," and "Other Types of Transmission and Their Prevention." For senior high and older readers.

**New York City Strategic Plan for AIDS. [RECORDED DOCUMENT.]**

Interagency Task Force on AIDS. May 1988. DI0376(04). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

Summarizes programs and describes integrated and individual agency plans.

**Private Acts, Social Consequences: AIDS and the Politics of Public Health. [RECORDED BOOK.]**

Ronald Bayer. 1989. DN0589 (05). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

Though the author emphasizes that AIDS is very much a private tragedy, he takes the view that the consequences of its transmission are a legitimate and essential concern of the state and the community.

**The Real Truth About Women and AIDS: How to Eliminate the Risks Without Giving Up Love and Sex. [BRAILLE BOOK.]**

Helen Singer Kaplan. 1987. BR 07397. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries.

A candid discussion of AIDS specifically aimed at answering questions that women may have about the virus. Includes an explicit discussion of the types of sex deemed "safe" and a warning against relying exclusively on condoms to eliminate the risks of exposure.

**Surgeon General's Report on Acquired Immune Deficiency Syndrome. [RECORDED DOCUMENT.]**

U.S. Department of Health and Human Services. 1988. CBF 911. Produced by the Florida Library for the Blind and Physically Handicapped and available on free loan through cooperating libraries.

Official report of the U.S. Surgeon General. Also available in Spanish.

**Surviving AIDS. [RECORDED BOOK.]**

Michael Callen. 1990. DQ0154(04). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

The author fights against the public ignorance and sloppy reporting that have created the "damaging lie" that AIDS is always fatal, an automatic death sentence. He tells his own story and, through in-depth interviews, the stories of thirteen other long-term survivors. This book profiles men and women, gay, straight, and bisexual, black, white, brown. These are stories of their fighting spirit, their courage, their drama, and their sometimes outrageous sense of humor, and presents their answers to the question "Why am I alive?"



The following books may be of particular interest to younger readers:

**Lynda Madaras Talks to Teens About AIDS (braille)**

**Teens with AIDS Speak Out (large print)**

**Understanding Aids (recorded)**

**We Have AIDS (recorded)**

**What You Can Do To Avoid AIDS (recorded)**

**You Can Do Something About AIDS (braille and recorded)**

### **Teens with AIDS Speak Out. [LARGE PRINT BOOK.]**

Mary Kittredge. Thorndike Press, 1993. (Originally published in 1991.) 163 pp. \$15.95. SCLS.

Teenagers with AIDS describe how they became infected and what it is like to live with the disease. ALA Best Books for Young Adults.

### **Thinking AIDS. [RECORDED BOOK.]**

Mary Catherine Bateson and Richard Goldsby. 1988. RC 29855. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

An anthropologist and a biologist discuss the nature of the AIDS virus and offer proposals for its management. They analyze the outbreaks of historical epidemics, describe the human immune system and how AIDS attacks it, and stress that key factors in limiting the spread of the disease in the context of present-day society are information and behavior.

### **Understanding AIDS. [RECORDED BOOK.]**

Ethan A. Lerner, M.D. 1987. RC 28963. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

Brief stories and questions explain how the AIDS virus is transmitted, who is at risk, and the disease's damaging effects on the body's immune system. For grades 5-7 and older readers.

### **Understanding AIDS. [RECORDED PAMPHLET; BRAILLE PAMPHLET.]**

U.S. Department of Health and Human Services. 1988. HHS Publication No. (CDC) HHS-88-8407. Braille edition produced by National Braille Press and distributed at no charge by the National AIDS Information Clearinghouse. Recorded edition produced by the Florida Library for the Blind and Physically Handicapped and available on free loan through cooperating libraries. SCLS.

This publication was prepared by the U.S. Surgeon General to let all Americans know how you do — and don't — get AIDS. Topics covered include risky behavior, dating, condoms, testing, giving and receiving blood, drug use, and babies. Also available in Spanish (see Entiendo el Sida).

### **We Have AIDS. [RECORDED BOOK.]**

Elaine Landau. 1990. RC 34681. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

Karen, Allen, Jackie, Gary, Cheryl, Jason, Allison, Maria, and Paul are all average teenagers — who have AIDS. They tell how they got

the disease, and how it has altered their lives and the lives of their families and friends. The stories are frank, poignant, frightening, and informative. Includes facts about AIDS and a list of resource organizations. For junior and senior high readers.

**What You Can Do To Avoid AIDS. Abridged ed. [RECORDED BOOK.]**

Earvin "Magic" Johnson. Introduction read by Earvin "Magic" Johnson. Random House Audio Books, 1992. \$5.99. SCLS.

The popular basketball star reaches out to teenagers and their parents in a frank and comprehensive exploration of AIDS and its prevention. Discusses safer sex, drugs, abstinence, condoms and other preventive measures, HIV testing, how to talk about sex with potential partners, and how to incorporate AIDS awareness into the choices teenagers make. A printed state-by-state resource listing is included. Contains explicit descriptions of sex.

**When Someone You Know Has AIDS: A Practical Guide. [RECORDED BOOK.]**

Leonard J. Martelli. 1987. RC 30512. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

A thorough description of what is known about the disease, with guidelines for safer sex. Discusses legal and financial issues. Includes personal accounts of patients and caregivers.

**Women, AIDS, and Activism. [RECORDED BOOK.]**

Marion Banzhaf, et al. 1990. DQ0460(04). Produced by Recording for the Blind. Available on free loan from Recording for the Blind.

A book about women in the AIDS epidemic, with discussions of safer sex and sexuality, HIV testing, treatment and drug trials. The book is an analysis of AIDS issues for women, including lesbians, heterosexuals, bisexuals, prostitutes, intravenous drug users, teenagers, mothers, pregnant women, and women in prisons.

**You Can Do Something About AIDS. [RECORDED BOOK; BRAILLE BOOK.]**

Alyson Sasha, editor. 1988. RC 28588; BR 07634. Produced by the National Library Service for the Blind and Physically Handicapped. Available on free loan through cooperating libraries. SCLS.

A public service project of the publishing industry, this book addresses the issues of what concerned individuals can do about the AIDS epidemic. Includes chapters by Elizabeth Taylor, Greg Louganis, Jody Powell, Whoopi Goldberg, and Abigail Van Buren. For high school and older readers.

**The following materials are available free or for purchase from commercial sources:**

**Teens with AIDS Speak Out (large print)  
Understanding AIDS (braille)  
What You Can Do To Avoid AIDS (recorded)**

## PROFESSIONAL RESOURCES

There are many resources which address the sex education needs of people with visual impairments. They can be located through the bibliographies listed in Appendix C.

**Vision loss can seriously compound the trauma of living with an AIDS diagnosis. Individuals with vision loss must relearn how to get around and to perform everyday activities like cooking, shopping, and working. The following organizations can provide assistance to people with recent vision loss in Suffolk County:**

**N.Y.S. Commission for the Blind and Visually Handicapped**

**Catholic Charities' Services for Blind and Visually Impaired Persons**

**Helen Keller Services for the Blind**

**Suffolk Lighthouse**

In addition, AIDS information providers should be aware that AIDS is also a cause of visual impairments. According to the American Academy of Ophthalmology, about 75 percent of AIDS patients develop eye involvement of some sort. Common problems include non-infectious AIDS retinopathy, characterized by cotton-wool spots which are transient, non-progressive, and asymptomatic; and CMV retinitis, a serious, progressive infection which often leads to severe visual loss and blindness. AIDS-related visual impairments may also result from other types of retinal infections, from Kaposi's sarcoma of the eyelids and conjunctiva, and from brain involvement.<sup>1</sup>

There is a great deal of technical medical information available relating to AIDS and the eye which is beyond the scope of this publication. However, AIDS information providers should be familiar with some of the basic effects of AIDS on vision and how they can assist affected individuals. The following publications may be helpful.

### **AIDS and Vision Loss. [BOOK.]**

Edwin Kiester, Jr. American Foundation for the Blind (New York) and The Lighthouse for the Blind and Visually Impaired (San Francisco). American Foundation for the Blind, 1990. 115 pp. \$29.95. SCLS.

Published in conjunction with the First International Conference on AIDS and Vision Loss in 1990, this handbook is intended for professionals in the AIDS and blindness networks. It provides a readable overview of AIDS and vision loss, including its demographics, treatment, and emotional impact. It also addresses agency policies, training, and services. It has many useful resources, bibliographies, and appendices.

<sup>1</sup>American Academy of Ophthalmology, Eye Facts About AIDS (San Francisco, CA: 1987), p.1.

**Eye Facts About AIDS. [FACT SHEET.]**

American Academy of Ophthalmology, 1987. 2 pp. Free. SCLS.

Geared for the public, this fact sheet discusses what AIDS is, how it affects the eye, what treatment is available, concerns about the AIDS virus in tears, and the importance of eye examinations.

**Implications of Acquired Immunodeficiency Syndrome for Professionals in the Field of Blindness. [ARTICLE.]**

William E. Daugherty. Education of the Visually Handicapped, Vol. XX, No. 3 (Fall 1988), 95-108. SCLS.

This article covers the causes of AIDS, its effect on vision, the importance of AIDS education and its historical and legal implications, and specific aspects of sex and AIDS-related education as they apply to the needs of children and youth with visual impairments.

## **IV.**

# **AIDS Information for People with DEVELOPMENTAL DISABILITIES**

## ADAPTING CONVENTIONAL INFORMATION

Developmental disabilities are a variety of conditions which constitute a life-long mental or physical impairment that becomes apparent during childhood. They can hamper an individual's intellectual growth as well as the ability to participate in the mainstream of society. Although the term is often used to represent mental retardation, it also includes cerebral palsy, autism, epilepsy, learning disabilities, and a wide variety of other impairments.

Much of the literature concerning AIDS/HIV and developmental disabilities suggests that individuals with developmental disabilities have characteristics which place them at particular risk for infection, i.e.: they may be sexually active, have poor judgment, have poor impulse control, have deficits in social skills, be easily influenced by others, have cognitive problems, have difficulty making decisions, have difficulty communicating, be less knowledgeable about their bodies and their sexuality, have difficulty distinguishing between reality and unreality, and have difficulty recognizing the consequences of their actions.

**"There is a lack of educational and curricular resources in comprehensive health education and HIV infection prevention education for children and youth with special needs." -- National Forum on HIV/AIDS Prevention Education for Children and Youth with Special Education Needs**

The National Forum on HIV/AIDS Prevention Education for Children and Youth with Special Education Needs has found that "there is a lack of educational and curricular resources in comprehensive health education and HIV infection prevention education for children and youth with special needs."<sup>1</sup> Some materials that are especially geared for people with developmental disabilities are described in the following section. However, AIDS information providers may find it necessary to use or adapt conventional resources.

Several of the professional publications described later in this section offer techniques for providing AIDS prevention instruction for individuals with developmental disabilities and for adapting general curricula and materials. In particular, HIV Prevention and AIDS Education: Resources for Special Educators contains detailed checklists for identifying and selecting curriculum and instructional materials that can be used to teach special education students about HIV and AIDS. Its "Materials Review" checklist is reprinted in Appendix D. The Supplement to AIDS Instructional Guide Grades K-12 contains suggestions for adapting the New York State Education Department curriculum for students with special needs.

When providing AIDS information to people with developmental disabilities, it is important to "draw out" what they already know in order to assess their understanding and concerns, to make extensive use of repetition and review, and to ask questions frequently to assure that the information presented is understood.

Information providers should not rely exclusively on reading materials for conveying information. Audiovisual materials, models, and pictures should be used as liberally as possible. Participatory exercises such as role playing are particularly helpful.

When using conventional AIDS information materials, select those which:

- are appropriate for the individual's education level, developmental level, and individual needs;
- are presented in a manner in which material can be easily extracted or adapted for individual use;
- use appropriate language and accurate terminology and vocabulary;
- are at an appropriate reading level;
- are as relevant to the individual's life experiences as possible;
- are sensitive to the individual's culture, sexual orientation, and disabling condition;
- are factual, honest, and nonjudgmental;
- emphasize practical and behavioral matters;
- are as concrete and as realistic as possible;
- make extensive use of pictures and other realistic visual aids which illustrate information presented in the text.

**"Special education students require instruction and practice in assertiveness techniques, including skills for negotiation and resistance to peer pressure. Instruction should also include resources that students can contact to obtain more information and help." -- Clearinghouse on Handicapped and Gifted Children**

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<sup>1</sup>Association for the Advancement of Health Education and the Council for Exceptional Children, Summary of the National Forum on HIV/AIDS Prevention Education for Children and Youth with Special Education Needs (1989), p. 25.

## CONSUMER RESOURCES

The materials listed below were developed for reading or viewing by people with various developmental disabilities. Some are intended to be used by professionals in conjunction with consumers. Many additional resources for professionals are listed in the following section.

**"Students are often unable to get information from written materials, because few publications are written on their reading level." - Clearinghouse on Handicapped and Gifted Children**

### **AIDS: Teaching Persons with Disabilities How to Better Protect Themselves. [CURRICULUM KIT.]**

Young Adult Institute, 1987. 17 min. Includes videotape and manual. \$145.00. SCLS. Also available on loan to professionals in Suffolk County through the Suffolk Family Education Clearinghouse.

This videotape was developed by the Young Adult Institute to help qualified instructors teach people with disabilities to better protect themselves against AIDS through safer sex. Material is presented in simple, concrete terms, with pauses for discussion and follow-up. Role plays with heterosexual and homosexual couples are nonjudgmental. Accompanying trainer's manual ("AIDS: Training People with Disabilities to Better Protect Themselves") provides step-by-step instruction for trainers. Includes sexually explicit scenes.

### **The Basics of HIV Disease: Questions and Answers. [BOOKLET.]**

Adapted and modified by Dick James. Originally prepared by Glenn Pierce. Hemophilia and AIDS/HIV Network for the Dissemination of Information, 1992. 28 pp. Free. SCLS.

Adapted from HIV Disease in People with Hemophilia: Your Questions Answered, this publication was developed to provide a shorter and easier to read version for individuals having less experience with medical terms and ideas. The question and answer format addresses management of HIV, treatment options, risks to sexual partners, children with HIV, and other issues. It is written in very clear, simple language.



**Circles: Safer Ways. [CURRICULUM KIT.]**

James Stanfield Publishing Co., 1988. Includes two programs (slide or video), teacher's guide, and supplemental materials about AIDS. \$395.00.

Circles is a series of curriculum kits for teaching self-protection strategies to people with developmental disabilities. The Safer Ways program is designed to provide instruction on communicable diseases, how to avoid them, and how to treat them. Part 1 covers communicable diseases and casual contact. Part 2 covers sexually transmitted diseases, AIDS, and intimate contact.

**Coping with AIDS; The Public Response to the Epidemic. Abridged ed. [BOOKLET.]**

Prepared and published through a joint project of the Kettering Foundation and the Public Agenda Foundation. Kendall/Hunt Publishing Company, 1988. 28 pp. \$2.95. SCLS.

This is an abridged, easy-to-read edition of a book prepared for the "National Issues Forum" about AIDS. It focuses on the public issues surrounding AIDS, and looks at four different ways of approaching the problem: "Getting Back to Moral Standards," "Protecting the Public," "A Practical Approach," and "Protecting Rights while Finding a Cure."

**An Easy Guide to Loving Carefully. Rev. ed. [BOOK.]**

Lyn McKee, Winifred Kempton, and Lynne Stigall. Rev. ed. Network Publications, 1987. 65 pp. \$5.95. SCLS.

A concise, well-illustrated guide to sexuality which is especially easy to read. Appropriate for adults with developmental disabilities of various age and reading levels. The small section on AIDS explains how the virus is passed sexually (but does not cover other modes of transmission), dispels common myths, and offers rules for safe sex. Includes sexually explicit material.

**Everything You Need to Know About AIDS. Rev. ed. [BOOK.]**

Barbara Taylor. (The Need to Know Library.) Rosen Publishing Group, 1992. 64pp. Available from Fearon/Janus/Quercus. \$13.95. SCLS.

Information about AIDS and safe sex practices targeted for teenagers, written at a fourth to sixth grade reading level. Illustrated. Contains some sexually explicit material.

**Learn to Be Safe. [BOOKLET.]**

The Arc, 1993. Item 40-11. 19 pp. Contact for price. SCLS.

Five comic book style stories about men and women facing the HIV/AIDS epidemic. The stories are printed on 8 1/2" x 11" sheets and can be reproduced for use in schools, homes, places of worship, and health care settings.

**Life Horizons I: The Physiological and Emotional Aspects of Being Male and Female. [CURRICULUM KIT.]**

James Stanfield Co., 1988. Five slide programs, over 500 slides, teaching guide and script. \$399.00. Available on loan to professionals in Suffolk County through the Suffolk Family Education Clearinghouse.

Life Horizons I is a comprehensive sex education course for people with developmental and learning disabilities which includes:

Part 1 - Parts of the Body Male & Female

Part 2 - Sexual Life Cycle

Part 3 - Human Reproduction

Part 4 - Birth Control Or Regulation Of Fertility

Part 5 - Sexually Transmitted Diseases and AIDS

**LifeFacts: AIDS. [CURRICULUM KIT.]**

James Stanfield Co., 1988. Includes curriculum guide, 57 laminated teaching pictures, 14 student worksheets, and a pretest and post-test. \$199.00. Available on loan to professionals in Suffolk County through the Suffolk Family Education Clearinghouse.

This is one of seven "LifeFacts" programs designed to teach independent living and self-protection skills for people with special needs. It includes five parts:

Part 1 - Germs

Part 2 - Risk

Part 3 - Risk-Taking

Part 4 - Sexually Transmitted Diseases

Part 5 - Understanding AIDS

The programs cover the dangers of AIDS, how it spreads, and how to reduce exposure to the disease. Nonexplicit as well as explicit versions of lessons on high-risk behavior are included.

Some people who have difficulty reading conventional print because of a learning disability may benefit from the recorded books about AIDS. They may be eligible to receive the recorded books described in the section on visual impairments. Contact the National Library Service for the Blind and Physically Handicapped (or Talking Books Plus) and Recording for the Blind for further information.

**SAFE: Stopping AIDS through Functional Education.**  
[CURRICULUM KIT.]

Child Development and Rehabilitation Center, 1990. Includes guidelines, 18 lessons, pretests and post-tests, six video segments, 5 illustrated brochures, 28 slides and illustrations, activities. \$75.00. Available on loan to professionals in Suffolk County through the Suffolk Family Education Clearinghouse.

SAFE is a multimedia instructional package for adolescents and adults who have severe learning problems secondary to mental retardation, learning disabilities, closed head injury, or mental illness. It contains information on preparing a complete HIV/AIDS prevention program, from assembling an HIV/AIDS Prevention Advisory Committee and developing policies to guide organizations in carrying out a prevention program, to providing training for both staff and clients in HIV/AIDS prevention and assessing outcomes of training. Lessons cover how people get AIDS, using universal precautions when cleaning up blood or other body fluids, saying "no" to unwanted sex, and using safe sex practice.

**SAFE: Stopping AIDS through Functional Education.**  
[BROCHURES.]

Child Development and Rehabilitation Center, 1990. Foldout. English or Spanish. \$1.00 per packet, plus 50 cents postage for each group of four packets or less. SCLS.

The simple, illustrated brochures included in the SAFE curriculum kit (see above) are also available separately in packets of 10. The titles are: "Russell Talks About the AIDS Virus," "Beverly Cleans Up Blood Safely," "Using Condorns," and "You Can't Get AIDS by Shaking Hands." A sample packet includes 2 copies of each brochure.

## PROFESSIONAL RESOURCES

### **AIDS and Adolescents with Learning Disabilities: Issues for Parents and Educators. [ARTICLE.]**

Nettie R. Bartel and Terry D. Meddock. Reading, Writing, and Learning Disabilities, Vol. 5 (1989), 299-311. SCLS.

Abstract: "Research suggests that the behavior of adolescents puts them at high risk for contracting Acquired Immune Deficiency Syndrome (AIDS). The literature on adolescents with learning disabilities suggests that certain behavioral characteristics may make them particularly vulnerable to AIDS and resistant to traditional educational approaches. [The authors] discuss the important role of parents and educators in AIDS education and the need for research on special populations for AIDS education."

### **AIDS and Persons with Developmental Disabilities: The Legal Perspective. [REPORT.]**

Sharon Rennert, John Parry, and Robert Horowitz. American Bar Association, Commission on the Mentally Disabled, and Center on Children and the Law. American Bar Association, 1989. 109 pp. \$15.00. SCLS.

Examines the major legal issues involving the rights and responsibilities of individuals with disabilities and service providers with respect to HIV infection. Major topics include: a medical overview; discrimination; HIV testing, medical treatment and informed consent; confidentiality; provider liability; isolation and involuntary civil commitment; and federal benefit and entitlement programs.

### **AIDS and State Developmental Disability Agencies: A National Survey. [ARTICLE.]**

Allen G. Marchetti, Ruth S. Nathanson, Ted. A. Kastner, and Raymond Owens. American Journal of Public Health, Vol. 80, No. 1 (January 1990), 54-56. SCLS.

This article describes a 1987 survey of state developmental disability agencies on AIDS policy development, education, and training and service provision.

### **AIDS Education for Individuals with Developmental, Learning or Mental Disabilities. [CHAPTER.]**

Lynne Stiggall. *In* The AIDS Challenge: Prevention Education for Young People, edited by Marcia Quackenbush and Mary Nelson with Kay Clark (Network Publications, 1988), 405-417. SCLS.

A concise, straightforward discussion about what students with learning or developmental disabilities need to know about AIDS; special issues such as sexual abuse, antibody testing and informed consent; special issues in educating those people who provide services, including mainstream and special education teachers; risks to these students; and current efforts and resources.

**AIDS Prevention & Management for Persons with Developmental Disabilities; The Workbook. Second and revised ed. [BOOKLET.]**

David Lynn-Hill. JLH Consulting Associates, 1988. 15 pp. \$12.00. SCLS.

This report is intended as a manual for service providers. Topics covered include policy development, confidentiality, prevention, and reduced-risk sexual education.

**Developing an AIDS Prevention Program for Persons with Developmental Disabilities. [ARTICLE.]**

Raymond Jacobs, Perry Samowitz, Joel M. Levy, and Philip H. Levy. Mental Retardation, Vol. 27, No. 4 (August 1989), 233-237. SCLS.

Discusses the particular problems that put people with developmental disabilities at risk for getting HIV infection. Describes the key principles of various models for effective AIDS prevention education programs that have been developed for other populations, and presents recommendations for adapting them for people with developmental disabilities. Reviews a model AIDS prevention education program developed by the Young Adult Institute for people with mild to moderate mental retardation.

**Forum Addresses HIV Education for Children and Youth with Special Education Needs. [ARTICLE.]**

Dianne L. Kerr. Journal of School Health, Vol. 59, No. 3, 129. SCLS.

Describes the objectives and summarizes the findings of the "National Forum on HIV/AIDS Prevention Education for Children and Youth with Special Needs."

**HIV & AIDS Prevention for People with Mental Retardation; Information for Service Providers. [PAMPHLET.]**

The Arc, 1992. Item 40-10. Fold-out. Contact for price. SCLS.

This poster-size brochure for HIV/AIDS agencies and professionals explains basic principles about mental retardation. Includes tips on modifying HIV counseling and testing and HIV prevention programs. Resource list included.

**HIV & AIDS Prevention Guide for Parents. [PAMPHLET.]**

The Arc, 1992. Item 40-9. 14 pp. \$2.50. SCLS.

This manual contains basic information for parents, including step-by-step instructions on how to talk with sons and daughters with mental retardation. Includes list of local and national organizations offering educational materials and speakers.

**The HIV Guide: Resources for Board Members and Professionals. [PAMPHLET.]**

The Arc, 1991. Item 40-6. 48 pp. \$6.00. SCLS.

This guide was developed to help executives of local and state chapters of The Arc, a national organization on mental retardation, to develop and adopt policies and procedures necessary to address AIDS and HIV infection with staff, consumers and volunteers. Includes reprints from Mental Retardation and the American Association of University Affiliated Programs.

**HIV Infection and Developmental Disabilities; A Resource for Service Providers. [BOOK.]**

Edited by Allen C. Crocker, Herbert J. Cohen, and Theodore A. Kastner. Paul H. Brookes Publishing Co., 1992. 292 pp. \$47.00. SCLS.

A collection of 33 articles which look at the medical, social, legal, and educational issues involved in the effort to provide appropriate services to people with developmental disabilities and HIV infection. The articles are divided into three sections: child and family, youths and adults, and policy considerations. A variety of materials about AIDS prevention education programs is included.

**HIV Prevention and AIDS Education: Resources for Special Educators. [BOOKLET.]**

Edited by Elizabeth Byrom and Ginger Katz. The Council for Exceptional Children (CEC) and the Association for the Advancement of Health Education (AAHE). Council for Exceptional Children, 1991. 34 pp. Singles copies free. SCLS.

This booklet was developed to help health educators and special educators who seek to teach special education students about HIV and AIDS. It includes basic information about HIV and AIDS; relevant policies, resolutions, and principles for AIDS prevention education; curriculum information for teaching about HIV infection and AIDS; and a list of additional resources. Of particular interest are the "Curriculum Review" and "Materials Review" checklists,

which are designed to help educators identify curricula and materials about HIV and AIDS which are appropriate for special education students. The "Resources" section includes professional materials as well as sources of anatomically correct and disabled dolls, body charts, and related materials.

**HIV Prevention Education for Exceptional Youth; Why HIV Prevention Education Is Important. [FACT SHEET.]**

Council for Exceptional Children, Clearinghouse on Handicapped and Gifted Children. ERIC Digest No. E 507, November 1991 (EDO-EC-91-12). 2 pp. Free. SCLS. Reprinted in Appendix E.

This fact sheet describes some of the factors which increase special education students' vulnerability for HIV infection and other sexually transmitted diseases; the status of prevention education for special learners; and the purpose of effective education about AIDS as it relates to special education students. References and additional resources are included.

**Proposed Guidelines for Agencies Serving Persons with Developmental Disabilities and HIV Infection. [ARTICLE.]**

Ted Kastner, Peter DeLotto, Bea Scagnelli, and William R. Bates. Mental Retardation, Vol. 28, No. 3 (June 1990), 139-145. SCLS.

Discusses the Association for Retarded Citizen's development of procedural guidelines for serving people with developmental disabilities living in the community and infected with HIV. Emphasizes the need for ethical decision-making and universal infectious disease recommendations that allow for the provision of services in the "least restrictive" environment.

**The Provision of Services to Persons with Mental Retardation and Subsequent Infection with Human Immunodeficiency Virus (HIV). [ARTICLE.]**

Theodore A. Kastner, Mary Lu Kickman, and Dennis Bellehumeur. American Journal of Public Health, Vol. 79, No. 4 (April 1989), 491-494. SCLS.

Presents the first reported cases of individuals with mental retardation who have subsequently become infected with HIV, and describes the implications of this finding for agencies which provide services to persons with mental retardation. Where conflicts arise, the authors propose that ethical review committees provide consultation to service agencies who must ultimately determine how they will provide for the needs of their clients.

**Q&A: HIV/AIDS and Mental Retardation. [FACT SHEET.]**

Marc Lerro. The Arc, 1991. 2 pp. \$13.00 per 100. SCLS.

Covers key concepts of HIV and mental retardation in question and answer format.

**Russell Talks About AIDS. [VIDEOTAPE.]**

The Arc, 1993. Item 40-7. 5.5 minutes. \$23.00.

A man with mental retardation and HIV talks about his life and the importance of HIV prevention. Useful for policymakers, parents and self-advocates.

**Summary of the National Forum on HIV/AIDS Prevention Education for Children and Youth with Special Education Needs; Reston, Virginia, January 31 - February 2, 1989. [BOOKLET.]**

Conducted by the Association for the Advancement of Health Education and The Council for Exceptional Children. Sponsored by the Division of Adolescent and School Health, Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control. 38 pp. Free. Available from the Association for the Advancement of Health Education. SCLS.

In February 1989, representatives of more than twenty-five national organizations and governmental offices met at the headquarters of The Council for Exceptional Children to assess the status of HIV infection and AIDS prevention education for special education students. This report provides presentation highlights and summarizes small group discussions and forum conclusions. It also includes a listing of forum participants and suggested readings.

**Supplement to AIDS Instructional Guide Grades K-12. [CURRICULUM GUIDE.]**

New York State Education Department, Office for Education of Children with Handicapping Conditions, Division of Program Development, 1990. 48 pp. Free. SCLS.

Designed to be used in conjunction with *AIDS Instructional Guide Grades K-12*, this publication provides general and special education teachers with additional suggestions and information to meet the needs of students with disabilities. The lessons are composed of teacher notes and additional information for modifying instruction in each of the lessons.



**What High School Students Who Are Mildly Mentally Retarded Know About the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome. [REPORT.]**

Hazel B. Cobb and Charles J. Horn, Jr. Presentation made at the Second International Conference on Mental Retardation, Best Practices in Mental Retardation, Davenport, IA, October 1989. ED 344 378. 16 pp. SCLS.

The results of a study of high school age students with mild mental retardation indicate that the students have some basic facts about HIV/AIDS, though probably not a full understanding of how to avoid contracting the disease. The students obtained their information primarily from the mass media (television and radio).

**V.**

**AIDS Information for People with  
OTHER DISABILITIES**

# HEMOPHILIA

## CONSUMER RESOURCES

### **Hemophilia and AIDS Network for the Dissemination of Information (HANDI). [ORGANIZATION.]**

A comprehensive information and referral network serving the needs of those affected by hemophilia/HIV, health care professionals, and the general public. Produces numerous publications.

## PROFESSIONAL RESOURCES

### **AIDS Education for the Hemophiliac Youth. [CHAPTER.]**

Donna DiMarzo. *In The AIDS Challenge: Prevention Education for Young People*, edited by Marcia Quackenbush and Mary Nelson with Kay Clark (Network Publications, 1988), 397-403.

The author discusses the demographics of AIDS and hemophilia, and their physical and psychological implications for youth with hemophilia. She suggests that AIDS prevention education for hemophiliac youths focus away from their identification with a "high risk" group and instead focus on high-risk behaviors and the need for all adolescents to be well-informed about AIDS transmission and prevention.

## MENTAL ILLNESS

Some of the problems involved in providing AIDS information and education to people with mental illness are described by Karen Sladyk, who writes: "The seriousness of [the] lack of public information is compounded when one wants to educate psychiatric patients about AIDS and safe sex, because these patients often have lower levels of insight, difficulty controlling impulses, reduced attention spans, and irrational thought processes."<sup>1</sup> Some of the consumer resources listed in the section on developmental disabilities are appropriate for these individuals. The following resources may be especially helpful for professionals who work with people who have mental illness.

### PROFESSIONAL RESOURCES

**"The stereotype of chronically mentally ill persons as asexual has had dangerous consequences - namely, the unavailability of sex education and AIDS prevention for high-risk members of this group' — "AIDS Risk in the Chronically Mentally Ill: Clinical Strategies for Prevention."**

#### **AIDS Risk and Prevention for the Chronic Mentally Ill. [ARTICLE].**

Elaine Carmen and Stephen M. Brady. Hospital and Community Psychiatry, Vol. 41, No. 6 (June 1990), 652-657.

The authors believe that stereotypes of people with mental illness as asexual or neutered have resulted in the absence of sex education and AIDS prevention as an integral part of treatment. To counter this neglect, they have developed an AIDS prevention program in a large inner-city mental health center which includes individual risk assessment, an innovative drop-in group, the distribution of condoms, and concrete instruction in their use.

#### **AIDS Risk in the Chronically Mentally Ill: Clinical Strategies for Prevention. [ARTICLE.]**

Stephen M. Brady and Elaine (Hilberman) Carmen. New Directions for Mental Health Services, No. 48 (Winter 1990), 83-95. SCLS.

Provides an overview of AIDS risk in people with chronic mental impairments; discusses HIV risk assessment evaluation; and describes the drop-in group model developed by the authors.

<sup>1</sup>Sladyk, Karen, "Teaching Safe Sex Practices to Psychiatric Patients," The American Journal of Occupational Therapy, Vol. 44, No. 3 (March 1990), 284.

**The Drop-In Group: An AIDS Risk and Prevention Program for the Mentally Ill. [CURRICULUM KIT.]**

Stephen Brady and Rita Martin. Fanlight Productions, 1991. Catalog No. CP-093. Videotape and curriculum workbook. 24 minutes. SCLS.

This training package presents an AIDS education and prevention program for people who are mentally ill. Under the direction of clinical staff, clients of the group learn about AIDS, and practice skills to reduce their risk of getting HIV. The model can also be used with other populations.

**Knowledge About AIDS Among Psychiatric Patients. [ARTICLE.]**

Jay W. Baer, Priscilla C. Dwyer, and Susan Lewitter-Koehler. Hospital and Community Psychiatry, Vol. 39, No. 9 (Sept. 1988), 986-988.

Concerned about potential difficulties in reaching people with major psychiatric illness and their possible increased risk for HIV, the authors conducted a study of the AIDS/HIV knowledge base of psychiatric inpatients. This article describes the results of the study, which has motivated increased efforts for AIDS education in the institution.

**Teaching Safe Sex Practices to Psychiatric Patients. [ARTICLE.]**

Karen Sladyk. The American Journal of Occupational Therapy, Vol. 44, No. 3 (March 1990), 284-286. SCLS.

Describes a 45-minute program about AIDS and safe sex tailored to the needs of psychiatric patients.

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**GENERAL****CONSUMER RESOURCES****Fact Sheet: HIV/AIDS Prevention for People with Disabilities.  
[FACT SHEET.]**

Sharon Wachsler. Information Center for Individuals with Disabilities, October 1991. 21 pp. \$2.00. SCLS.

This comprehensive fact sheet for people with disabilities (and their partners or caregivers) covers HIV infection and AIDS; transmission of HIV; the HIV antibody test; intravenous drug use; pregnancy and AIDS; safer sex, generally; safer sex for people with physical disabilities; HIV-infection prevention for people with mental disabilities; resources. Includes some explicit material.

**PROFESSIONAL RESOURCES****National AIDS Clearinghouse. [COMPUTER DATABASES.]**

The National AIDS Clearinghouse maintains several database files which contain information relating to people with disabilities, their families, and professionals. Of particular interest are its "Resources and Services Database," "Educational Materials Database," and "AIDS School Health Education Database." Custom searches can be conducted upon request.

**Teaching About AIDS: Youth with Sensory or Physical Disabilities.  
[CHAPTER.]**

Katherine M. Simpson. *In The AIDS Challenge: Prevention Education for Young People*, edited by Marcia Quackenbush and Mary Nelson with Kay Clark (Network Publications, 1988), 419-428. SCLS.

This overview addresses the special concerns relating to the provision of AIDS prevention education to youth with sensory and physical disabilities, and offers practical suggestions for implementing them.

# APPENDICES

**APPENDIX A****SELECTED AIDS HOTLINES  
AND INFORMATION NUMBERS****National AIDS Hotline**

(800) 342-AIDS (Voice)  
(800) 344-SIDA (Spanish)  
(800) AIDS-TTY or (800) 243-7889 (TDD)

**New York State AIDS Hotline**

(800) 872-2777 (HIV Counseling Hotline)  
(800) 541-AIDS (AIDS Tape Library)  
(516) 853-2999 (Anonymous testing and counseling  
for Suffolk County residents)  
(800) 462-6786 (Anonymous testing and counseling  
for Suffolk County residents)

**Long Island Association for AIDS Care (LIAAC)**

(516) 385-AIDS (Hotline)  
(516) 385-2451 (Business)

**People with AIDS Coalition (PWAC) of Long Island**

(516) 225-5700 (Lifeline - Voice and TDD)  
(516) 225-5797 (Business)

**Copies of this list are available in large print and braille  
from Talking Books Plus**



## APPENDIX B

### NEW YORK STATE AIDS HOTLINE TAPE LIBRARY

Tape recordings are a good source of information for people who cannot read print because of a visual or learning disability. The New York State AIDS Hotline operates a tape recorded AIDS Information Service which can be accessed by calling (800) 541-AIDS. When the operator answers, ask for the taped message by number:

#### Transmission/Prevention

- 269 Reducing Your Risk for HIV Infection and AIDS
- 280 Adolescents, Sex, HIV Infection and AIDS
- 283 Adolescents, Substance Use, HIV Infection and AIDS
- 284 IV Drug Use: HIV Infection and AIDS
- 286 HIV Infection and AIDS in the Workplace

#### Diagnosis/Treatment

- 260 The HIV Antibody Test
- 266 Diagnosis of HIV Infection and AIDS
- 289 Treatment Issues Relating to HIV Infection and AIDS
- 290 Caring for Someone with HIV Infection and AIDS

#### Women and Children

- 268 Children with HIV Infection and AIDS
- 273 Women, HIV Infection and AIDS
- 280 Adolescents, Sex, HIV Infection and AIDS
- 283 Adolescents, Substance Use, HIV Infection and AIDS

#### Miscellaneous

- 267 Care and Rights of People with HIV Infection and AIDS
- 281 Nutrition: HIV Infection and AIDS
- 288 Food Safety: HIV Infection and AIDS

#### Spanish

- 262 The HIV Antibody Test
- 264 Diagnosis of HIV Infection and AIDS
- 270 Care and Rights of People with HIV Infection and AIDS
- 271 Reducing Your Risk for HIV Infection and AIDS
- 275 Women, HIV Infection and AIDS
- 287 IV Drug Use: HIV Infection and AIDS
- 291 Caring for Someone with HIV Infection and AIDS

## APPENDIX C

### SEX, DRUGS, AND DISABILITIES: ADDITIONAL SOURCES OF INFORMATION

**"Students with disabilities are generally less knowledgeable than other students about their bodies and their sexuality. This leads to poor decision-making related to their sexuality and an inability to protect themselves."- Clearinghouse on Handicapped and Gifted Children**

AIDS prevention is inextricably tied to sex education and substance abuse prevention. In many cases, people with disabilities have special needs regarding sex education and substance abuse prevention which are not addressed by the traditional resources in these fields.

Although the scope of this publication is limited to materials specifically concerning AIDS prevention information for people with disabilities, there are many valuable resources that deal with the broader issues of sex education and substance abuse prevention. The following resources are particularly helpful in identifying these materials.

#### **CYDLINE Reviews: Issues in Sexuality for Adolescents with Chronic Illness and Disabilities. [BOOKLET.]**

National Center for Youth with Disabilities, June 1992. 47 pp. \$6.00. SCLS.

Describes bibliographic, educational and training materials about various aspects of sexuality and disability.

#### **CYDLINE Reviews: Substance Use by Youth with Disabilities and Chronic Illness. Second ed. [BOOKLET.]**

National Center for Youth with Disabilities, August 1990. 34 pp. \$6.00. SCLS.

Abstracts of articles about substance abuse by youth with mental retardation; learning disabilities and ADD; mental illness and emotional disturbances; sensory disabilities; other physical disabilities; chronic illness; and multiple disabilities. There is also a section of training materials and a treatment selection checklist.

#### **Disability, Sexuality, and Abuse; An Annotated Bibliography. [BOOK.]**

Dick Sobse, et al. Paul H. Brookes Publishing Co., 1992. 185 pp. \$24.00. SCLS.

This comprehensive bibliography describes over 1,000 publications, clinical reports, and media accounts relating to sex education, abuse, and developmental disabilities. Includes author and subject indexes.

**National Information Catalog "...Addressing the Chemical Health Needs of the Deaf and Hard of Hearing Population."**

Minnesota Chemical Dependency Program for the Hearing Impaired, n.d. 16 pp. Free. SCLS.

Lists articles, books, pamphlets, and videotapes relating to prevention/education; assessment; treatment/therapeutics; deafness and substance abuse; 12 step materials; sexuality, STD and AIDS; and general materials.

**Resource Center on Substance Abuse and Disability.**  
[ORGANIZATION.]

Provides information about print and audiovisual resources, programs, and research materials concerned with substance abuse prevention and disability. Publishes fact sheets and a newsletter.

**Sexuality and Disability; A SIECUS Annotated Bibliography of Available Print Materials.** [ARTICLE.]

James Shortridge and Laura Steele-Clapp. *SIECUS Report*, August/September 1992, 15-21. Reprints of the bibliography are available from The Sex Information and Education Council of the United States (SIECUS) for \$2.50 plus 15% postage and handling. SCLS.

This publication describes dozens of useful books for consumers, parents, and professionals concerned with sexuality and disabilities. Separate sections describe curricula, periodicals, and databases.

**Sexuality Education for Children and Youth with Disabilities.**  
[NEWSLETTER.]

*NICHCY News Digest*, Vol. 1, No. 3 (1992). 27 pp. Free from the National Information Center for Children and Youth with Disabilities. SCLS.

This special issue of the *NICHCY News Digest* addresses the concerns that parents and professionals face in informing and guiding children and young adults with disabilities in their social-sexual development. Each section presents an overview of important points to consider and concludes with an extensive list of materials that families and professionals can use to guide them more fully.

**Social-Sexuality Education for the Developmentally Disabled; Print and Audiovisual Resources.** [PAMPHLET.]

Barbara Jordan, comp. Suffolk Family Education Clearinghouse, n.d. [9 pp.] Free.

A list of audiovisual materials and print publications available from the Suffolk Family Education Clearinghouse of the Middle Country Public Library.

## MATERIALS REVIEW

The following items are related to instructional materials aimed at teaching special education students about HIV infection prevention. Check all items that apply to the materials being reviewed.

## I. Learner Characteristics

- 1. Are the materials designed to match the instructional or educational level of the target population(s)?
- 2. Are the materials appropriate for the target students' developmental levels?
- 3. Are the materials appropriate for learner's needs?
- 4. Are the materials oriented toward behavior change rather than just information transfer?
- 5. Are the materials adaptable? Are they designed such that the core information can be extracted and adapted for individual students?
- 6. Do the materials present a variety of strategies for teaching the same concept?
- 7. Are there opportunities for repetition and review?
- 8. Are terminology and vocabulary correct?
- 9. Is the language appropriate for the target audience?
- 10. Is the reading level appropriate for the target population?
- 11. Are the materials sensitive to particular features of the target population?
  - a. culture?
  - b. sexual orientation?
  - c. handicapping condition?

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## II. Orientation

- 1. Do the materials emphasize responsibility and prevention?
- 2. Are the materials sensitive to the values of the target community?

- 3. Do the materials promote compassion for individuals with HIV infection or AIDS?
- 4. Do the materials emphasize risk behaviors, rather than risk groups?
- 5. Do the materials use generic references, such as "one's partner" - avoiding use of personal pronouns?
- 6. Do the materials use appropriate terminology in referring to people with HIV infection, e.g., "people with AIDS" rather than "AIDS victims"?

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## III. Presentation

- 1. Are the design and layout of the material appealing?
- 2. Is there effective use of photographs and illustrations, and if so, are they appropriate for the target audience?
- 3. Do the materials support the use of a variety of media?
- 4. Are the teaching units well-organized?
- 5. Are various methodologies for teaching about HIV prevention described?

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## IV. Content

- 1. Do the materials support the objectives of the curriculum?

Source: Association For the Advancement of Health Education and The Council For Exceptional Children, HIV Prevention and AIDS Education: Resources For Special Educators (Reston, VA: Council for Exceptional Children, 1991), 24-25.

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Source: Association For the Advancement of Health Education and The Council For Exceptional Children, HIV Prevention and AIDS Education: Resources For Special Educators (Reston, VA: Council for Exceptional Children, 1991), 24-25.

# DIRECTORY

**DIRECTORY**

AIDS Education/Services for the Deaf  
 6565 Sunset Boulevard  
 Suite 415  
 Hollywood, CA 90028  
 (213) 383-2220 (Voice/TTY)

American Academy of Ophthalmology  
 P.O. Box 7424  
 San Francisco, CA 94120-7424  
 (415) 561-8500

American Bar Association  
 Commission on the Mentally Disabled  
 1800 M Street N.W., Suite 200 South  
 Washington, DC 20036  
 (202) 331-2240  
 (202) 331-3884 (TDD)  
 (202) 331-2220 (FAX)

American Foundation for the Blind  
 15 West 16th Street  
 New York, NY 10011  
 (212) 620-2000  
 (800) 232-5463  
 (718) 935-9647 (FAX)

American Speech-Language-Hearing  
 Association  
 10801 Rockville Pike  
 Rockville, MD 20852  
 (301) 897-5700 (Voice/TDD)  
 (800) 638-8255 (Helpline)

The Arc  
 P.O. Box 1047  
 Arlington, TX 76010  
 (817) 261-6003  
 (817) 277-0553 (TDD)

Association for the Advancement of Health  
 Education  
 1900 Association Drive  
 Reston, VA 22091  
 (703) 476-3439

Catholic Charities' Services for Blind and  
 Visually Impaired Persons  
 143 Schlegel Boulevard  
 Amityville, NY 11701  
 (516) 789-5213

Child Development and Rehabilitation  
 Center  
 CDRC Publications  
 Oregon Health Sciences University  
 P.O. Box 574  
 Portland, OR 97207-0574  
 (503) 494-7522  
 (503) 494-4447 (FAX)

The Council for Exceptional Children  
 1920 Association Drive  
 Reston, VA 22091-1589  
 (703) 620-3660  
 (703) 264-9494 (FAX)

Dallas County Health Department  
 600 Commerce, 9th Floor  
 Dallas, TX 75202  
 (214) 653-6840

Deaf Communication Foundation  
 11684 Ventura Boulevard  
 Suite 937  
 Studio City, CA 91604  
 (818) 885-4973 (Voice /TDD)

Deaf Life  
MSM Productions, Ltd.  
85 Farragot Street  
Rochester, NY 11461-2485  
(716) 328-6720 (FAX)

Eastern Paralyzed Veterans Association  
75-20 Astoria Boulevard  
Jackson Heights, NY 11370-1177  
(718) 803-EPVA  
(718) 803-0414 (FAX)

Fanlight Productions  
47 Halifax Street  
Boston, MA 02130  
(617) 524-0980  
(617) 524-8838 (FAX)

Fearon/Janus Quercus  
500 Harbor Boulevard  
Belmont, CA 94002  
(800) 877-4283  
(415) 595-8143

Gallaudet University  
Department of TV, Film & Photography  
Washington, DC 20002-3695  
(202) 651-5115 (TTY)

Gallaudet University Bookstore  
800 Florida Avenue, NE  
Washington, DC 20002-3695  
(800) 451-1073 (Voice or TDD)

Helen Keller Services for the Blind  
320 Fulton Avenue  
Hempstead, NY 11550  
(516) 485-1234  
40 New York Avenue  
Huntington, NY 11743  
(516) 424-0022

Hemophilia and AIDS/HIV (HANDI)  
Network for the Dissemination of Information  
The National Hemophilia Foundation  
110 Green Street, Suite 303  
New York, NY 10012  
(212) 431-8541  
(800) 42-HANDI (Toll-free)  
(212) 431-0906 (FAX)  
(212) 431-3081 (Message)

Information Center for Individuals with  
Disabilities  
Fort Point Place  
27-43 Wormwood Street  
Boston, MA 02210-1606  
(617) 345-9743 (TTY/TDD)  
(617) 727-5540 (Voice)  
(617) 345-5318 (FAX)

International Deaf/Tek, Inc.  
IDT Communications  
P.O. Box 2431  
Framingham, MA 01701-0404  
(508) 620-1777

JLH Consulting Associates  
711 West Balboa Boulevard  
Newport Beach, CA 92661-1105  
(714) 720-1250

James Stanfield Publishing Company  
P.O. Box 41058-S  
Santa Barbara, CA 93140  
(800) 421-6534

Kendall/Hunt Publishing Company  
4050 Westmark Drive  
Dubuque, IA 52005  
(800) 228-0810

Mid-Hudson Library System  
103 Market Street  
Poughkeepsie, NY 12601-4098  
(914) 471-6006



Minnesota Chemical Dependency  
Program for the Hearing Impaired  
Riverside Medical Center  
Minneapolis, MN 55454  
(612) 672-4402

National AIDS Hotline  
P.O. Box 13827  
Research Triangle Park, NC 27709;  
(919) 361-4622  
Hotline numbers are:  
(800) 342-2437 (voice/English)  
(800) 344-7432 (voice/Spanish)  
(800) 243-7889 (TDD) or,  
(800) AIDS-TTY (TDD)

National AIDS Information Clearinghouse  
U.S. Department of Health and Human  
Services  
Public Health Service  
Centers for Disease Control  
P.O. Box 6003  
Rockville, MD 20850  
(800) 458-5231

National Association of Visually  
Handicapped (NAVH)  
22 West 21st Street  
New York, NY 10010  
(212) 889-3141

National Braille Press  
88 St. Stephen Street  
Boston, MA 02115  
(617) 266-6160  
(617) 437-0456 (FAX)

National Captioning Institute  
5203 Leesburg Pike  
Falls Church, VA 22041  
(703) 998-2400 (Voice/TDD)  
(800) 533-9673 (Voice)  
(800) 321-8337 (TDD)  
(703) 998-2458 (FAX)

National Center for Youth with Disabilities  
Box 721 UMHC  
Harvard Street at East River Road  
Minneapolis, MN 55455  
(800) 333-6293  
(612) 626-2825

National Coalition on Deafness and HIV/  
AIDS (NCDH)  
c/o UCCD  
3333 California Street  
Suite 10  
San Francisco, CA 94143-1208  
(415) 476-4980 (Voice)  
(415) 476-7600 (TDD)

National Easter Seal Society  
70 East Lake Street  
Chicago, IL 60601  
(312) 726-6200  
(312) 726-4258 (TDD)  
(312) 726-1494 (FAX)

National Federation of the Blind  
Information Access Project for Blind  
Individuals  
1800 Johnson Street  
Baltimore, MD 21230  
(410) 659-9314

National Information Center for  
Children and Youth with Disabilities  
P.O. Box 1492  
Washington, DC 20013-1492  
(800) 999-5599  
(703) 893-6061  
(703) 893-8614 (TDD)

National Information Center on Deafness  
Gallaudet University  
800 Florida Avenue NE  
Washington, DC 20002-3695  
(202) 651-5051 (Voice)  
(202) 651-5052 (TDD)  
(202) 651-5054 (FAX)

National Library Service for the  
Blind and Physically Handicapped  
Library of Congress  
Washington, DC 20542  
(202) 707-5100  
(800) 424-8567

National Technical Institute for the Deaf  
Rochester Institute of Technology  
Public Information Office  
One Lomb Memorial Drive  
P.O. Box 9887  
Rochester, NY 14623  
(716) 475-6400 (Voice)  
(716) 475-2181 (TDD)  
(716) 475-6500 (FAX)

Network Publications  
P.O. Box 1803  
Santa Cruz, CA 95061-1830  
(408) 438-4060

New York Society for the Deaf  
Long Island Service Center  
Herricks Community Center  
Herricks Road  
New Hyde Park, NY 11040  
(516) 877-2620 (Voice and TTD)

New York State Commission for the Blind  
and Visually Handicapped  
175 Fulton Avenue, Room 300  
Hempstead, NY 11550  
(516) 564-4311

New York State Education Department  
Office for Education of Children with  
Handicapping Conditions  
Division of Program Development  
Room 1071, Education Building Annex  
Washington Avenue  
Albany, NY 12234  
No phone number available

New York State Education Department  
Office of Vocational and Educational  
Services  
for Individuals with Disabilities (VESID)  
State Office Building  
Veterans Highway  
Hauppauge, NY 11788  
(516) 360-6357  
(800) 441-0320  
(516) 360-6370 (TTY)

New York State Office of the Advocate for  
the Disabled  
1 Empire State Plaza, 10th Floor  
Albany, NY 12223-0001  
(518) 474-5567  
(800) 522-4369 (TDD)

Northeast Disability and Business  
Technical Assistance Center  
(800) 949-4232 (Voice/TDD), ADA Hotline

Paul H. Brookes Publishing Company  
P.O. Box 10624  
Baltimore, MD 21285  
(800) 638-3775

Random House Audiobooks  
Subs. of Random House Inc.  
201 E. 50th Street  
New York, NY 10022  
(800) 733-3000

Recording for the Blind  
20 Roszel Road  
Princeton, NJ 08540  
(609) 452-0606  
(800) 221-4792

Registry of Interpreters for the Deaf, Inc.  
8719 Coleville Road, Suite 310  
Silver Spring, MD 20910-3919  
(301) 608-0050 (Voice/TDD)

Resource Center on Substance Abuse, Prevention and Disability  
 1331 F Street, NW  
 Suite 800  
 Washington, DC 20004  
 (202) 783-2900 (Voice)  
 (202) 737-0645 (TDD)  
 (202) 628-3812 (FAX)

**SCLS**

*The designation SCLS indicates that the item has been acquired by the Suffolk Cooperative Library System. Suffolk County residents may borrow SCLS print books, pamphlets, periodicals and videotapes through their local public library. Suffolk County residents who are registered with Talking Books Plus may borrow SCLS recorded books (talking books) from SCLS/Talking Books Plus.*

Self Help for Hard of Hearing People, Inc.  
 7800 Wisconsin Avenue  
 Bethesda, MD 20814  
 (301) 657-2248 (Voice)  
 (301) 657-2249 (TDD)  
 (301) 913-9413 (FAX)

Self-Initiated Living Options, Inc. (SILO)  
 3241 Route 112, Bldg 7  
 Medford, NY 11763  
 (516) 698-1310 (Voice)  
 (516) 698-1392 (TDD)

Central Islip Satellite Office  
 (516) 348-0207 (Voice)  
 (516) 348-7655 (TDD)

Sex Information and Education Council of the United States (SIECUS)  
 130 West 42nd Street  
 Suite 2500  
 New York, NY 10036  
 (212) 819-9770

Suffolk County Office of Handicapped Services  
 395 Oser Avenue  
 Hauppauge, NY 11788  
 (516) 348-5340  
 (516) 582-6616 (TDD)

Suffolk Family Clearinghouse  
 Middle Country Public Library  
 101 Eastwood Boulevard  
 Centereach, NY 11729-2745  
 (516) 585-9393

Suffolk Lighthouse  
 1731 North Ocean Avenue  
 Medford, NY 11763  
 (516) 654-3525

Thorndike Press  
 P.O. Box 159  
 Thorndike, ME 04986  
 (800) 257-5755

U.S. Department of Justice  
 Office of Americans with Disabilities Act  
 P.O. Box 66118  
 Washington, DC 20035-6118  
 (202) 514-0301 (ADA general information)  
 (202) 514-0383 (TDD)

U.S. Equal Opportunity  
 Employment Commission  
 1801 L Street NW  
 Washington, DC 20507

Young Adult Institute  
 460 W. 34 Street  
 New York, NY 10001  
 (212) 563-7474