

HIV/AIDS RESOURCE LIST FOR PEOPLE WITH DISABILITIES

Listed by Disability Type

Compiled by the Health & Disability Working Group at the Boston University School of Public Health
for the Massachusetts Department of Public Health HIV/AIDS Bureau
July, 2002

GENERAL RESOURCES FOR INDIVIDUALS WITH DISABILITIES

RE: HIV/AIDS

1. CDC National Prevention Information Network (NPIN): Website designed to share HIV/AIDS, STD and TB resources and information. Includes up-to-date news and related links as well as online databases that provide immediate information about local resources and services, funding opportunities and educational materials. In order to access information relevant to people with disabilities, search for “PERSONS WITH DISABILITIES”. Information about the following disabilities are featured: blindness and visual impairments, deafness and hearing impairments, developmental disabilities, hemophilia and mental disabilities.
<http://www.cdcnpin.org>
2. Combined Health Information Database (CHID): Database produced by health-related agencies of the federal government. The database provides information and resources on HIV/AIDS, STDs and TB for a variety of audiences, including persons with disabilities. Search for keywords “HIV” and “AIDS” and “disabilities” to find information related to people with disabilities.
<http://www.chid.nih.gov/>
3. AIDS Education Global Information System (AEGIS): Internet website which provides “readily and widely disseminated information” about HIV/AIDS. Information regarding HIV/AIDS and mental illness, mental retardation, deaf and hard of hearing, as well as spinal cord injury, can be accessed by searching the AEGIS database with those words as keywords.
<http://www.aegis.com>
4. Sexuality Information and Education Council of the U.S.(SIECUS): SIECUS provides sexuality information to healthcare professionals, educators, policy makers, students and the general public. Under a federal grant from the CDC, SIECUS has initiated a National AIDS Education and Information program. SIECUS also produced in 1995 an annotated bibliography titled “Sexuality and Disability”, available through their website. The search goes as follows: in “publications”, search “annotated bibliography” for “sexuality and disability” and then “books for professionals”.
<http://www.siecus.org>

5. Educational Resources Information Center (ERIC) database: The ERIC database, the world's largest source of education information, contains more than one million abstracts of documents and journal articles on education research and practice. By searching AskERIC's web-based version of the ERIC Database, you can access the ERIC abstracts which are also found in the printed medium, *Resources in Education* and *Current Index To Journals in Education*. The database is updated monthly, ensuring that the information you receive is timely and accurate. Do an Advanced Search for the keywords "HIV" and "Mental Health"; "HIV" and "Mental Retardation"; "HIV" and "Special Education"; "HIV" and "Deaf"; "HIV" and "Physical Disabilities" (No records found for "HIV" and "Blind").

<http://askeric.org/eric/>

RESOURCES FOR INDIVIDUALS WITH MENTAL ILLNESS RE: HIV/AIDS

Organizations:

1. Vinfen (LOCAL): Private and nonprofit human services organization that provides a wide array of programs and facilities to help people with disabilities live independently and with pride. Their program includes a more comprehensive HIV/STD curriculum for both staff and consumers. Vinfen also funds, in the first state partnership of its kind with the Department of Mental Health, a treatment residence in downtown Boston for persons with HIV and mental health issues.

CONTACT: Michelle Howden, Director of Services--MH and HIV
950 Cambridge St,
Cambridge, MA 02141
Tel: 1- 877-2VINFEN
Fax: 617 441-1858
TTY: 617 225-2000

2. Zinberg Clinic (LOCAL): An HIV/AIDS Clinic within the Cambridge Health Alliance, which provides mental health services to their clients. Maintains a large community of referral networking, care coordination and mental health clinicians onsite. They increase their awareness of disability-specific issues through regular trainings.

CONTACT: Jean Haley
Zinberg Clinic
Cambridge Health Alliance
1493 Cambridge Street
2nd Floor, Cahill Building
Cambridge, MA 02139
Tel: 617 665-1606

Internet/Websites

1. National Alliance for the Mentally Ill: This website offers general information for people with mental illness, including fact sheets on HIV/AIDS and other relevant health and medical information for persons living with mental illness and HIV/AIDS.
<http://www.nami.org>
2. National Institutes of Mental Health (NIMH): Website that provides information about current research into mental health issues, including information about research into the psychosocial aspects of living with HIV/AIDS.
<http://www.nimh.nih.gov>
3. American Psychiatric Association AIDS Resource Center: Provides education and training, resources, information and policies as well as a network of clinical expertise on the mental health dimensions of HIV/AIDS. Coordinates the AIDS Education Project, which offers educational activities, develops curricular materials and links practitioners with HIV-related support and professionals. Also coordinates the APA Commission on AIDS, established to guide the development and implementation of APA's organizational response to AIDS epidemic. The material directly related to mentally ill individuals can be found by choosing to search "all" of the database under the specific heading: "people living with mental illness".
www.psych.org/aids

American Psychiatric Association, AIDS Program Office
1400 K Street
NW, Washington, DC 20005
Tel: (202) 682-6163
Fax- (202) 789-1874
AIDS@psych.org

Print Materials

1. NAMI General Guidelines for Treatment: Developed by the National Alliance for the Mentally Ill, guidelines indicating the characteristics of care needed by individuals with mental illness in order to have their needs met and ensure them access to integrated systems of care, education and rehabilitation.
2. NAMI Legal Guidelines Concerning the Care and Treatment of People with Mental Illness: Policy regarding the right to treatment as well as the right to make one's own decisions regarding medical treatment.
3. HIV/AIDS Staff Training Course Outline: In-depth curriculum for training staff around HIV/AIDS/MH issues. This outline is also adapted for Vinfen consumers. Developed by Vinfen. For further information, contact Michelle Howden (**SEE ORGANIZATIONS LISTING ABOVE**).

4. Resident Confidentiality Statement: Description of policy, purpose and procedures related to individual records and protection of information, as well as exceptions to confidentiality requirements.
Developed by Vinfen.
5. Vinfen Risk Assessment Form: Person served risk assessment for sexually transmitted diseases. Also includes guidelines for assessing general sexual behavior. Adapted from DMH guidelines.
6. Department of Mental Health's HIV/AIDS Testing and Counseling for Patients and Clients: Counseling and testing guidelines developed by the Massachusetts Department of Mental Health around HIV/AIDS. This policy sets out minimum requirements for staff training and Patient and Client education about HIV/AIDS related issues. In addition, it clarifies and interprets statues related to HIV/AIDS that protect the confidentiality of HIV testing.
7. CDC Revised Guidelines for HIV Counseling, Testing and Referral: Set of guidelines, issued by the Center for Disease Control and Prevention, and adopted by the Department of Public Health.
8. HIV Testing and Counseling of VA Patients: A chapter from the Veteran Health Association's HIV Prevention Handbook. Of particular interest is the in-depth procedure outlined for assessing competency during the consent process. This is useful for consumers who may have cognitive impairments due to mental illness. Developed by the Veteran's Health Association
9. Psychiatric and Neurologic Conditions: References and Suggested Reading
Bibliography of resources found in *Mental Health Care for People Living with or Affected by HIV/AIDS: A Practical Guide* by Catherine Acuff et al (1999), Research Triangle Institute, www.RTI.org .
10. Greater Lynn Mental Health and Retardation Association Inc. MH HIV/AIDS Infectious Disease Policy and Procedures: Policy that establishes GLMHRA standards and procedures regarding the identification, care and treatment of individuals with infectious diseases as well as procedures for infection control.

**RESOURCES FOR INDIVIDUALS WITH MENTAL RETARDATION/
DEVELOPMENTAL DISABILITIES RE: HIV/AIDS**

Organizations:

1. Association for Retarded Citizens of the United States: Educates adults with mental retardation and their parents and peers about HIV/AIDS prevention and provides prevention education and policy training to healthcare workers who serve people with mental retardation. ARC also produces and distributes educational resources for adults with mental retardation and for HIV/AIDS service providers.

Association for Retarded Citizens of the United States
500 East Border Street, Suite 300
Arlington, TX 7010 (Street address)
P.O. Box 1047
Arlington, TX 76004 (Mailing address)
800-433-5255 (English Toll-Free)
817 261-6006 (Main)
817 277-0553 (TTY)
817 277-3491 (Fax)
theca@metronet.com
<http://www.thearc.org/welcome.html>

2. Toward Independent Living and Learning, Inc. (TILL, Inc.) (LOCAL): Local agency that provides materials and resources for sexuality education for consumers with mental retardation.

TILL, Inc.
CONTACT: Ellen Erdwein, Sexuality Trainer
East Brook Executive Park
20 Eastbrook Road, Suite 201
Dedham, MA 02026-2056
781 302-4600

3. Fernald Metro Region Services (LOCAL): Provides sexuality counseling to consumers with mental retardation, both individually and in groups (DMR clients only). DMR also coordinates staff orientation out of the training department for DMR agencies and provider programs around HIV/AIDS issues specifically related to people with mental retardation.

CONTACT: Frank Hurley, Sexuality Counselor re: consumer education
(781) 314-7507
CONTACT: Mary Jo Veling, Training Department re: staff training
(781) 314-7556
Fernald Metro Region Clinical Services, Department of Mental Retardation
200 Trapelo Rd.
Waltham, MA 02452-6302

4. Planned Parenthood of Massachusetts (LOCAL): State-wide agency providing train-the-trainer curriculum for staff and consumer education for individuals with mental retardation.

1055 Commonwealth Avenue
Boston MA 02215
Tel: 617 616-1660
Fax: 617 616-1665
TTY: 617 787-3276

5. Berkshire County ARC (BCARC) (LOCAL): One of the only Massachusetts ARCs known to employ a part-time sexuality educator to provide prevention education to consumers, staff, and parents. Curriculum consists of both original materials and adapted materials from other sources. Has also developed a 15-page policy manual, pending agency approval, that addresses the consent process, and rights and responsibilities for both consumers and staff.

CONTACT: Bob Gray, Sexuality Educator
Berkshire County Arc (BCARC)
395 South Street
P.O. Box 2
Pittsfield, MA 01202
Tel: 413 499-4241
Fax: 413 445-7863
Email: bcarc@bcarc.org

6. Bay Cove Human Services (LOCAL): Runs a residence for dual-diagnosis individuals with MR and MI or MR and HIV. Provides internal case management for quality care coordination. Also provides individually-adapted education to all consumers.

CONTACT: Mary Jo Cooper, Director of Program Services
Bay Cove Human Services
66 Canal Street
Boston, Massachusetts 02114
Phone (617) 371 3000
Fax (617) 371 3100

Print Materials

1. Training Materials: Circle of Relationships: Verbal, visual and gesture cues for training individuals with mental retardation. Also includes, but not limited to, sexuality topics.
Circle of Relationships used (but not developed) by Berkshire County Arc, TILL, Inc, and Fernald Metro Region Services. For more information, contact Ellen Erdwein at TILL (**SEE ORGANIZATIONS LISTING ABOVE**)

2. Social/Sex Education Core Curriculum: Teaching curriculum that includes self-awareness, understanding of bodily functions, relationship with other and medical aspects of sexuality.
Developed by Berkshire County Arc. For more information, contact Bob Gray **(SEE ORGANIZATIONS LISTING ABOVE)**
3. Materials and Resources for Sexuality Education for Consumers with Mental Retardation: Bibliographic and resource compilation for teaching sex education to individuals with mental retardation. Easily available and in keeping with guidelines offered for a sex education program.
Compiled by Toward Independent Living and Learning Inc.
4. Individual Socialization/Sexuality Risk Assessment: Sexuality assessment tool for individuals with mental retardation. Topics include anatomy, menstruation, reproduction, pregnancy, birth control and sexual behavior. Currently used with DMR clients only.
Developed by the Department of Mental Retardation. For more information, contact Frank Hurley at the Fernald Center **(SEE ORGANIZATIONS LISTING ABOVE)**.
5. Socialization and Sexuality Group: Curriculum overview for sexuality education groups. Each session talks about a different topic, including relationships and privacy issues, physiology, goals, choices and feelings, peer pressure and consent. Currently used with DMR clients only.
Developed by the Department of Mental Retardation. For more information, contact Frank Hurley at the Fernald Center **(SEE ORGANIZATIONS LISTING ABOVE)**.
6. Sexuality Training for Staff and Parents: Materials aimed at training staff and parents of individuals with mental retardation. Materials include considerations regarding consent, a sex questionnaire for parents, a personal attitude test, a test of attitudes toward the sexuality of persons with disabilities.
Developed by Berkshire County Arc. For more information, contact Bob Gray **(SEE ORGANIZATIONS LISTING ABOVE)**.
7. Safety First Teaching Tool: Comprehensive multi-media teaching tool to address safety issues with individuals who have developmental disabilities who work and/or live alone in the community. This program covers social safety skills, ways to prevent physical and sexual abuse, effective ways to be safe when out alone in the community. It includes 135 color slides divided into 19 teaching segments and a spiral bound instructor manual.
Developed by Toward Independent Living and Learning, Inc. (TILL, Inc.). For more information, contact Ellen Erdwein **(SEE ORGANIZATION LISTING ABOVE)**.

8. Stopping AIDS through Functional Education (SAFE): Comprehensive curriculum package designed to provide people who have developmental disabilities with information that can protect them from HIV infection. For more information, contact Ellen Edwein (**SEE ORGANIZATION LISTING ABOVE**).
9. AAMR Policy Statements: Series of guidelines developed by the American Association of Mental Retardation regarding the rights of people with mental retardation to advocate for themselves, and to self-determination in every aspect of decision-making that affects them as individuals.
10. Greater Lynn Mental Health and Retardation Association Inc. MH HIV/AIDS Infectious Disease Policy and Procedures: Policy that establishes GLMHRA standards and procedures regarding the identification, care and treatment of individuals with infectious diseases as well as procedures for infection control.
11. AIDS Prevention: Universal Precautions, a User's Guide (Guide and Video Cassette): A printed guidebook with a 37-minute video, designed for staff orientation at DMR agencies and provider programs around HIV/AIDS issues specifically related to people with mental retardation. Developed by the Department of Mental Retardation in conjunction with the Shriver Center. For more information, contact Mary Jo Veling at the Fernald Center's Training Department (**SEE ORGANIZATIONS LISTING ABOVE**).
12. Self Determination and Medical Decision Making for People with Cognitive Limitations: Report describing a policy model around informed consent and medical decision making for people with mental retardation. By Judy Levy, in conjunction with the Kennedy Krieger Institute.

Kennedy Krieger Institute
707 North Broadway
Baltimore, MD 21205
Toll Free: 1 888-554-2080

13. Healthcare Concerns for Individuals with Mental Retardation and Developmental Disabilities: General assessment of barriers to healthcare for people with mental retardation and developmental disabilities. Includes case studies, as well as a list of health care concerns to prioritize, such as sexual health (ie. safer sex practices to prevent STD's) and infection control to prevent Hep B, HIV, and TB. Different authors, compiled by ARC of Massachusetts.
14. HIV Testing and Counseling of VA Patients: A chapter from the Veteran Health Association's HIV Prevention Handbook. Of particular interest is the in-depth procedure outlined for assessing competency during the consent process. This is useful for consumers who may have cognitive impairments. Developed by the Veteran's Health Association

15. HIV Infection and Developmental Disabilities: A Resource for Service Providers:

This book provides a comprehensive look at HIV/AIDS for children, youth, and adults with developmental disabilities. Although written several years ago, the content is diverse and still highly relevant today. Topics covered include: educational programming, developing policies and procedures, confidentiality, and consent.

Edited by Allen C. Crocker, Herbert J. Cohen, and Theodore A. Kastner.
Balitmore : P.H. Brookes Pub. Co., c1992

RESOURCES FOR DEAF INDIVIDUALS RE: HIV/AIDS

Organizations:

1. CDC National AIDS Hotline TTY Service: Toll-free service available to people with hearing disabilities 24 hours a day. The hotline provide callers with confidential information, education, and referrals to AIDS and HIV infection.

American Social Health Association

P.O. Box 13827

Research Triangle Park, NC 27709

800-342-AIDS

TTY: 800 243-7889

nahl@asha.emcdc.gov

<http://www.ashastd.org> (American Social Health Association). This website also provides a chat room for deaf individuals re: HIV/AIDS, as well as an HIV/AIDS videotape resource list and a published research list for this population--go to:

www.ashastd.org/nah/tty.html

2. National Deaf Education Center (NDEC): Provides fact sheets and HIV prevention education for deaf people.

Gallaudet University

800 Florida Avenue, NE

Washington, DC 20002-3695

202 651-5051 (Main)

202 651-5052 (TTY)

3. AIDS Education Services for the Deaf (AESD): Provides quality education and HIV-related services to the deaf. AESD also provides brochures, fact sheets and videos.

Greater Los Angeles Council on Deafness

2222 Laverna Avenue

Los Angeles, CA 90041

323 478-8005 (Voice/TTY)

4. Deaf AIDS Project: Helps deaf and hearing-impaired people with HIV/AIDS to obtain services such as counseling, referrals, living support, interpreting, assistive devices and HIV/AIDS prevention education

Deaf AIDS Project

University of California San Francisco (UCSF), Center on Deafness
3333 California Street, Suite 10
San Francisco, CA 94143-1208
415 476-4980 (Voice)
415 476-7600 (TTY)

4.1 Deaf AIDS Center: program of Deaf Communities Together in collaboration with Deaf AIDS Support Services at UCSF Center on Deafness. Deaf AIDS Center provides proactive support and services in a safe environment. Services include preventive education, video tape library, brochures and materials, referral information, outreach and networking systems.

415 476-7113

<http://www.queernet.org/dbs/dac/>

5. New York Society for the Deaf Ryan White Case Management Program: Ensures that people who are deaf or deaf-blind and who are living with AIDS receive the same quality and range of services as other people with HIV/AIDS

817 Broadway, Seventh Floor
New York, NY 10003
212 777-3900 (Voice, TTY)
212 777-5740 (Fax)

6. Developmental Evaluation and Adjustment Facilities, Inc. (D.E.A.F. Inc.)
(LOCAL): Multi-service community-based agency run by and for people who are Deaf or Hard of Hearing in Massachusetts. Runs an AIDS project called “The HOPE Program”, which provides case management services; information and referral to other health and human services including HIV/AIDS testing; education materials re: HIV/AIDS and other health related issues; educational workshops on various health topics; advocacy while accessing the medical system; and peer support for deaf and hard of hearing people living with HIV/AIDS.

The Hope Program
D.E.A.F. Inc
215 Brighton Ave
Allston, MA 02134
V/TTY: 617 254-4041 or (800) 886-5195
Fax: 617 254-7091

Internet/Websites:

1. Deaf Source: Internet guide to resources for helping professionals who work with Deaf and Hard of Hearing individuals. This particular resource page provides videos, articles, documents and publications about HIV/AIDS, as well as their availability across the United States.
<http://home.earthlink.net/~drblood/hivaids.htm>

Print Materials

1. The Hearing Loss Awareness Project, Readings and Resources: Although not directly related to HIV/AIDS, this is a useful compilation of books and literature, as well as self help group information for deaf and hard of hearing people. Compilation sponsored by D.E.A.F. Inc. in cooperation with the Hearing Rehabilitation Foundation.
2. Healthcare Delivery for Deaf and Hard of Hearing Patients Bibliography: Although not limited to HIV/AIDS, this bibliography provides a wealth of information for medical treatment of individuals who are deaf or hard of hearing, including an article on the second page regarding HIV education for the deaf. Developed by the National Deaf Education Network and Clearinghouse at Gallaudet University's Laurent Clerc National Deaf Education Center.
3. Working with Deaf and Hard of Hearing Patients: A Guide for Medical Professionals (3rd Ed.): This resource is not specifically HIV/AIDS focused, but provides a good foundation regarding the practical considerations in the medical treatment of people who are deaf and hard of hearing. Developed by D.E.A.F. Inc. (2001)
4. The Deaf & Hard of Hearing and HIV/AIDS—Federal HIV/AIDS Bureau Fact Sheet: This fact sheet highlights the surveillance, critical issues, CARE Act programs, and resource reports of HIV/AIDS among the deaf and hard of hearing . Resources available include: report entitled, *HIV and the Deaf Population in the United States*, regarding diagnosis and care; report from the National Meeting on HIV/AIDS and the Deaf and Hard of Hearing Community (Nov, 2000), which outlines next steps to raise awareness and increase access to services; and a special publication of HRSA Care ACTION on HIV/AIDS in this community, available online.

RESOURCES FOR BLIND INDIVIDUALS RE: HIV/AIDS

Organizations [Note: most are not specifically related to HIV/AIDS]

1. Center for the Partially Sighted: Located in CA, this local agency provides comprehensive rehabilitation services for persons who become visually impaired as a result of HIV infection.

702 Wilshire Boulevard, Suite 200
Santa Monica, CA 90401-1713
310 458-3501

2. Horizons for the Blind: A not-for-profit organization with the capabilities of translating HIV/AIDS material and information in Braille.

2 North Williams Street
Crystal Lake, IL 60014
Tel: 815 444-8800
<http://www.horizons-blind.org/>

3. National Library Service for the Blind and Physically Handicapped: This service provides, free of charge, recorded and Braille materials to persons with visual impairments.

Library of Congress
1291 Taylor Street, NW
Washington, DC 20542
202 707-5100 (Main)

4. Recording for the Blind: Provides textbooks, library services and other educational services to individuals who cannot read regular print because of a visual, perceptual or physical disability.

Recording for the Blind
Roszel Road
Princeton, NJ 08540
609 452-0606 (Main)
800-221-4972 (Book only)

5. American Printing House for the Blind: Provides material for persons who are blind, including textbooks and magazines, in Braille and large print. APH also records books and produces educational tools such as Braille writing and embossing equipment, computer software and hardware, and low-vision aids.

1839 Frankfort Avenue
Louisville, KY 40206-0085
502 895-2405

RESOURCES FOR INDIVIDUALS WITH PHYSICAL DISABILITIES RE: HIV/AIDS

Organizations

1. Boston Community Medical Group (BCMG): A small medical group practice of doctors and nurse-practitioners that specializes in working with people with physical disabilities, including providing treatment for HIV/AIDS. They also offer ongoing health and risk reduction education to patients.

CONTACT: Mary Glover, Registered Nurse Practitioner
Boston Community Medical Group (BCMG)
88 East Newton St, F42
Boston, MA 02115
Tel: (617)-638-7062

No other specific resources were found for people with physical disabilities, re: HIV/AIDS. However, Independent Living Centers are willing to disseminate information via their consumer resource service. Local ILCs are listed as follows:

1. Massachusetts Statewide Independent Living Council
374 Congress Street
Suite 301
Boston, MA 02210-1807
Tel:
Fax: 617 482-8099
2. AD LIB, Inc.
215 North Street
Pittsfield, MA 01201
Tel: 413 442-7047
3. Boston Independent Living Center
95 Berkeley Street
Suite 506
Boston, MA 02116
Tel: 617 338-6665
4. Center for Living and Working, Inc.
484 Main Street
Suite 435
Worcester, MA 01608
Tel: 508 798-0350

5. CORD
1019 Itannogh Rd. #4
Hyannis, MA
02601
Tel: 508 775-8300

6. Independent Living Center of the North Shore and Cape Ann Inc.
27 Congress Street
Suite 107
Salem MA 01970
Tel: 978 741-0077

7. Independence Associates, Inc.
55 City Hall Plaza
Brockton, MA 02401
Tel: 508 875-7853

8. Southeast Center for Independent Living
66 Troy Street
Merrill Building
Fall River, MA 02720
Tel: 508 679-9210

9. Stavros Center for Independent Living
691 South East Street
Amherst, MA 01002
Tel: 413 256-0473

In addition to Independent Living Centers, the Greater Boston Chapter of the National Spinal Cord Injury Association is another resource to disseminate HIV/AIDS-related information to their spinal cord injured clients.

Greater Boston Chapter of national Spinal cord Injury Association
2 Rehabilitation Way
Woburn, MA 01801
Tel: 781 933-8666
Fax: 781 933-0043
Email: sciboston@aol.com

NB: *Please be aware that websites may change without notice; those presented here are confirmed to be accurate at of July, 2002.*

NB: *This list is not comprehensive. If you are aware of other resources, please let us know and we will be happy to incorporate them.*

NB: *All print materials and local organizations were listed with permission.*