



HIV/AIDS & Disability: Capturing Hidden Voices



The World Bank/Yale University
Global Survey on HIV/AIDS and Disability

Global Survey on HIV/AIDS and Disability

April 2004

Nora Groce, Ph.D.
Global Health Division
Yale School of Public Health
60 College Street
New Haven, Connecticut
06520

Telephone: 203-785-2866
Fax: 203-785-6193

Project website: <http://cira.med.yale.edu/globalsurvey>

This research paper was prepared as part of the World Bank's Global HIV/AIDS Program, in collaboration with the Office of the Advisor on Disability and Development. The research was conducted by Dr. Nora Groce of Yale School of Public Health under the supervision of Dr. Debrework Zewdie, of the Global HIV/AIDS Program and the Hon. Judith Heumann of Office of the Advisor on Disability and Development at the World Bank. The author would like to acknowledge Laura Cooley, PhD, Joan MacNeil, PhD, and Pamela Dudzik of the World Bank; faculty and staff at the Yale Center for the Interdisciplinary Study of AIDS (CIRA); and Bernadette Thomas, Willyanne DeCormier, and Reshma Trasi of the Global Health Division, Yale School of Public Health.

1/09/04

HIV/AIDS and Individuals with Disability

The Yale University/World Bank Global Survey on HIV/AIDS and Disability

Rationale/Background

It is commonly assumed that individuals with physical, sensory (deafness, blindness), or intellectual disabilities are not at high risk of HIV infection. They are incorrectly believed to be sexually inactive, unlikely to use drugs or alcohol, and at less risk of violence or rape than their non-disabled peers. (1,2) Risk factors for individuals with mental illness have received more attention, but research and programming for this population still lag behind that available for the general population. (3-8) Yet a growing literature indicates that individuals with disability are at equal or increased risk of exposure to all known risk factors. It is argued here that there is a pressing need for research and for better general and disability-specific services for individuals with disability. This study critically reviews the known social, economic, and medical risks associated with living with a disability with reference to implications for HIV infection and proposes a three-tiered typology of intervention.

According to the World Health Organization (WHO), one person in every ten, 600 million individuals, live with a disability significant enough to make a difference in their daily lives. (9) Eighty percent live in the developing world, with a larger proportion in rural rather than urban areas. (10) They are among the most stigmatized, poorest, and least educated of all the world's citizens. (11)

Disability is often addressed as a medical concern. While some individuals with disability do have health issues and rehabilitation needs, there is a growing realization that the greatest problems they face are social inequity, poverty, and lack of human rights. (12) Indeed, the United Nations has clearly stated that one can be both disabled *and* healthy. (9, 12)

Strikingly little is known about HIV/AIDS within disabled populations. Only a handful of prevalence studies, all from North America, has been published. However, findings from these studies raise serious concerns. For example, a small survey from the United States reported an HIV infection rate among deaf individuals twice that of the surrounding hearing population. (13) In the early 1990s, infection rates among institutionalized schizophrenic women in two urban hospitals were between 5% and 9%. (14) Collins *et al.* report that AIDS is now the leading cause of mortality among women with psychiatric illness in New York City. (5) There are few comparable studies on HIV prevalence rates among disabled populations in the developing world. (15) Mulindwa, using STDs as a proxy for potential HIV exposure, conducted a study on Uganda and found that 38% of women and 35% of men with disability reported having had an STD at one time. (16)

Moreover, the AIDS epidemic may increase disability rates. The disabling effects of AIDS on previously non-disabled individuals are well established, but other sequelae have received less attention. (17) For example, in-utero exposure to the HIV virus can cause significant developmental delays. (18) There is only a limited, though often innovative, group of articles and small-scale reports on AIDS education and intervention strategies for disabled populations. (19-22)

While there is no large body of research, anecdotal evidence from disability advocacy groups points to significant and unreported rates of HIV infection, disease, and death. Indeed, the extent of the problem in sub-Saharan Africa prompted Johnson to state unequivocally that efforts to provide rehabilitation services to disabled populations "are no longer possible" unless HIV issues are addressed. (23)

In accordance with WHO guidelines, "disability" is defined in this document as individuals with physical, sensory, intellectual, or mental health impairments that have a significant and long-lasting effect on the individual's daily life and activities.

A cursory review of the literature confirmed that, while considerable attention was paid to the disabling effects of HIV/AIDS on previously healthy people, there was nearly no mention of the impact of the AIDS epidemic on people with a pre-existing disabling condition.

Purpose

This research project, based at the Yale School of Public Health, through the Center for Interdisciplinary Research on AIDS (CIRA), sought to do the following:

- 1) Assess current state of knowledge about the impact of HIV/AIDS on individuals with disability and on disabled populations;
- 2) Document current activities related to HIV/AIDS and disability worldwide;
- 3) Identify models of good interventions currently in place or in the planning stage;
- 4) Identify gaps in the current system where individuals with disability are overlooked or systematically excluded from HIV/AIDS outreach efforts, service delivery, etc.

Methodology

Collection of the data involved the following methodologies:

- 1) All relevant literature was searched for scientific articles on HIV/AIDS as it relates to individuals with disability and to disabled populations.
- 2) All relevant literature and Internet sources were searched to identify resources, training manuals, and researchers currently working on HIV/AIDS issues within disabled populations.
- 3) A survey on HIV/AIDS was developed and disseminated via e-mail and ground mail, and the initial results of the survey were analyzed.

Data Collection

Because so little attention had been paid to the threat of HIV/AIDS among individuals and populations with disability, it was felt from the outset of this study that a widely disseminated survey would be helpful in determining whether disability and AIDS advocacy groups, service organizations, and government ministries were aware of the threat of AIDS to disabled populations. The survey also sought to discover whether AIDS outreach efforts are reaching

individuals or populations with disability, either as members of the general population or through more targeted, disability-oriented efforts. The survey was also designed to determine whether individuals with disability were being included, and if not, why. Where individuals with disability were included, attention was also directed toward ascertaining what types of programs were available to them and whether any assessment had been made of the efficacy of these programs.

The following were surveyed:

- 1) organizations and groups working with individuals with disability
- 2) organizations and groups working with disabled populations
- 3) organizations and groups working on HIV/AIDS issues for the general population;
- 4) ministries of health, education, and other government programs

The survey involved a series of questions (*see* Appendix B), but concentrated on determining the answers to two key questions:

- 1) Do organizations regularly involved with disability issues consider HIV/AIDS a significant problem? If yes, why? If not, why not?
- 2) Do HIV/AIDS education, prevention, intervention, and services delivery organizations consider individuals with disability at risk? If yes, why? If not, why not?

A series of follow-up questions were then asked of both groups –

- 1) What types of policies, programs, and interventions does the organization have in place to ensure inclusion of individuals with disability?
- 2) What groups/ individuals within the disabled population does the responding organization find are reached by these policies, programs, and interventions? How does the organization know that these individuals are actually being reached?

The survey was written in English and translated into the following languages: Spanish, French, Chinese (Mandarin), Arabic, and Swahili. Consultation with experts on computer accessibility also ensured that the survey was formatted to allow easy access for blind users.

An announcement of the survey followed by the survey itself were e-mailed or mailed to 2800 sites. The names on the listserv and mailing lists were compiled from a series of listservs that targeted specific and general disability and AIDS organizations. The survey was also copied and disseminated widely via publication in the newsletters and on the websites of various advocacy organizations, such as Disabled Peoples' International, World Federation of the Deaf, the Gay Men's Health Alliance, Rehabilitation International, Disability Awareness in Action (London) and Handicap International (Paris), World Federation of Psychiatric Users, and some 20 additional organizations of varying size. Inclusion on such sites increased dissemination of the survey to an estimated additional 2500-3000 sites.

The survey was sent to organizations that included:

- 1) Governmental organizations
 - a) United Nations
 - b) National governments/ministries of health

- 2) Non governmental organizations:
 - a) Disability advocacy organizations
 - b) AIDS outreach organizations
 - c) Community-based rehabilitation (CBR) organizations
 - d) Disability service organizations
 - e) Medical and rehabilitation organizations

The completed surveys returned included:

- 1) 476 fully completed surveys or e-mail responses with useable (quantifiable) information
- 3) 678 e-mail follow ups with additional information
- 4) Information on individuals with all types of disabilities represented, including physical, sensory, intellectual, and mental health impairments.

The responses were distributed as follows:

- 1) 34% from governments (local/regional/national)
- 2) 37% from NGOs

- 3) 22% from medical and/or rehabilitation facilities
- 4) 5% from researchers involved in some aspect of disability and/or HIV/AIDS research
- 5) 2% from individuals with disability who are HIV positive *

Responses came from 57 countries, ranging from small programs in the Faroe Islands to large programs in India and Bangladesh serving more than 100,000 people. The distribution, as of January, 2004, was as follows:

- 1) 43% Sub-Saharan Africa
- 2) 21% Asia (India, Bangladesh, Pakistan, Afghanistan, Thailand, Myanmar, Australia, Sri Lanka, etc.)
- 3) 15% Europe
- 4) 10% North America
- 5) 8% Latin America
- 6) 3% Pacific Island

Only limited responses were received from mainland China.

Project Timeline

The scientific literature was reviewed between January and February 2003, and the search is ongoing. Some 78 articles were located and reviewed and a state of the field summarized. An

* Individuals were not the focus of this particular survey, nor were the questions asked in the survey intended to elicit answers of a personal nature. Indeed, the cover letter accompanying the survey expressly stated that personal information was not being sought. Nonetheless, a handful of people wrote to share their personal experiences. This information was received with the understanding that the names and specific, identifying details would remain confidential. In all but two cases, these individuals were disability advocates or health care workers who had received the survey at work and wanted to elaborate in a more personal way about things that they had experienced.

Internet search for any information, training manuals, or reports related to HIV/AIDS and disability was also initiated at that time and is ongoing. Some 27 different training manuals, videos, and handouts have been identified thus far, and the materials are currently being assembled for inclusion on the website (<http://www.globalsurvey.med.yale.edu>). Responses to this study have been much greater than anticipated. The survey itself was written, refined, and piloted in April-May 2003, following a review of current survey materials and resources related to HIV/AIDS knowledge, policies, and practices. The survey was first disseminated on June 1, 2003 via electronic or ground mail where websites did not exist. Subsequent mailings have been made as potential new sites have been identified – the most recent, as noted above, was an attempt to redistribute to China. Responses were initially strong and then slowed through the summer. In early fall, a second appeal was made for respondents via email on November 15, 2003 to those on our listserv, resulting in a significant number of new replies.

Findings to Date

Risk Factors

Individuals with disability were at significant risk of becoming HIV infected in all countries surveyed. While data analysis is ongoing, the following interim conclusions can be drawn based on the survey data analyzed. All risk factors associated with HIV are increased for individuals with disability.

1) Poverty

- a) Even among the very poor, it is generally recognized that those with disability are the poorest members of the community. (11)
- b) As James Wolfensohn has noted: “unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy a chance to achieve a primary education by the same date.” (24)
- c) There is a cycle of disability and poverty: the poor are more likely to become disabled due to poor nutrition, lack of medical care, dangerous housing, injuries on the job, and violence.
- d) The World Bank estimates that individuals with disability may account for as many as one in five of the world’s poorest. (11)

2) Lack of education

- a) Children with disability are shut out of education because they are not considered in need of an education, are assumed to be a distraction in schools, or because it is believed that they are not capable of learning.
- b) Schools are physically inaccessible.
- c) As a result, the global literacy rate for all individuals with disability may be as low as 3% and as low as 1% for disabled women. (7)
- d) Even if in school, disabled children and adolescents are less likely to receive science and health education, and are more likely to be excused from sex education courses. (5)
- e) According to UNICEF, one-third of all street children are disabled. (5)

3) Lack of information and resources to ensure 'safer sex'

- a) There is an incorrect assumption among the general public, and within the HIV/AIDS research community as well that individuals with disability are not sexually active.
- b) Adolescents and adults with disability are as likely to be as sexually active as their non-disabled peers.
- c) Adolescents with many (although not all) types of disability reach puberty at the same age as their peers.
- d) Homosexuality and bisexuality occur at the same rate among individuals with disability as among the non-disabled.
- e) *However*, individuals with disability are less likely to receive messages about AIDS and are less likely to have access to condoms or other prevention methods.

4) Elevated risk for violence and rape and lack of legal protection in specific relation to this risk

- a) There has not been a great deal of research in this area, but what studies do exist and the responses we have elicited through the survey show that individuals with disability are up to three times more likely to be victims of physical abuse, sexual abuse, and rape.
- b) Most individuals with disability have little or no access to police, legal counsel, and courts for protection

- c) Should sexual abuse/rape occur, individuals with disability have less access to medical interventions, including psychological counseling and prophylactic care, than their non-disabled peers.
- 5) Substance abuse
- a) Survey responses, as well as limited information from the literature, report drug abuse among select groups studied (the deaf and women with physical disabilities) at rates significantly higher than the general population.
 - b) Most of this information is from the developed world. Virtually nothing is known about this from developing countries, other than information provided by the Global Survey. These results indicate that substance abuse exists and is a problem.
- 6) Disabled AIDS Orphans
- a) Children with disability orphaned because of their parent's death through AIDS – whether they themselves are HIV+ or not –
 - i. Require extra care (feeding, toileting, etc.) from already overburdened caregivers with many other children to care for.
 - ii. Are more likely to be malnourished, neglected, institutionalized and abandoned.
- 7) Access to and Affordability of Care if Individuals with disability become HIV+
- a) Health care facilities are often physically inaccessible (stairs, lack of sign language interpreters, etc.)
 - b) Health care is unaffordable for the impoverished disabled.
 - c) Health care professionals are unaware of the needs of individuals with disability and, as this survey shows, routinely deny disabled individuals access to HIV testing, AIDS care, and place a lower priority on disabled individuals with AIDS when scarce AIDS drugs and services need to be rationed.
 - d) Allied services, such as drug and alcohol programs, domestic violence intervention programs, and places where condoms are distributed and where AIDS education materials are available are also inaccessible and non-inclusive.
- 8) Stigma
- a) Stigma has been associated repeatedly with AIDS.

- b) Stigma has also been repeatedly associated with individuals who are born with or who acquire a disability.
- c) Individuals with disability who become HIV+ are doubly stigmatized, particularly within the “charity model” framework.

Reasons People With Disability Are Not Being Reached

- 1) Lack of education inhibits ability to obtain and process information.
- 2) Information is in inaccessible formats.
 - a) Radio campaigns miss the deaf.
 - b) Billboards do not reach the blind.
 - c) Complex or vague messages do not reach those with intellectual impairments.
 - d) Clinics/services are inaccessible.

People with disability are not being included either implicitly or explicitly in most HIV/AIDS outreach efforts. Lack of knowledge of disability and awareness of disability issues among AIDS workers, government ministers, NGOs, etc., is the primary barrier. Unfamiliar with disabled populations, they are unaware that individuals with disability are sexually active or otherwise at risk. Most view individuals with disability largely as a medically dependent, childlike population, isolated from the real world.

Subgroups at Still Higher Risk

Women with disability, compared with both non-disabled *and* men with disability are:

- 1) Less likely to be educated
- 2) More likely to be unemployed or marginally employed
- 3) Less likely to marry
- 4) More likely to live in a series of unstable relationships

Disabled members of ethnic and minority populations:

- 1) Are marginalized within their own societies as well within the larger, national society
- 2) Have lower levels of education, employment, and access to disability programs
- 3) Are less likely to be reached by national AIDS education and outreach

- 4) Face “triple discrimination” if they are women

Results to Date

There is an acute need for more research on every level:

- 1) Epidemiological
- 2) Medical
- 3) Social science
- 4) Program/ services
- 5) Assessment and evaluation of existing and future interventions

There is a felt and immediate need for HIV/AIDS education, intervention, and services to reach individuals and groups with disability worldwide.

There is also a need for:

- 1) An understanding of what programs work for disabled populations and why
- 2) Research on what specific clinical needs might exist for individuals with disability vis-à-vis AIDS distinct from those of the general population (For example, the combination of psychotropic medications taken in conjunction with antiretrovirals has yet to be addressed.)
- 3) Monitoring and evaluation of those few pilot projects already available

On the basis of the information collected to this point of this study, a typology of intervention (covering a continuum, from Type I to Type III) could be proposed as follows:

- TYPE I: Individuals with disability included as members of the general population requiring little or no additional adaptation or expense
- TYPE II: Individuals with disability included as members of the general population with minor to moderate adaptations included as part of the outreach to the general population to ensure inclusion of those with disability
- TYPE III: Disability specific interventions targeting individuals who would otherwise not be reached

Type I	Individuals with disability are reached by same AIDS education messages and services as are members of the general public.	<p>Ensure that AIDS educational outreach and services available to the general population include individuals with disability</p> <p>Use materials already available to the general public, incorporating simple adaptations to ensure accessibility by all</p> <p>Train AIDS educators, outreach workers, and clinical and social service staff on disability issues</p> <p>Train individuals with disability to be AIDS educators</p>	Little or no additional costs	<p>Depicting individuals with disability (i.e., wheelchair users, blind individuals as part of group scenes in AIDS posters and billboards)</p> <p>Moving HIV/AIDS education, testing, and service delivery programs, as well as drug, alcohol, and domestic violence programs to accessible meeting places</p> <p>Making simple adaptations, such as allowing blind individuals to feel what a condom is, rather than just talking to them about it</p> <p>Delivering simple AIDS messages, allowing intellectually disabled individuals to hear safety messages enough times to allow them to memorize them</p>
Type II	Adaptations are made to AIDS outreach campaigns to ensure that individuals with disability are included as members of the general public.	<p>Adapt existing HIV materials to ensure inclusion</p> <p>Make simple alterations to facilities to increase inclusion</p> <p>Train HIV/AIDS educators and clinicians not only about disability in general, but also on understanding that there are differences in the needs of individuals with different types of disabilities</p> <p>Train individuals with disability to be AIDS educators</p>	Low to moderate cost	<p>Captioning of televised AIDS public service announcements for the deaf</p> <p>Making AIDS materials available for the blind in inexpensive cassette formats</p> <p>Building ramps at meeting halls or clinics (ramps can be made of mud, stone, bamboo, wood, etc.)</p> <p>Ensuring the dissemination of HIV/AIDS information in a variety of formats, such as radio and billboards to reach specific groups like the blind and deaf</p>
Type III	Disability-specific adaptations are made to existing materials and new materials are developed to reach individuals with disability outside the bounds of the general public, targeting harder to reach individuals and populations.	<p>Develop disability-specific outreach efforts</p> <p>Develop new materials to use in outreach efforts</p> <p>Train/hire AIDS educator and staff specializing in the issues related to serving the specific disabled population targeted</p> <p>Train disability advocates to be AIDS educators specifically for the disability community</p>	Moderate to high cost	<p>Having videos in sign language for the deaf</p> <p>Targeting schools and institutions serving disabled populations for special programs to ensure that students and residents have been informed</p> <p>Rewriting of training materials in simpler language and in an easy-to-understand format for those with intellectual impairments, or for disabled individuals who are illiterate or have limited reading skills</p> <p>Having a sign language interpreter available for clinics/hospitals to explain complicated regimes of AIDS drugs and follow-ups</p> <p>Training HIV educators and service providers on disability issues</p>

Table I describes the typology in greater detail. Please note that the typology is very rough at this point. The research team will further refine the typology through continued data analysis, critique, and thought.

Table 1 is found below.

In addition to the findings of the study to date, presentations at international conferences, and publications resulting from the study, an unanticipated result of the survey has been that a number of organizations have reported that the process of filling out the survey has sparked recognition that they are currently not addressing the needs of disabled populations and individuals in their communities. Five organizations reported they will soon initiate programs in direct response to completing the survey itself. A number of other organizations indicated that they intend to review current programming as a result of the survey. It is hoped that other organizations will also be prompted to consider inclusion of individuals with disability based on the lack of inclusion that became evident when they reviewed their current HIV/AIDS programming in order to complete the survey.

Conclusions

Over the past year, this study has started to establish that HIV/AIDS represents a significant threat to disabled individuals and populations around the globe, at rates at least comparable to – and quite possibly significantly higher than – rates found in the general public. Moreover, findings from the survey clearly document that individuals with disability are not included in most AIDS outreach efforts. Dissemination of these findings and on-going research in connection with the Global Survey, as well as associate research efforts, should help bring the issue of HIV/AIDS onto the global AIDS and disability agendas. Given the size of the global disabled population (10% of the world’s citizens) and the degree of risk that the AIDS epidemic poses, it seems evident that the AIDS crisis cannot be addressed successfully unless individuals with disability are routinely part of all AIDS outreach efforts.

Note: Findings from the literature search, accounts of interventions where they were available and notices of current and upcoming events related to the impact of HIV/AIDS on the global disability community are posted on the following website to allow researchers and advocates easier access to those materials we have been able to identify. The website will be updated regularly and we would appreciate learning of any additional materials that might be included.

Website: <http://cira.medl.yale.edu/globalsurvey>

References

- 1) Fine M., Asch, A. (1988). Women with disability. Philadelphia, PA: Temple University Press.
- 2) Russo, H. (2000). Girls and women with disabilities. . Oakland, CA: World Institute on Disability/ NY: Rehabilitation International.
- 4) Alford, J., Aruffo, J. (1994). HIV and psychiatric clients with developmental disability. *Psychosocial Rehabilitation Journal*. 17:4:41-49.
- 5) Collins, P., Geller, P., Miller, S., Toro, P., Susser, E. (2001). Ourselves our bodies, our realities: an HIV prevention intervention for women with severe mental illness. *Journal of Urban Health*, 78:1:162-175.
- 6) Cook, J., Razzano, L. (1994). HIV-risk assessment for psychiatric rehabilitation clientele: implications for community-based services. *Psychosocial Rehabilitation Journal*. 17:4:105-114.
- 7) Menon, A., Pomerantz, S., Harowitz, S. et al. (1994). The high prevalence of unsafe sexual behaviors among acute psychiatric inpatients. *Journal of Nerv. Mental Diseases*. 182:661-666.
- 8) Weinhardt, L., Carey, M., Carey, L., Verdecias, S. (1998). Increasing assertiveness skills to reduce HIV risk among women living with severe and persistent mental illness. *Journal of Consulting Clinical Psychology*. 66:680-684.
- 9) Helander, E. (1993). Prejudice and dignity: an introduction to community-based rehabilitation. NY: UNDP.
- 10) DFID. (2000). Disability, poverty and development. London: DFID.
- 11) Elwan, A. (1999) Disability and Poverty. Washington: World Bank. Social Protection Unit.
- 12) United Nations. (1993). Standard rules on the equalization of opportunities for persons with disability. New York: UN General Assembly 48/96.
- 13) Van Biema, D. (1994). Deafness and AIDS. *Time Magazine*. 143:14:76-78.
- 14) Cournos, F., Empfield, M., Horwath, E., Schrage, H. (1990). HIV infection in state hospitals. *Hospital Community Psychiatry* 41:163-166.
- 15) Groce, N. (2003) Preliminary Report: Global Survey on HIV/AIDS and Disability. New Haven: Yale School of Public Health.
- 16) Mulindwa I. (2003) Study on Reproductive Health and HIV/AIDS among Persons with Disabilities in Kampala, Katakwi and Rakai Districts. Kampala, Uganda: Disabled Women's Network and Resource Organization.

- 17) UN AIDS (2003) Report on the Global HIV/AIDS Epidemic. 2002: UN AIDS. Geneva.
- 18) Kastner T. in Crocker, A., Cohen, H., Kastnre, T. (Eds.) (1992) HIV infection and developmental disabilities. London: Brookes.
- 19) Holmes, A., Parrish, A. (1996). Health of the nation for people with learning disabilities. British Journal of Nursing. 5:19:1184-1187.
- 20) CDC. (1995). CDC frequently asked questions: HIV/AIDS and developmentally disabled persons. http://www.aegis.com/pubs/Cdc_Fact_Sheets/1995/CFAQ0005.html.
- 21) Gaskins, S. (1999). Special population: HIV/AIDS among the deaf and hard of hearing. Journal of the Association of Nurses in AIDS Care. 10:2:75-78.
- 22) McGillivray, J. (1999). Level of knowledge and risk of contracting HIV/AIDS amongst young adults with mild/moderate intellectual disability. Journal of Applied Research in Intellectual Disabilities, 12:2:113-126.
- 23) Johnson, T. (2003). Particularly in Africa, 'rehabilitation' is no longer possible... CBR Forum. <http://dag.virtualave.net/cbrforum.htm>
- 24) Wolfensohn: "Poor, Disabled and Shut Out" The Washington Post, December 3, 2002

Appendix A
Materials Sent to Survey Respondents

Yale/World Bank



Global Survey on HIV/AIDS and Disability

Please help:

The Office of the Advisor on Disability and Development and The Global HIV/AIDS Program of the World Bank are sponsoring this Global Survey on HIV/AIDS and Disability in conjunction with the Yale University School of Public Health.

Today, little is known about HIV/AIDS among people with disability. We would like to know how the epidemic is affecting individuals and groups with disability around the world and we ask you to help.

We send this survey with the request that you fill it out on behalf of the organization or advocacy group you work with. (If you think someone else in your organization would know more about these questions, we would appreciate it if you were to give it to them to fill out).

We are interested in hearing both from organizations that are working on HIV/AIDS issues and from organizations that are not currently involved in HIV/AIDS issues.

We will be looking for information about programs that provide HIV/AIDS education, interventions, and services to disabled people and communities. We would also welcome stories from disability advocates about attempts to get help for HIV/AIDS in one's community, examples about not being able to get help for one's community, stories about governments and HIV/AIDS voluntary organizations that have tried to reach disabled people, and so forth.

Please note that there are no 'right' or 'wrong' answers to any of these questions. Also, feel free to leave blank any questions for which you may not know the answer or which you may not feel comfortable answering. However, keep in mind we realize there is often little information available on this topic and so we are also interested in people's ideas, impressions, knowledge, practices, and attitudes. Also, please note that we are not asking (and do not want) personal information or names of individuals who might have HIV/AIDS – *we feel it is very important that we do not invade anyone's privacy.*

If you already have information about HIV/AIDS and disability from your own organization or educational materials, information on training, studies, meetings or other materials relating to HIV/AIDS that you would like to share with us, we would appreciate it. If you know of a program or project that you think we should learn more

about, please let us know. Finally, if you know of other Disability organizations or advocates who might have information about HIV/AIDS and Disability, we would appreciate it if you would forward this announcement on to them.

Language: Please fill out the form in whatever language is easiest for you to write in.

Sincerest thanks,

Nora Groce, Ph.D
Associate Professor, Global Health Division
Yale School of Public Health, 60 College Street
New Haven, Connecticut 06520, USA
Phone: + 203-785-2866/ FAX: + 203-785-6193
e-mail: Nora.Groce@yale.e

Project website: [hppt://cira.med.yale.edu/globalsurvey](http://cira.med.yale.edu/globalsurvey)

**YALE UNIVERSITY SCHOOL OF PUBLIC HEALTH
&
WORLD BANK OFFICE OF THE ADVISOR ON
DISABILITY AND DEVELOPMENT
&
WORLD BANK GLOBAL HIV/AIDS PROGRAM
Project website: <http://cira.med.yale.edu/globalsurvey>**

GLOBAL SURVEY ON HIV/AIDS AND DISABILITY

Background Information

Name of person filling out form:

Name of Organization:

Mailing Address:

E-mail:

Phone number:

Type of Organization:

_____ Government Organization

_____ National

_____ State

_____ Municipal/City

_____ Other

_____ United Nations

_____ International

_____ National

_____ Local

_____ Other

_____ Non-Governmental Organization

Are you a disability-run organization?

_____ Yes

_____ No

Type of services provided:

- Advocacy/Policy
- Education
- Medical/Counseling
- Rehabilitation Services

- Development/ Economic
- Legal
- Other

Type of Disability Served:

- Physically Disabled
- Blind/ Low vision
- Deaf/Hard of Hearing
- Intellectually Disabled
(Mentally Retarded)
- Mentally Ill
- Multiply Handicapped
- Epilepsy
- Chronic Disease
- Hemophilia
- All disability groups
- Other

Number of individuals with disability/ families served

- 1-100
- 100-500
- 500- 1000
- 1,000- 10,000
- Above 10,000

PART I: RISK FOR HIV/AIDS: AWARENESS

1. Do you think that disabled people might be at risk for HIV/AIDS?

No Do not know
If no, why not?

Yes
If yes, why?

2. Do you think that disabled people are at greater risk for HIV/AIDS than non-disabled people?

No Do not know
If no, why not?

Yes
If yes, why?

3. Do disabled people themselves feel they are at risk?

No Do not know
If no, why not?

Yes
If yes, why?

- Sexually active
- Rape/Sexual abuse
- Drugs
- Medical procedures
- Lack of information concerning HIV/AIDS
- Don't have access to prevention programs
- Families will not let them participate in programs
- Police will not prosecute if the victim has a disability
- They live in an institution
- Prevention programs are not in a language that can be understood
- Other (Please explain)

4. If the people you work with feel that they are at risk, what types of help have they asked for?

5. Do you have any information on how many disabled people in your area:

A). have died from AIDS?

_____ No

_____ Yes

_____ If yes, please describe:

B). are living with HIV or AIDS?

_____ No

_____ Yes

_____ If yes, please describe:

6. If there are individuals with disability in your community who have died from, or are infected with HIV/AIDS, how have others in the community responded?

_____ HIV/AIDS is not discussed

_____ It is said that they died from something else

_____ Stigma/prejudice against those who are infected

_____ Other (Please explain)

**PART II: TEACHING DISABLED PEOPLE ABOUT HIV/AIDS THROUGH
DISABILITY ORGANIZATIONS**

7. A). Is your organization involved in teaching disabled people about:

_____ HIV/AIDS?

_____ Safe Sex?

_____ Sexually Transmitted Diseases?

_____ Drug Usage?

_____ Other topics relevant to HIV/AIDS? (Please describe)

B). If your organization is involved in these activities, please describe the program/s in more detail here:

C). If your organization has not set up an HIV/AIDS program, what are the reasons:

_____ It is not the type of thing your organization does

_____ Other organizations are better able to handle it

If so, which organizations?

_____ You do not think it is a significant problem for the populations you serve

_____ You worry about making disabled people even more stigmatized

_____ Lack of resources and/or money

_____ Other (Please explain)

8. Are there any other disability organizations in your area that are reaching or trying to reach your people with HIV/AIDS prevention information? Please describe:

9. Have you asked for help from HIV/AIDS experts and others from your government, ministry of health, or local voluntary agencies to reach people in the disability community?

_____ No

_____ Yes

If yes, what type of organization did you ask?

10. If you did ask for help from other groups or organizations, were they helpful?

_____ No

If no, what were the reasons they gave for not helping disabled people?

_____ Yes

If yes, what did they do for disabled people that you found to be helpful?

PART III: TEACHING DISABLED PEOPLE ABOUT HIV/AIDS THROUGH NON-DISABILITY ORGANIZATIONS

11. Have there been efforts by non-disability groups to educate the population you serve about:

_____ HIV/AIDS

_____ Safe Sex

_____ Sexually Transmitted Diseases

_____ Drug Usage

_____ Other topics relevant to HIV/AIDS (Please explain):

12. A). Have you ever seen any of the disabled people you serve reached by HIV prevention messages meant for the general population?
- No
- Yes
- If yes, how many of the people in your community do you think were reached?
- Few
- Some
- Most
- All
- If yes, what types of information were received?
- B). Do you think the amount of information concerning HIV/AIDS that is reaching the disability community is:
- Less than that reaching the general population?
- Equal to that reaching the general population?
- More than that reaching the general population?
- C). Do you think that the information concerning HIV/AIDS that is reaching the disability community is:
- Less accurate than that reaching the general population?
- Equal to that reaching the general population?
- More accurate than that reaching the general population?
13. Have there been large HIV/AIDS campaigns (by non-disability organizations) that were inaccessible to the people you serve in the following formats:
- Radio programs
- Television programs
- Billboards
- Other written materials
- Complex materials not appropriate for the intellectually disabled
- Training/education sessions in locations not accessible by wheelchair
- Training/education sessions in which no sign language or captioning was available for those who are deaf
- Other ways (please explain)
14. Has there been any attempt by non-disabled organizations to put HIV/AIDS prevention messages into a format that would be more accessible to your people?
- No Do not know
- Yes
- If yes, what kinds of formats?
- If yes, how well do you think these programs have worked?

PART IV HELP AND SUPPORT FOR DISABLED PEOPLE WHO ARE INFECTED WITH HIV/AIDS

15. Have disabled people you know been able to find out about their HIV status (been able to get tested for HIV)?

No Do not know
 Yes

16. Do you know any disabled people who were not able to be tested for HIV, or had trouble getting tested because of:

Inaccessible clinics
 No one willing to treat them
 No Sign Language translation
 Other difficulties (Please explain)

17. Do you know any disabled people who could not access health care programs for people with

HIV/AIDS or obtain treatment for HIV/AIDS because of their disability?

No
 Yes
If yes, please explain.

18. Sometimes people who are disabled are diagnosed with HIV/AIDS much later than non-disabled people, either because they do not recognize the symptoms, no one tells them about the symptoms, no AIDS clinic welcomes disabled people, or they are afraid and do not know much about HIV/AIDS. Have people you know had any experience with this?

19. Sometimes people who are disabled do not get as good medical care as people who are not disabled. This is particularly true when people who are disabled need expensive drugs, or extra care or hospitalization. Have you ever seen this happen when someone with a disability is diagnosed with HIV/AIDS?

20. Because the disabled community is also often small, there may be additional reluctance to come forward to ask for diagnosis and care. People are worried about word 'getting around.' Have you ever heard of this happening?

21. Sometimes people with HIV/AIDS need help from lawyers or advocates: either to get care and services, or to allow them a say in how they live and what services they want to use. Have the disabled people with HIV/AIDS you work with ever tried to get help from the law?

_____ No

_____ Do not know

_____ Yes

If yes, were they able to get legal assistance or were they turned away?

PART V ADDITIONAL COMMENTS OR OBSERVATIONS

Appendix B
Article Appearing in *The Lancet*
(Vol. 361, April 26, 2003, pp. 1401-1402)

HIV/AIDS and people with disability

Although AIDS researchers have studied the disabling effects of HIV/AIDS on previously healthy people, little attention has been given to the risk of HIV/AIDS for individuals who have a physical, sensory, intellectual, or mental health disability before becoming infected. It is commonly assumed that disabled individuals are not at risk. They are incorrectly thought to be sexually inactive, unlikely to use drugs, and at less risk for violence or rape than their non-disabled peers. Yet a growing body of research indicates that they are actually at increased risk for every known risk factor for HIV/AIDS. For example, in a recent article, S Blumberg and W Dickey (1) analyse findings from the 1999 US National Health Interview Survey and show that adults with mental health disorders are more likely to report a medium or high chance of becoming infected with HIV, are more likely to be tested for HIV infection, and are more likely to expect to be tested within the next 12 months than are members of the general population.

Such findings should not be unexpected for individuals with disability. There are significant risk factors for disabled populations around the globe. For example, despite the assumption that disabled people are sexually inactive, those with disability—and disabled women in particular—are likely to have more sexual partners than their non-disabled peers. Extreme poverty and social sanctions against marrying a disabled person mean that they are likely to become involved in a series of unstable relationships.(2) Disabled individuals (both male and female) around the world are more likely to be victims of sexual abuse and rape than their non-disabled peers. Factors such as increased physical vulnerability, the need for attendant care, life in institutions, and the almost universal belief that disabled people cannot be a reliable witness on their own behalf make them targets for predators.(3,4) In cultures in which it is believed that HIV-positive individuals can rid themselves of the virus by having sex with virgins, there has been a significant rise in rape of disabled children and adults. Assumed to be virgins, they are specifically targeted.(5) In some countries, parents of intellectually disabled children now report rape as their leading concern for their children's current and future well-being. Bisexuality and homosexuality have been reported among deaf and intellectually disabled adults, while awareness of HIV/AIDS and knowledge of HIV prevention is low in both these groups.(6) Individuals with disability are at increased risk of substance abuse and less likely to have access to interventions. It is estimated that 30% of all street children have some type of disability and these young people are rarely reached by safe sex campaigns.(5)

Furthermore, literacy rates for disabled individuals are exceptionally low - one estimate cites an adult literacy rate of only 3% globally (7), thus making communication of messages about HIV/AIDS all the more difficult. Sex education programmes for those with disability are rare.(8–10) and almost no general campaigns about HIV/AIDS target (or include) disabled populations.(11) Indeed, where AIDS campaigns are on radio or television, groups such as the deaf and the blind are at a distinct disadvantage.

The future for disabled individuals who become HIV positive is equally grim. Although little is known about access to HIV/AIDS care, disabled citizens receive far fewer general health-services than others.(12,13) Indeed, care is not only often too expensive for impoverished disabled

persons, but it can also be physically inaccessible—e.g., clinic steps bar the way for a wheelchair user and consultation with a physician without a sign-language interpreter is meaningless for most deaf persons.

Currently, little is known about HIV/AIDS and disability. Only a few studies have estimated prevalence(14,15) and no prevalence data exist for any disabled populations from sub-Saharan Africa, Asia, Europe, Central and South America, or the Caribbean. However, a growing number of stories from disability advocates worldwide point to significant unreported rates of infection, disease, and death.(16) Over the past decade there have be a handful of articles on HIV/AIDS pilot programmes and interventions for intellectually disabled adults or services for deaf adolescents.(17,18) Many of these projects are innovative but almost all are small and underfunded. There is a real need to understand the issue of HIV/AIDS in disabled people in global terms and to design and implement programmes and policy in a more coherent and comprehensive manner. The roughly 600 million individuals who live with a disability are among the poorest, least educated, and most marginalised of all the world's peoples. They are at serious risk of HIV/AIDS and attention needs to be focused on them. In January, 2003, the World Bank and Yale University, started a global survey on HIV/AIDS and disability that seeks to better understand variables of the current epidemic as well as to identify best-practice interventions and grassroots efforts.

Nora Ellen Groce
Global Health Division, Yale School of Public Health, Yale University,
New Haven, CT 06520, USA
(e-mail: nora.groce@yale.edu)

References for Lancet Article

1. Blumberg, SJ, and Dickey WC. "Prevalence of HIV risk behaviors, risk perceptions, and testing among US adults with mental disorders." *J Acquir Immune Defic Syndr* 2003; 32: 77–79.
2. Economic and Social Commission for Asia and the Pacific. "Hidden sisters: women and girls with disabilities in the Asian Pacific region." New York: United Nations, 1995.
3. Nosek, MA; Howland, CA; and Hughes, RB. "The investigation of abuse and women with disabilities: going beyond assumptions." *Violence Against Women* 2001; 7: 477–99.
4. Chenoweth, L. "Violence and women with disabilities: silence and paradox." *Violence Against Women* 1996; 2: 391–411
5. UNICEF. "Global survey of adolescents with disability: an overview of young people living with disabilities: their needs and their rights." New York: UNICEF Inter-Divisional Working Group on Young People, Programme Division, 1999.
6. Cambridge, P. "How far to gay? The politics of HIV in learning disability." *Disabil Soc* 1997; 12: 427–53.
7. Helander, E. "Prejudice and dignity: an introduction to community-based rehabilitation." New York: UNDP, 1993.
8. Collins, P; Geller, P; Miller, S; Toro, P; and Susser E. "Ourselves, our bodies, our realities: an HIV prevention intervention for women with severe mental illness." *J Urban Health* 2001; 78: 162–75.
9. Gaskins, S. "Special population: HIV/AIDS among the deaf and hard of hearing." *J Assoc Nurses AIDS Care* 1999; 35: 75–78.
10. Robertson, P; Bhate, S; and Bhate, M. "AIDS: education and adults with a mental handicap." *J Mental Def Res* 1991; 35: 475–80.
11. UNAIDS. "Report on the global HIV/AIDS epidemic 2002." New York: Joint UN Programme on HIV/AIDS, 2002.
12. Altman, BM. "Does access to acute medical care imply access to preventive care: a comparison of women with and without disabilities." *J Disabil Policy Stud* 1997; 8: 99–128.
13. Lisher, D; Richardson, M; Levine, P; and Patrick, D. "Access to primary health care among persons with disabilities in rural areas: a summary of the literature." *Rural J Health* 1996; 12: 45–53.
14. Van Biema, D. "AIDS and the deaf.." *Time Magazine* 1994; 143: 76–78.
15. Cournos, F; Empfield, M; Howarth, E; and Schrage, H. "HIV infection in state hospitals: case reports and long-term management strategies." *Hosp Comm Psychiatry* 1990; 41: 163–66.
16. Moore, D. "HIV/AIDS and deafness." *Am Ann Deaf* 1998; 143: 3.

17. Gaskins, S. "Special population: HIV/AIDS among the deaf and hard of hearing." *J Assoc Nurses AIDS Care* 1999; 10: 75-77.

18. McGillivray, J. "Level of knowledge and risk of contracting HIV/AIDS amongst young adults with mild/moderate intellectual disability." *Journal of Applied Research in*