

4/28/03
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 all types of disability around the world and we ask you to help. We are interested in disabled people of all ages, and disabled people living with their families, on their, own, or in institutions.

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, please 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, newspaper articles, 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, advocates, or government agencies who might have information about HIV/AIDS and Disability, we would appreciate it if you would forward this announcement on to them.

Language: If it is easier for you to write in a language other than English, please fill out the form in whatever language is easiest for you.

Sincerest thanks,

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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

Non-Governmental Organization
 International
 National
 Local
 Other

United Nations

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?

- Do not know
- No
- If no, why?

- Yes
- If yes, why?

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

- Do not know
- No
- If no, why?

- Yes
- If yes, why?

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

- Do not know
- No
- If no, why?

- 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?
- AIDS education
 - HIV testing
 - Counseling
 - Condoms
 - Other (please explain)

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 the 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 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 large HIV/AIDS campaigns (by non-disability organizations) been inaccessible to the people you serve because they were:
- 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?
- Do not know
 - No
 - 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)?

- Do not know
- No
- 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 at 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? (Please explain)

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? (Please explain)

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

21. Sometimes disabled people with HIV/AIDS and disability advocacy groups need help from the law: either to get care and services, or to allow them a say in what services they want to use.

A). Have the disabled people with HIV/AIDS you work with ever tried to get help from the police or legal system?

_____ Do not know

_____ No

_____ Yes

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

B). Has your organization ever tried to get help on HIV/AIDS issues from the police or legal system?

_____ Do not know

_____ No

_____ Yes

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

PART V

ADDITIONAL COMMENTS OR OBSERVATIONS