

Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts

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Introduction

This paper is intended to provide guidelines for the inclusion of individuals with pre-existing disabilities in HIV/AIDS outreach efforts. It is based on a synthesis of materials collected in the course of the Global Survey on HIV/AIDS and Disability by the World Bank and Yale University. (World Bank: 2004) The strategies for interventions proposed here can provide a framework upon which disability advocates and HIV/AIDS advocates, educators and policy makers can begin to build interventions and support mechanisms for ‘at-risk’ disabled populations.

To date, there have been few HIV/AIDS interventions that have directly targeted (or indirectly included) individuals with disability and almost none of these interventions have been systematically monitored or evaluated. The framework proposed here therefore, is intended only as a ‘first step’ in a series of publications on various aspects of disability-inclusive HIV/AIDS interventions and tool kits.

We propose here a three part typology which constitutes a continuum of inclusion in and access to HIV/AIDS services that range from: I) inclusion of individuals with disability in general HIV/AIDS outreach efforts at little or no additional expense to currently existing programs, II) programs where minor to moderate modifications can be made to existing programs to ensure greater participation of individuals with disability at relatively little expense, to III) outreach efforts that are targeted to disabled audience that entail specific allocation of resources. (And it should be noted that even such disability-specific efforts are not exceptionally expensive or resource intensive).

The authors of this study would appreciate feedback from individuals or groups who are attempting to design interventions based on this proposed framework. We would also welcome hearing from colleagues who have designed other HIV/AIDS intervention models for disabled

populations or have identified existing non-disability specific HIV/AIDS training materials or related materials that have been effective in working with disabled populations.

Background

335 million individuals are estimated to live with a pre-existing physical, sensory, (blindness, deafness) or intellectual impairment, and a further 450 million people world-wide are affected by mental, neurological or behavioral problems. They are among the poorest and most marginalized of all the world's peoples. Eighty percent live in developing countries and a larger proportion live in rural rather than urban areas.

Despite the fact that the risk factors associated with disability – extreme poverty, social stigma and marginalization, strikingly high rates of unemployment and lack of access to education and health care - are similar to those for HIV/AIDS, there has been almost no attention to the impact of the AIDS epidemic on this large and largely overlooked population. In 2004, the World Bank, working in association with the Yale School of Public Health, conducted a Global Survey on HIV/AIDS and Disability, which specifically sought to determine the impact that the AIDS epidemic is having on individuals with disability around the world. The specific details of the various interventions identified are provided in full on the Global Survey website (<http://globalsurvey.med.yale.edu>). Over a thousand responses from 57 countries allowed researchers to conclude that the impact of the AIDS epidemic is largely unrecognized among both disability and AIDS outreach and advocacy groups. Individuals with disability are at equal to significantly greater risk for all HIV/AIDS risk factors, and as such, must begin to be included in all AIDS outreach efforts. Sub-groups within disabled populations (e.g. women with disability, disabled adolescents, members of ethnic and minority populations with disability), are at even greater risk (World Bank: 2004; Yousafzai and Edwards 2004, Groce: 2005).

There are a variety of reasons why children, adolescents and adults who live with disability have gone unnoticed in HIV/AIDS outreach efforts. Among these is the fact that it is commonly and incorrectly assumed that individuals with disability are sexually inactive, unlikely to use drugs or alcohol and are at less risk of violence or rape than their non-disabled peers. Stigma and marginalization, poverty, illiteracy, unemployment and the lower probability that individuals with disability will be considered eligible marriage partners, significantly diminish the ability of many individuals with disability worldwide to be able to negotiate safer sex. Furthermore, in many communities, the belief that individuals with disability will not become sexually active results in

little or no sex education for adolescents and adults with disabilities, severely limiting their ability to understand safer sex messages and to negotiate safer sexual behaviors.

Risk factors for individuals with mental illness have received more attention, but research or programming for this population still lags significantly behind that available for the general population. (World Bank 2004)

Current Gaps in Reaching Disabled Populations

A number of questions about HIV/AIDS and disability remain unanswered. How can individuals with disability best be reached by AIDS outreach efforts? Should they be included in general AIDS outreach campaigns and services? Are special initiatives and targeted approaches needed? If so, will this entail greater expense? If there are greater expenses, where should such funding come from? Part of the problem is that when discussion of this issue has taken place, it has largely been framed as a choice between doing nothing or implementing expensive, resource intensive outreach efforts. Calls for the inclusion of individuals with disabilities in HIV/AIDS outreach efforts are regularly countered with concerns that HIV/AIDS activities are already stretched to the breaking point and that funding to develop new disability-specific activities is not available.

It is strongly argued here that inclusion of individuals with disability in HIV/AIDS outreach efforts simply cannot wait until all other groups in the population are addressed. The issue is one of both basic human rights AND basic public health. We begin with the following assumptions:

- The lives of individuals with disability are no less valuable than the lives of all other citizens and there can be no substantive argument that justifies assigning individuals with disability to the bottom of an HIV/AIDS priority list.
- Moreover, if individuals with disability are not included in HIV/AIDS outreach efforts, efforts to slow the spread of the virus or eliminate it will be unsuccessful. Individuals with disability are simply too large a proportion of the population not to be included.

Furthermore, we also believe that a variety of options are available. The choice is not only *between* the inclusion of individuals with disability in general AIDS outreach efforts or the design

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of separate outreach initiatives that specifically targets individuals with disability. Both approaches are desperately needed and at this point, most individuals with disability are not being reached by either. A *combination* of strategies however would begin to reach a significant portion of the disabled community.

Below we suggest a three part typology which constitutes a continuum of inclusion and access of services that range from I) inclusion of individuals with disability at little or no additional expense to current HIV/AIDS programs through II) programs where modifications are made to existing HIV/AIDS programs to ensure greater participation of individuals with disability to III) outreach efforts that are specifically targeted to disabled audiences and that would cost more because of the need for specialized knowledge, time and materials.

Such a continuum of potential interventions is presented with the caveat that no single intervention strategy works for every member of any group. The need for a variety of intervention strategies is of particular importance for disabled populations, because individuals with different types of disabilities face different challenges when it comes to:

- Being reached by HIV/AIDS messages
- Accessing HIV prevention educational materials and condoms
- Accessing AIDS related services, including AIDS-related medications, care and social support systems

For example, radio campaigns will not reach individuals who are deaf or those who have hearing impairments, billboard and print campaigns will not reach those who are blind. AIDS messages that convey too much information, or that use euphemisms for AIDS and safer sex may be confusing to individuals with intellectual impairments.

Many HIV/AIDS intervention programs use a combination of educational, clinical and social support approaches to ensure that at-risk populations – be it women or adolescents or intravenous drug users - are reached and served. Just as no AIDS campaign is expected to reach every member of society, there is no reason to anticipate that any one intervention will reach every disabled member of a community. Organizations implementing HIV/AIDS interventions for disabled populations could select one or a combination of approaches based on availability, local resources and expertise.

A General Framework for Inclusion of Disabled People in HIV/AIDS Outreach Efforts

The strategies for inclusion of disabled groups are conceptualized as a continuum from Type I to Type III as follows:

- **Type I : Inclusion as Part of General HIV/AIDS Outreach with No Adaptations**
Individuals with disability are included in HIV/AIDS outreach efforts and services as members of the general population requiring little or no additional adaptation or expense.
- **Type II Minor Adaptations to General Programs that Foster Inclusion**
Individuals with disability are included as members of the general population with minor to moderate adaptations to existing programs made to ensure that existing outreach efforts include individuals with disability and/or new programs are inclusive from the outset.
- **Type III : Disability Specific Programming**
Disability-specific interventions addressing needs of groups within the disabled population; who would otherwise not be reached through HIV/AIDS outreach campaigns addressed to the general population because of disability-specific limitations. Although activities in section III are labeled as having moderate to higher costs, in fact, none of the costs associated with these interventions are particularly high. In most cases, the interventions suggested in Section III would be only slightly more costly because of greater requirements for staff time, specialized materials and dedicated resources for such efforts.

The various types of approaches suggested here are seen in the Tables I – III (page 15)

Discussion

The various types of interventions proposed in the Tables present a range of options. Below we provide points related to the suggested interventions noted in the preceding Tables:

Type I: (Table I: No or Low Cost Modifications to Existing Programs)

In the inclusive interventions suggested in Type I, some interventions need little more than awareness of disability issues by AIDS advocates and outreach workers. An invitation to join a

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training session or a change of venue may cost nothing. Many effective actions can be taken immediately by AIDS advocates and health care workers if they are made aware that individuals with disability are at risk. For example, one South African disability activities reported: “I see AIDS educators going door-to-door in my village, inviting all adults to an AIDS meeting. They walk by and wave to the woman sitting in her doorway in a wheelchair watching her children, but they do not invite her to come” (Groce: 2005). In many cases, failure to include community members with disability are simply cases, such as this, of missed opportunities.

Another woman who uses crutches told a researcher that she would like to attend the AIDS education sessions open to all members of her community, but it is hard – ‘they chose to have the meeting at the court house in town. I would have to climb all those stairs. If they had the session in the one story school house next door to the court house it would be much easier. If they moved the courthouse session outdoors under the trees in the yard, would be good too.’

The leader of an organization for blind people in southern Africa reported that he knew blind people were at risk for HIV/AIDS indeed, several blind people he knew had already died of the disease. Because of this, he invited an AIDS educator to come give a lecture to members of his association. The AIDS educator came and spoke of many things, repeatedly holding up a condom packet in front of the room to illustrate his points. Holding up anything in front of a room full of blind people is rarely productive and because AIDS is already such a stigmatized subject in this region, the members of the blind audience were far too embarrassed to ask the AIDS educator to allow them to touch the condom so they could understand what it was or how it was to be used. It was only months later, the leader of the blind association noted, that another AIDS outreach worker thought to open the packet and allow those blind people present to feel it. “Then of course I understood at once what it was and how it would work,” said the blind advocate.

Interestingly however, even here, the AIDS educator lost an opportunity to transmit knowledge to the members of the blind association that simple awareness of disability issues would have eliminated. ‘Now that you know what condoms are’ the blind leader was asked, ‘where can you go to get them?’ He replied, ‘I do not know’ – even though he lived in a community where almost every public bathroom had a box of condoms available in plain sight on the counter next to the sink and many public buildings had boxes of condoms prominently displayed near the entryway or in a corridor. Because the AIDS educator had not thought to tell members of the

blind association about where condoms were available, they did not know to seek them out in these public places.

Type II (Table II: Low to Moderate Cost to Modify or Add to Existing Programs).

While many interventions can be implemented at little or no cost or allocation of additional time or energy on the part of outreach workers, other interventions will require minor to moderate amounts of planning and resource allocation. However, even here, creativity, innovation and a willingness to work with local resources can keep costs to a minimum while maximizing the number of disabled individuals who are reached.

For example, reaching blind people has often been cited as a particular challenge. While putting AIDS outreach materials into Braille would be an optimum solution, for many, Brailing documents is an expensive proposition, well beyond the means of many AIDS outreach or disability advocacy organizations. The expense of putting AIDS information into Braille was cited by a number of groups who responded to the Global Survey, as the reason why they were not attempt to reach blind individuals with AIDS messages. However, while many educated blind people read Braille, in fact, 90% of all individuals with vision impairments do not read Braille or are not literate.

An inexpensive alternative may be available for many, however. Walking through almost any market place today, even in rural and remote areas, a traveler can usually find inexpensive tapes and CDs featuring popular local vocalists and dance bands. If inexpensive tapes and CDs of the most popular local music groups are often found in the market place, there can be no reason why AIDS information can not be put in similar formats. Many – not all of course – but many individuals who are blind or have low vision also have some access to tape or CD players or live in families or neighborhoods where these are available. Inexpensive tapes and CDs on AIDS could be produced and distributed to the local blind population. Production of such low-cost tapes or CDs has an added benefit. In many countries, while there is one national language which is used in school and the workplace, a local tribal language or regional dialect is spoken in the home and the surrounding community. Using tapes, AIDS information can be produced in many local languages and dialects to allow better comprehension by individuals who are most comfortable in their native tongues. And where individuals with vision impairment have little access to education, it is likely that many or most would fall into this category.

A similar low-cost technology can be used to reach some portion of the deaf population through sign language interpretation. Where television is available, many deaf individuals will watch TV, although their ability to fully understand what is going on may be limited because of their inability to follow the sound track. While captioning for the hearing impaired is often costly and requires additional technologies, a simple televised image of a sign language interpreter in the corner of the screen can be easily added when a commercial on AIDS is run or an AIDS program is played. Because many AIDS commercials are made once and continually rerun, bringing in a sign language interpreter one time to interpret a pre-recorded message could pay for itself many times over. Sign language interpreters are usually paid by the hour and their wages are usually quite reasonable.

Type III: (Table III: Moderate to Higher Cost Disability-Specific Programs)

Other populations will be harder to reach. For example individuals with significant mental illness have been identified in the current HIV/AIDS outreach literature as especially hard to reach and deliver care to. Compromised decision making ability, increased high risk behaviors such as exposure to intravenous drugs and unprotected sex, as well as the poverty and social isolation unfortunately place many individuals with significant mental health issues at substantial risk. Despite this, creative programs have effectively reached such populations. For example, Collins et al (2001) described an innovative program in New York City, where talks, presentations and warnings about AIDS had done little to get the attention of 'high risk' women with mental illness. However, a new intervention proved successful – an AIDS training session was set up like a TV talk show – with one woman designated as moderator, several others designated as guests of the show and the rest of the participants assigned to be the studio audience. A small hand-held mike was passed around and the moderator interviewed the 'guests' about HIV/AIDS and then threw the session open to questions from the audience. The AIDS educator stood off to the side, ready to add the correct information or ask a targeted question to make sure the information was getting through. Participation from moderator, guests and audience members was enthusiastic. The expense of the program was no more than the paying for the time of an AIDS educator to hold a session specifically for this subgroup – and the use of a microphone for an afternoon, (a child's microphone toy found at the local toy store would do just as well).

Other interventions will need a more targeted approach - For example, the Deaf community in most countries is a cohesive social network bound together not only by the local sign language, but by shared social and educational experience, families and friendships. While a number of deaf

individuals in such social networks are able to speak and read the local oral language, many are not as fluent in this language as they are in their primary sign language. The need for presentations about AIDS to be clearly made in the local sign language is clear. It is only in this language that deaf individuals would be able to fully understand, ask questions and receive answers about HIV/AIDS that they are able to use in their daily lives.

On-Going Programs, Monitoring and Evaluation

In conjunction with the suggested interventions listed above, several additional points found during data collection for the Global Survey should be raised:

1. Currently, HIV/AIDS interventions for individuals with disability are few and far between. Those that do exist are often very small – at most reaching only a few hundred individuals in populations that number in the millions. Most are disability-specific; an outreach effort will reach members of the local Deaf community, but not those who are blind or mentally ill. A program will reach individuals who are physically disabled but will not be appropriate for individuals who are intellectually disabled. Most programs that are now running do not reach across disability groups nor do they integrate individuals with disability into more general outreach efforts. Some of those HIV/AIDS interventions that do exist are outstanding; innovative, creative and effective. Others are less comprehensive. Most have only been presented to small groups and almost none have been systematically evaluated.

2. If individuals with disability are to be included in HIV/AIDS outreach efforts, it is also imperative that this be done as part of regular programming and not be undertaken as a ‘one time’ or isolated effort. In the majority of cases reported to the Global Survey, a series of two or three training sessions were run, a small number (20 to 40) of individuals with disability were trained and then the sessions were discontinued. While any attempt to bring HIV/AIDS education to disabled populations is to be commended, such small, scattered and short-lived attempts at educating other vulnerable groups about HIV/AIDS – (women for example or members of tribal groups) – would not be considered adequate.

3. In implementing AIDS outreach efforts, it is important to make sure that individuals with disability are reached not only regularly, but also reached in numbers that reflect their presence in society. According to the World Health Organization, at least 10% of the world’s population is disabled. If AIDS educators, AIDS outreach programs or health care workers who provide AIDS

medications and outreach services do not find that some 10% of all those reached and served are disabled, then questions about appropriately targeting and including individuals with disability should be asked. If one is running an HIV/AIDS campaign and has never seen someone with a disability in the audience or if one is responsible for a clinic that provides HIV testing and no one with a disability has ever appeared for a test, then part of the community that is supposed to be served is not being reached.

4. Not only have there been exceptionally few HIV/AIDS interventions for disabled populations, but those interventions that have been undertaken have rarely been evaluated. The need for evaluation of HIV/AIDS outreach programs for individuals with disability is immediate and pressing. We need to know not only what programs are put in place, but also whether these programs actually make a difference in the knowledge, attitudes and practices of individuals with disabilities towards HIV/AIDS and in the effective delivery of AIDS education and services to this population. Furthermore, we need to know not only if these programs are working, but also why they are effective. Such programs also need to be regularly monitored to ensure that they continue to be effective and that they adapt and expand as new information and approaches to HIV/AIDS become available.

5. Involvement of Disabled Peoples' Organizations (DPOs): AIDS advocates, health care professionals, policy makers and others now interested in reaching out to the disability community have a powerful ally: Disabled People's Organizations (DPOs) can be an invaluable source of information and guidance. Increasingly, Disabled Peoples' Organizations are taking the lead in organizing and implementing HIV/AIDS outreach efforts – and in such cases AIDS organizations, advocates and policy makers will be important factors for success.

Disabled people's organizations often can provide the best insight into local attitudes, beliefs and practices on disability, have the best information available on the numbers of individuals with disability in their communities and maintain strong networks that can notify disabled people throughout the area about AIDS education and services available. Not every disabled individual in any community is linked to formal or informal disabled people's networks, but many are and such groups can be invaluable partners in the fight against AIDS.

It is also important to note, that such formal and informational disability advocacy groups can be most helpful if they are included as partners in HIV/AIDS initiatives at the outset of a program

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and not just contacted for their approval at the very end of the process. Importantly such groups are often run on shoestring budgets. If they are asked to participate in HIV/AIDS outreach efforts, funding to help support such outlay of time and energy would be most helpful

Finally, individuals with disability should never be considered solely as the recipients of such outreach efforts. Individuals with disability can and should be recruited and trained to themselves be HIV/AIDS outreach workers both for the general public and for disability focused outreach efforts.

Check list to Ensure Inclusion: The following check list might prove useful in assessing current efficacy in reaching individuals with disability and disabled populations with HIV/AIDS messages:

<i>Question</i>	<i>Yes (<input checked="" type="checkbox"/>)</i>	<i>No (<input type="checkbox"/>)</i>
Are individuals with disability coming for trainings/ receiving services?		
How many are coming? Are you seeing individuals with disability in proportion to their numbers in the community – (~10% of the total population)?		
Are you serving individuals with all types of disabilities (physical, intellectual, blindness, deafness, and mental health concerns)?		
Are you serving subgroups: equal numbers of men and women? Disabled adolescents? Disabled members of local ethnic/ minority populations?		
Are allied services – HIV testing centers, care and treatment programs - equally accessible and inclusive?		
Are you monitoring knowledge/attitudes/practices to ensure that disabled members of the community have levels of knowledge and awareness about AIDS comparable to non-disabled peers?		

Finally, it would be helpful for the purposes of programming and future planning, to keep track of what proportion of the training is being done as part of general inclusion (type I); adapted to ensure inclusion (type II) or disability specific (type III).

Conclusions and Recommendations for the Future

The typology proposed here is currently being further developed and will be linked with evidence-based data on 'best practices' to develop a series of forthcoming tool kits.

But a number of questions remain regarding the impact of the AIDS epidemic on disabled populations. Among the most pressing of these are:

- Research on the epidemiology of the HIV/AIDS epidemic within disabled populations.
- Clearer understandings of the current factors that limit access to HIV/AIDS information and services for disabled populations and better understanding of the mechanisms that can improve access.
- Better understanding of the role and efficiency of community rehabilitation, clinical outreach efforts and other existing HIV/AIDS services for reaching disabled populations around the world
- More research on the leadership role that Disability Lead advocacy organizations can and should play around HIV/AIDS issues and health related matters in general

The typology that is proposed here is intended only to be a first step to facilitate the practical inclusion of this too often overlooked population

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Table 2: Low to moderate costs for modification and/or additions to existing programs

Strategy	Purpose of strategy & Cost implication	Suggested activities	Examples of suggested activities	Check points
<p>Type II</p> <p>Cost</p>	<p>Adaptations are made to AIDS outreach campaigns to ensure that individuals with disability are included as members of the general public</p> <p>Low to moderate cost</p>	<p>1. Adapt existing HIV materials to ensure that messages are accessible and available to the disabled population</p> <p>2. Ensure access to, and dissemination of, HIV/AIDS information in a variety of formats and media</p> <p>3. Establish a partnership with local disabled peoples' organizations (DPOs) and identify training needs</p>	<p>1.1 AIDS public service announcements adapted for the Deaf community with text captioning and Sign Language interpretation. (Sign Language interpreters are generally hired by the hour, rates are moderate and only a couple of hours of work would be needed)</p> <p>2.1 Creating picture story boards, photo novellas</p> <p>2.2 Making AIDS materials available for the blind in inexpensive cassette formats</p> <p>2.3 Making AIDS materials available for the deaf through visual formats</p> <p>2.4 Making meeting places accessible to individuals with physical impairments through inexpensive infrastructure modifications</p> <p>3.1 Developing a Training of Trainers curriculum with relevant topics to train AIDS outreach workers about disability</p> <p>3.2 Train individuals with disability to be AIDS educators for the whole community</p>	<p>1.1.1 Is the captioning of AIDS announcements clear and in simple language – remember many deaf individuals have low literacy levels</p> <p>1.1.2 Are there specific terms in local sign language for discussing HIV/AIDS?</p> <p>1.1.3 Are there local members of the Deaf community and local sign language interpreters you can contact for information and support?</p> <p>2.1.1 Are your materials in simple formats and illustrations that could be understood by those who are not highly literate? Remember many individuals with disability have little chance to go to school. Some deaf people will not know the local sign language</p> <p>2.2.1 Are AIDS messages available on inexpensive tape or cd versions to distribute to individuals who are blind or have little vision?</p> <p>2.2.2 Is there a local radio station that will be willing to talk about HIV/AIDS using simple messages that could reach blind individuals?</p> <p>2.2.3 Is there a local program specifically targeting the blind?</p> <p>2.3.1 Have you made sure that if you are planning a radio campaign about HIV/AIDS – which will not reach the deaf – you also have a newspaper campaign or a series of billboard ads?</p> <p>2.4.1 Have you looked into building ramps at meeting halls (e.g. ramps can be made of mud, stone, bamboo, wood).</p> <p>2.4.2 Have you talked to local officials about building a ramp into the local HIV clinic or Voluntary Counseling and Testing Center?</p> <p>3.1.1 Are members of the HIV outreach team in contact with DPOs for guidance and oversight to ensure they understand disability issues and concerns?</p> <p>3.2.1 Have you identified individuals with disability who are willing to help disseminate HIV/AIDS messages? Have you worked with local disability groups (DPOs) to ensure outreach to all members of the disabled community?</p>

