

Guidelines to Foster Disability-Friendly HIV/AIDS Programs

Funded by

United Kingdom
Department for International
Development (DFID)

RESEARCH AND LEARNING FUND

**For use by
the HIV/AIDS and
Disability Sectors in
Manipur and Nagaland
(North-east India)**



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and



Project ORCHID, Emmanuel Hospital Association, India



March 2007

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ACKNOWLEDGEMENTS

The authors wish to thank the UK Department for International Development, Research and Learning Fund, for funding all aspects of this project, and the Delhi-based Program Management Office that administered the scheme, for their practical support and flexibility. Warm thanks are due to the research teams in each state. In Manipur this included Dr Rajeev Irengbam, Dr Pebam Krishnakumari and Ms Gurumayum Pritam Devi. In Nagaland this included Dr Jamedi Longkumer, Ms Ella Mary Kaje, Mr Wetshokhrolo Lasuh and Ms Toshi Rongsenyangla Aier. The authors are also very grateful for the support and interest shown by the Directors and staff of the Manipur and Nagaland State AIDS Control Societies. The authors wish to highlight the invaluable logistical support provided at many points during the past year by staff from Project ORCHID in Dimpur, Imphal and Guwahati, including its Director, Dr B Langkham.

Finally, the authors wish to express their enormous debt to all those who generously agreed to participate in the research and workshops, openly sharing their experiences, ideas, insights and energy. These individuals include representatives of HIV and disability organisations, as well as people with disability, living in Manipur and Nagaland. We wish all of them the very best for the future.

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LIST OF ACRONYMS

AIHI	Australian International Health Institute (University of Melbourne)
AIDS	Acquired immunodeficiency syndrome
CBR	Community based rehabilitation
EHA	Emmanuel Hospital Association, India
DFID	Department for International Development (UK)
DPO	Disabled People's Organisation
HIV	Human Immunodeficiency Virus
IDU	Injecting drug user
NACP	National AIDS Control Programme
NGO	Non-governmental organisation
Project ORCHID	Collaborative HIV-prevention project (AIHI and EHA) in NE India
PWD	People with Disabilities
SACS	State AIDS Control Societies
STI	Sexually-transmitted infection
VCT	Voluntary counselling and testing (for HIV)



FOREWORD

These Guidelines were developed through a collaborative research project funded by the UK Department for International Development (DFID), Research and Learning Fund, which supported a range of HIV-prevention projects in India during 2006 – 07. The content of this publication (including any errors) is entirely the responsibility of the research team and does not necessarily reflect the views of the British government or DFID, nor the organisations where the authors are based. The authors of this document and their affiliations follow.

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The authors also acknowledge the technical input of Dr Rebecca Sinate, Deputy Director, Project ORCHID (a collaborative project implemented by the Emmanuel Hospital Association, India, and the Australian International Health Institute).

INTRODUCTION

The northeast Indian states of Manipur and Nagaland have a high prevalence of HIV, with an estimated 1.25% and 1.63% of pregnant women, respectively, testing positive in antenatal screening. (1, 2) HIV organisations have to date maintained a strong emphasis on working with so-called “high risk groups”, such as sex workers, intravenous drug users (IDUs) and truck drivers. Recent surveillance data suggests, however, that the epidemic is no longer restricted to these sub-groups, and is in fact increasing amongst the general population, primarily through heterosexual sex. (3-5)

Research in a variety of resource-poor settings has demonstrated that people with disability (PWD) are as likely to engage in high HIV risk behaviours as the general population (6-9). The research component of this project found that some PWD living in Nagaland and Manipur may in fact be more vulnerable to HIV infection due to a lack of awareness and knowledge of HIV transmission, social exclusion and poverty. As HIV organisations move to curb the increasing prevalence amongst the general population with mainstream HIV prevention, there is an opportunity to promote the inclusion of the needs of PWD from the outset.

Fostering Disability-Inclusive HIV/AIDS Programs in Manipur and Nagaland is a Department for International Development (DFID) funded project undertaken by the Australian International Health Institute (AIHI), University of Melbourne, and their research partners in the states of Nagaland and Manipur, in collaboration with Project ORCHID and the Emmanuel Hospital Association of India. The first phase of the project involved participatory research and a structured survey to document the risk perceptions of PWD and HIV programmers and to identify the needs and preferences of PWD in HIV responses. The second phase of the project consisted of state-level Guidelines Drafting Workshops with PWD and representatives from disability and HIV organisations, where findings were presented and participants gave recommendations to make HIV programs more disability-inclusive. Findings




and recommendations were used to draft a set of guidelines. The third, and final, phase involved meetings in Imphal and Dimapur to present the draft guidelines to stakeholders and elicit their feedback. The research design was given ethics approval by the University of Melbourne’s Human Research Ethics Committee and the Emmanuel Hospital Association’s Institutional Review Board.

This document incorporates and synthesises a review of published research, the findings of the participatory research component, and the recommendations derived from stakeholders who attended the Guidelines Drafting Workshops and Dissemination Meetings. The document is the final product of the DFID-funded project, providing Guidelines to Foster Disability-Friendly HIV/AIDS Programs. The Guidelines are intended for use by both the HIV/AIDS and disability sectors in the states of Manipur and Nagaland, but may be relevant in other settings.

In these guidelines, “disability” is used in accordance with the definition found within the World Health Organization’s International Classification of Functioning and Health¹ “HIV organisations” refers to government and non-government organisations (NGOs) working in the field of HIV prevention, care and treatment, as well as the State AIDS Control Societies (SACS). “Disability organisations” refers to Disabled People’s Organisations (DPOs)², government agencies, the welfare sector, and NGOs working with or for PWD. “HIV programs” refers to projects and interventions that offer information and/or services, such as:

¹ This classification scheme adopts a *biopsychosocial* model in which ‘impairment’ is defined as loss or dysfunction of a body part or system, and ‘disability’ as the interaction between the individual’s impairment and his/her ability to function. The latter, in turn, is a product of the community, environmental, personal and social practices that enable or prevent participation in all spheres of life. See www.who.int/classification/icf.

² DPOs are sometimes also referred to as “self-help organisations”. Such organisations are formed and run by people with disability, who represent the majority of the board responsible for decision making. Such organisations often play an important role in advocacy and awareness-raising in the community. (10)

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- HIV education and awareness programs;
 - prevention services, such as the diagnosis and treatment of sexually transmitted infections (STIs), provision of condoms and safe injecting equipment and voluntary counselling and testing (VCT); and
 - HIV/AIDS care, treatment and support.


This document begins by discussing some of the challenges of making programs disability-friendly and then identifies some basic principles and considerations for this task. It then offers suggestions for taking action in relation to PWD as a whole, and according to type of disability. It concludes with suggestions for modification of existing programs or approaches undertaken by HIV organisations and disability organisations to make these more useful in relation to PWD and HIV risk. It concludes with suggestions for modification of existing programs or approaches undertaken by HIV organisations and disability organisations to make these more useful in relation to PWD and HIV risk.

CHALLENGES IN RESPONDING TO THE NEEDS OF PEOPLE WITH DISABILITY

During the course of this research a number of challenges in responding to the needs of PWD were identified and explored. These findings have primarily been drawn from published work in the field and analysis of the first phase of the research project.

Obstacles to identifying and accessing PWD

- There is little reliable prevalence data on disability in Manipur and Nagaland. The 2001 census identified that 2.2% of the Indian population were living with a disability. (11) Census and local survey data have, however, been contested by organisations working in the field, who claim that strong stigmatisation of disability results in an underestimation of its true prevalence. Hence, disability activists, NGOs and many government agencies in India estimate the prevalence of people living with a disability to lie between 5 and 6% of the total population. (12, 13)
- Some disability organisations in Nagaland and Manipur have registers of PWD living in these areas, but there are doubts about the completeness of these records.
- It is especially difficult to access people with learning impairments and mental illness, as the disability itself may interfere with communication, it may not be clearly defined, and people with these disabilities often face greater levels of stigma and discrimination.(14)
- It is difficult to identify and ensure access for those PWD who live in rural areas or far from services.

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- Families, guardians and other “gatekeepers” (those who care for PWD and can permit or prevent access to them) may be uneasy if PWD are contacted by outsiders, or may not recognise their need for HIV programs. PWD are often perceived as not sexually active, but this is not true for many. (6, 7, 9, 15-17)
 - Gatekeepers also include so-called *point people* who control the placement and income of disabled beggars. The involvement of criminal rings in some instances poses risks for those wishing to contact and assist this sub-group of PWD.
 - Finally, a proportion of the disabled population are mobile, even homeless, and particularly difficult to locate.

Data gaps about HIV prevalence amongst PWD living in India

Globally, there has been very little investigation of HIV prevalence amongst the disabled population. The limited prevalence studies which do exist are based in the North American populations. (9, 18, 19) Mulindwa (8), however, demonstrated that young people living with disability in Uganda reported a high incidence of STIs, with 38% of females and 35% of males having experienced symptoms. No such studies or data were located on the prevalence of HIV or STIs amongst the disabled population in India.

No PWD-targeted HIV programs or policies

The National AIDS Control Organisation (NACO) has not yet explicitly recognised this population as a vulnerable group in relation to HIV, and there are no programs or policies at a national level which target PWD.

HIV programmers report difficulties in reaching PWD because their funding typically is tied to delineated areas of work or target groups, leaving little flexibility to alter or expand their focus. Furthermore, many HIV organisations have been established with specific mandates to serve recognised risk groups, particularly IDUs and sex workers.

Social exclusion of PWD


PWD often lack the confidence to engage with the wider community, attend community HIV campaigns and to express their needs due to:

- Being “overlooked” within their household and community.
- Reduced opportunities for social interaction. (20)
- The protective role of gatekeepers. This is particularly true for PWD living in Nagaland where communities perceive a charitable responsibility towards them. (20)
- Low self esteem as a result of the negative attitudes of family members and the wider community including, in some cases, superstitions that lead to stigma. (20)
- Fear of ridicule and concerns regarding their personal safety when in public. (20)
- Gender roles which reduce the independence and capacity of women in general to voice their needs. Hence, women with disability may face greater social exclusion than men with disability.
- PWD who are HIV positive may face the challenge of being stigmatised for both their disability and their HIV status. Both the HIV and disability sectors have an important role in supporting such individuals facing this double stigma.

Challenges in engaging PWD are not unique to the states of Manipur and Nagaland. Thomas (13) reported similar difficulties during participatory rapid appraisals in Gujarat, where “it was noted that disabled people sat at the back and participated only when specifically asked to do so.” (13, p. 23)

Disability networks and advocacy groups are not well-developed

There are a number of organisations with disability interests in Nagaland and Manipur, but these are poorly linked,. Moreover, there are very few established and supported DPOs or organisations formed and run by PWD. Those that



do exist primarily focus on the acquisition of benefits, rather than advocacy, empowerment and inclusion of PWD within the community. This represents a lost opportunity for awareness-raising about rights and needs among PWD and the wider community.

Lack of educators and interpreters

There is a lack of formally trained educators for the vision- or hearing-impaired in general. Thus, there is a lack of educators and interpreters able to convey information to PWD in Braille or sign language. This presents challenges for the dissemination of information and for maintenance of confidentiality, as PWD may have to rely on a carer, family member or friend to translate questions and even their history to a health professional.

Cost of specialised services

Representatives of HIV and some disability organisations perceive that the needs of PWD require specialised services that are beyond their financial capacity. Such specialised services were identified as an option by some participants in the study, and a preference by others, and cited in some international literature (17, 21). However, as will be discussed below, there are many potential ways to meet the needs of PWD within existing programs. The high cost of specialist services is an enormous barrier in low-income settings such as northeast India.

Cultural taboos

Cultural taboos in Indian society prevent the free discussion of sex and sexuality. (20, 22) As in the general community, there are misconceptions that educating PWD on HIV risk may lead to increased high risk behaviour. The effects of school based sex education have been well investigated and there is no evidence of an association between such education and increased sexual activity. (23)



Didactic teaching and learning approaches

As in many countries, the traditional lecture method of education remains strong in the Indian school system, and is often carried into public health education campaigns. Participatory and adult learning approaches have been found to be more effective for transferring knowledge.

Specialised HIV strategies may increase stigma and discrimination faced by PWD


Participants in the Guidelines Drafting Workshops expressed concerns that some specialised HIV strategies could potentially increase the stigma faced by PWD. For example, the use of PWD on public HIV posters or the establishment of HIV testing centres and services solely for PWD may lead the community to perceive PWD as a group that engages in HIV risk behaviours.

GENERAL PRINCIPLES AND CONSIDERATIONS IN RESPONDING TO THE NEEDS OF PEOPLE WITH DISABILITY

The following principles and considerations in HIV programming are based upon research findings and lessons learned from projects implemented internationally and in India, as well as the participatory research conducted in this DFID-funded project. These considerations apply in general to PWD. The subsequent section outlines suggestions for responding to the needs of PWD in relation to these considerations. Suggestions for responses according to specific types of disability are covered in Part IV of this document.

Access to information and care is a basic right

Where disabled people lack information or face conditions of extreme poverty, they may be more vulnerable to HIV risk behaviours than the general population. Like all the community, PWD have a basic human right to receive, in an accessible format, all the HIV information and services which are afforded to the general public by government agencies and NGOs. Similarly, all people share an equal right to health services, including HIV treatment and support. Organisations that offer HIV services, including those for HIV-positive people, should consider setting aside (reserving) a designated proportion of total resources specifically for PWD, e.g. places in antiretroviral therapy programs. Another suggested approach is a mechanism so that PWD are not forced to stand or wait for lengthy periods in queues. As already discussed, it is important however that any



specialised services or strategies consider potential negative attitudes or stigmatisation these may inadvertently foster.³

PWD are not all the same and each individual may have unique needs

PWD cannot be treated generically as a homogeneous population. There is great variety amongst people with disability in the type of disability, their level of knowledge and awareness, their level of independence, the roles of gatekeepers, and their ability to gain information and protect themselves from HIV. As such, no single intervention strategy will meet all their needs. Likewise, no single communication method will effectively reach or be received by all disabled people.


Meeting the HIV needs of PWD involves many sectors and organisations

HIV organisations disseminate information and provide programs and services to the general population. PWD are part of this population. Disability organisations and the state departments responsible for the welfare of PWD should consider the general and particular needs of PWD, including the needs of those who are HIV-positive. Communication and networking between these sectors is vital in meeting the needs of PWD.

Many PWD can only be reached through “gatekeepers”

Parents, guardians and family members are often protective of PWD’s safety and exposure to the outside community, which may treat them with stigma and discrimination. This level of concern and protectiveness varies according to type of disability and the age, sex and marital status of the disabled person.

³ Smith and colleagues (15) reported that staff in reproductive health services in Zambia had women with disabilities seen first when they entered the clinic. “These gestures may have been well-meaning. But they, in turn, contribute to perpetuating the notion that there is something abnormal about such women using reproductive health services.” (15, p.124)




The level of education, economic status and HIV knowledge and awareness of the gatekeeper also influences their ability to perform this role effectively. For example, Wazakili (6) found in a South African study that parents of young people with disability felt they did not have enough knowledge of HIV to effectively educate their offspring.

Existing community structures could be involved in meeting the needs of PWD

There are many existing community and government structures in both Manipur and Nagaland which could be utilised in the formation of strategies, dissemination of information and promotion of the needs of PWD in HIV programming. This is desirable because of the acceptance, effectiveness and reach of these organisations.

In Nagaland

- The Christian church is a powerful social institution with the potential to play an important role in supporting disability-inclusive HIV programs. The impact of HIV has been recognised by some Christian organisations and HIV topics are now being incorporated into Sunday school programs and theological college syllabus. Commitment to specific HIV prevention strategies, however, varies between organisations. There are reports of some churches becoming increasingly supportive of harm reduction strategies, such as promotion of condom use, whilst others continue to focus promotion activities on the principles of abstinence and faithfulness.
- In Nagaland all programs undertaken within that district must be approved by local village councils. These councils are male dominated and there are very few organised women's groups active within the community.
- Tribal unions are strong in Nagaland and can be prescriptive in a way that churches can not (e.g. churches can request attendance at a meeting, whereas Unions can command it). All Nagas belong to a tribal union



and there may be several unions within a tribe (e.g. in the Ao tribe, each village has its own union). Individuals may be members of the same union but attend different churches.

A note about the people of Nagaland

In Nagaland, people are often referred to as “local” or “non-local”. Non-locals are from other parts of India, such as Bihar, and are more likely to be Muslim or Hindu and, as such, less likely to be reached by Christian church networks. There are anecdotal reports that sex workers are more likely to be “non-locals” and that PWD have been engaging in transactional sex, both as a clients and providers. Hence, any strategies seeking to address HIV vulnerability of PWD will need to also consider engaging ethnic minority groups in this area.

In Manipur

- As in Nagaland, Manipur has a system of village councils. In Manipur, however, there are more organised networks of women’s groups which have varying levels of influence on community decision making.
- Christian Churches are involved in HIV prevention (some promote condom use) and thus could provide opportunities for sensitisation on the importance of including PWD in these programs. However, at least half the population of Manipur are not Christian.
- Hindu temples and leaders apparently are not yet involved in HIV prevention. It is unclear whether this is because they do not see it as their duty, have not yet considered the need, or lack the appropriate strategies.
- Outreach, Angalwadi, Community Based Rehabilitation (CBR) and multi-purpose rehabilitation workers are already in direct contact with PWD and their gatekeepers. With sufficient training and the establishment of links to the HIV organisations, these workers may have many opportunities to support the access and inclusion of PWD to HIV services.

Economic and social factors influence PWD's access to mainstream HIV services

Poverty and discrimination affect many PWD and limit their access to mainstream HIV messages and services.

- Attitudes of the wider community contribute to social isolation that acts to discourage PWD from attending community meetings and services. (20)
- With only 9% of Indian PWD having achieved secondary level education and only 26% being actively employed (24), many cannot afford expensive media such as television and radio, or transportation to community meetings.
- It was also suggested in FGDs and in depth interviews that limited employment opportunities may drive some PWD into high risk behaviours, such as sex work. (20) It is therefore important to recognise that development projects which include PWD in their programs may also play a role in reducing the vulnerability of PWD to HIV infection.

Preference for peer education

The FGDs and interviews identified a preference for peers to provide education to PWD. (20) The Sonagachi Project, based in West Bengal, successfully utilised peer outreach educators (in addition to health service development), to demonstrate a significant and sustained increase in condom use amongst sex workers. (25) Peer outreach educators have also been employed to provide education on HIV and STIs in rural Karnataka. (26)

Principles of group interaction

- Conveying information to a particular target group, such as PWD attending a vocational training program, will require that this information first passes through appropriate organisation channels and staff.
- Bringing people together in informal groups of similar age, sex, status, religious affiliation, linguistic and ethnic background promotes greater exchange of information.

GENERAL SUGGESTIONS FOR RESPONDING TO THE NEEDS OF PEOPLE WITH DISABILITY

The suggestions which follow have been developed in light of the considerations listed previously, through analysis of existing research in the field of HIV and disability, and the recommendations made by stakeholders during the Guidelines Drafting Workshops convened within the DFID-funded project.

1. **Modification of existing HIV programs and/or the development of specialised programs for PWD to ensure equal access**

Groce and colleagues (21) describe three different levels of modification to ensure inclusion of PWD in HIV programs that are derived from the findings of the *Global Survey on HIV/AIDS and Disability*.

- **Type I** strategies require little or no modification to mainstream HIV services when including PWD. Examples of such an approach are disability sensitisation training for HIV professionals and creating networks between DPOs and HIV programs.
- **Type II** strategies require minor adaptations, such as producing HIV education material in a variety of formats to make it accessible to PWD. For example, HIV information may be conveyed in poster or community play format making it accessible to hearing-impaired people, whilst information in radio broadcasts can be accessible to people with visual impairments.

- **Type III** strategies require the establishment of specialist HIV programs for PWD. (21)

The majority of recommendations which follow in these *Guidelines* fall into the categories of Type I and Type II. They utilise existing structures and services and involve adaptations which would not require significant additional economic resources. There is a need to inform both non-disabled and disabled people about the cost-benefits of PWD inclusion in existing services, with provision for a limited number of special services as required, rather than setting up parallel systems. By making adaptations to mainstream HIV responses, organisations also promote the social inclusion of PWD within the wider community. This may have positive social impacts, e.g. improving PWD support networks, community involvement and perceptions of self-efficacy.


2. National and state level policy modification are important

The new phase of HIV policy and programming at national level via the National AIDS Control Programme, NACP III (2007 – 2011), offers a superb opportunity to incorporate the needs of PWD into existing and new approaches. SACS and activists could play a role in the short term to influence the refinement of NACP III by drawing attention to weaknesses in, and opportunities for, strategies to address PWD. It may be useful to draw attention to the rights of *all* people, including PWD, for HIV prevention, care and support.

Similarly, SACS in Manipur and Nagaland have the opportunity to modify state level policies, programs and activities to incorporate PWD needs into the medium term.

3. Networks should be developed between the HIV and disability sectors

The establishment of links between disability organisations, social welfare sectors, SACS and NGOs working in the fields of disability and HIV would




provide many avenues for the sharing of knowledge and skills. Such networks would also improve the awareness and sensitivity of the HIV sector to the needs of PWD, and likewise, the sensitivity of the disability sector to the needs of PWD for HIV education and support. Advocacy efforts by activists and organisations from either sector can play a crucial role in this process, especially given the low level of awareness of PWD needs for HIV programs within these sectors and the wider community.

- The coordination and cooperation of local organisations is important for galvanising this process. At a state level, SACS, Social Welfare and other public sector departments that are involved in either sector should be approached regarding the provision of adequate funding to ensure that PWD receive the same services as the mainstream population.
- State agencies responsible for the welfare of PWD should actively engage in HIV prevention activities. This has the advantage of utilising the specialised outreach and communication skills that already exist within disability organisations. It can be argued that it is faster and cheaper to add HIV prevention activities to the range of activities undertaken by these organisations than to train HIV programmers in the specialised skills needed for outreach with PWD. However, both sides are necessary to develop and implement these activities at an acceptable standard.

4. Provide capacity building for both sectors

In order to maximise effective efforts undertaken by both the HIV and disability sectors, training to enable staff to meet PWD needs should be conducted.

- Those working in disability, who are likely to have existing skills in supporting PWD in particular ways, need a clear understanding of HIV transmission and prevention in order to convey this information to PWD. Discussion within the sector of potential risks and vulnerabilities may be confronting for some individuals, but is important to counteract assumptions about risk that may be incorrect. Capacity building should




involve those with expertise in HIV prevention and care in order to benefit from the large array of tools, games and approaches (developed over many years) that could be adopted or adapted by the disability sector. Basic facts about HIV/AIDS should be incorporated into general curricula used to educate PWD, whether in school settings or adult education programs.

- Similarly, the disability sector is best placed to enlighten those working in HIV organisations about the particular challenges and opportunities for communicating with and accessing PWD. Whilst it is probably impractical to train HIV programmers in sign language, for example, basic information about the needs and circumstances of PWD would enable many HIV organisations to address at least some of these needs with little or no additional effort.

5. “Gatekeepers” should be targeted for HIV education


Gatekeepers should be sensitised to the needs of PWD for HIV education, their rights to services, and the support networks available to them. Gatekeepers can be a variety of people associated with PWD and a disabled person may have more than one. Examples of possible gatekeepers are family, friends, guardians or hostel wardens. PWD who are involved in begging may be controlled by a *point person* who also needs to be involved when trying to access this particularly vulnerable sub-group of PWD.

- Parents, guardians and family members should be educated on how to recognise and respond to high risk behaviours in the individual with a disability, which may include lack of sexual inhibitions in the intellectually disabled, use of injecting drugs by the mobile PWD, etc. They should also be made aware of the risk of sexual abuse and rape, and be given methods of recognising and responding to such assaults, which could occur in the home or the community. Awareness-raising is needed in particular where the disability interferes with communication (e.g. deaf-mute, intellectually disabled).

- 
- Formal gatekeepers, such as hostel wardens, may be less emotionally attached and therefore less protective of the individual with a disability. Such gatekeepers should receive training not only on recognising high risk behaviours, but also on the provision of care for PWD engaging in such activities, on the goals of harm reduction, and on gender and human rights.
 - Organisations that provide outreach support to people on the street, including disabled beggars, are well-placed to work with the local *point person* to raise awareness about HIV vulnerability.
 - HIV organisations working to improve the knowledge and awareness of the general community are already reaching a portion of those who are family members and carers for PWD. As well, HIV organisations could consider developing specific education programs for gatekeepers and families of PWD. Such programs should not require new personnel, but rather slight changes in orientation of communication and content.
 - Disability organisations provide a potentially important link between HIV organisations and gatekeepers. They too may also be involved in the establishment of specialist training programs for the parents and carers of PWD, with appropriate support from the HIV sector. Providing opportunities for gatekeepers to visit services and gain better understanding of these is another useful option.

6. Engage and educate community and religious leaders in the HIV needs of PWD

As the Christian church plays an important role in the communities of these states, religious leaders should be consulted in the programming process and sensitised to the needs of disabled people within their community. Church fellowships may also provide a variety of forums for the inclusion of PWD in community HIV activities. Hindu and Muslim leaders should also be similarly engaged.



It is also important to increase the awareness of the needs of PWD amongst village leaders. These leaders are the local village head men and representatives from local youth or community groups. Such an approach will facilitate the reach of programs to people not affiliated with Christian institutions.

7. Improve access to services through provision of transportation, allowances or outreach


HIV and disability organisations should consider providing transportation or travel allowances to enable PWD to access community HIV services and events. Where this is not possible outreach services should be considered. Such a service does not need to serve only PWD. A generalist outreach service could be utilised if the workers are sensitised to identifying and engaging PWD within that community.

8. Identify and train members of the disabled community as peer educators

Appropriate members of the disabled community could be selected to receive training and support from HIV programs. They could then take this knowledge back to the community to create awareness and enable PWD to protect themselves more effectively. Such an approach will have greater success and sustainability if linked with existing programs and structures. These trained peer educators could provide education to the wider community, thereby increasing the awareness and acceptance of PWD, and the self-confidence of the educators.

9. HIV prevention messages should be conveyed in a variety of formats

Delivery of effective public HIV education for PWD can be partly achieved by strengthening the quality of generalised public education. Dissemination of HIV prevention messages in appropriate language and in a variety of



formats, such as radio, television, seminars, posters and plays, will ensure that they reach the greatest proportion of the general population, including those with disabilities.

10. Promote rights to education amongst PWD

Promoting literacy and general education amongst PWD will improve their socioeconomic circumstances, and over time, reduce their vulnerability to HIV infection. Disability and government sectors should therefore liaise regarding the provision of incentives and funds to facilitate education for PWD.

SPECIFIC SUGGESTIONS FOR RESPONDING TO THE NEEDS OF PEOPLE WITH DIFFERENT TYPES OF DISABILITY


The following guidelines are specific to the HIV prevention and treatment needs of people with visual, hearing, physical and intellectual impairments in Manipur and Nagaland. They are derived from findings of the participatory research component of the project and suggestions made by stakeholders in the Guidelines Drafting Workshops convened during the project. *It should be noted that the participatory research did not directly involve people with intellectual or hearing impairments.* Recommendations for responding to the needs of such individuals have been developed from the information gathered through in-depth interviews and workshops involving representatives of disability organisations working with these groups.

No recommendations are made here for *people with mental illness*, as this sub-group was not the focus of the project due to limitations of expertise and time. However, research has identified that people living in India and experiencing mental illness may engage in high risk behaviours and be at risk of sexual coercion. (27, 28)

BLIND/VISION-IMPAIRED

1. Provide HIV information in simple non-visual form

While HIV information in Braille format would be of great benefit to those individuals who are literate, it is unlikely to reach the wider visually impaired



population who are illiterate. Interview and FGD participants reported a preference for HIV education material to be in audio format, such as television, radio or CD ROM. (20) Some material in Braille should be provided to places where blind PWD gather, such as schools and hostels.

Considerations

Audio information should be available in Manipuri, Nagamese and tribal dialects. Organisations conducting community plays and meetings should also consider having extra descriptive dialogues in their presentations to ensure those with limited sight are able to understand the key messages.

2. Provide practical sessions on self protection

Practical, hands-on education is vital for the vision-impaired. For example, opportunities should be provided for them to handle and practice condom application. As described in *A Health Handbook for Women with Disabilities* (29), published online by the Hesperian Foundation, people with visual impairments can also be educated on ways of recognising STI infection through self-examination techniques.⁴


Considerations

Small groups will facilitate the interaction of people with visual impairments and ensure that practical components can be achieved.

3. Develop networks between the Blind Associations and HIV organisations

The National Association of the Blind could facilitate the formation of small groups of visually impaired people to be trained by local HIV organisations on peer education and other outreach. These associations could also provide

⁴ *A Health Handbook for Women with Disabilities* (29) also provides suggestions for self-examination techniques appropriate to people with different types of physical impairments. The document is available online from: http://www.hesperian.org/publications_download.php#wwd



condoms, safe injecting equipment and educational material using back up support from HIV organisations.

Considerations

Some members and representatives from disability organisations themselves were found to have limited or inaccurate knowledge about HIV. (20) Ensuring appropriate training of such staff undertaking HIV activities is therefore vital to facilitate more effective referral of those visually impaired individuals who require specialist HIV services, such as STI treatment or VCT.

4. Provide outreach services to access the visually impaired

Outreach may provide opportunities to increase the awareness of the visually impaired and their carers on the relevance of mainstream or specialist HIV programs. Outreach workers could also assist the blind to access these programs where appropriate and feasible.

DEAF/MUTE/HEARING-IMPAIRED

1. Ensure the literate hearing impaired have access to mainstream written material

To disseminate written material to the literate hearing-impaired would require the assistance of disability organisations and gatekeepers.

Considerations

Such information will only be available to those members of the hearing community who are literate, which make up less than half of this sub-group, according to the 2001 Indian census. (11)



2. Provide information to the hearing impaired in visual format

Mainstream visual messages, such as plays, posters and illustrated publications, have the benefit of reaching hearing impaired individuals.

Considerations

To ensure that hearing-impaired people receive these messages, HIV organisations may consider dissemination through disability organisations or those local community structures which include people with hearing impairments.

3. Provide information to the hearing-impaired through sign language

Considerations


In many situations, people with hearing impairments use a local or family sign language. One strategy to improve the dissemination of information to this group of people might be to identify and train an individual who already possesses the skill of local sign language to act as a peer educator. Another would be to educate the gatekeepers and seek their assistance in transmitting this information.

PHYSICALLY DISABLED

People with physical impairments often experience geographical or physical barriers which prevent them from accessing mainstream HIV programs and materials.

1. Ensure facilities are physically accessible

Disability organisations should liaise with HIV organisations as well as community leaders to ensure that offices, health facilities and meeting places are physically accessible to all. Examples of ways to achieve this include:

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- Providing appropriate transportation.
 - Locating services on ground floor levels.
 - Providing chairs for people to sit in.
 - Conducting information sessions and meetings during times of good weather in places that are geographically accessible and easy to locate.

Considerations

A large proportion of the mainstream population experience difficulties with movement, but are not identified as physically disabled. Such adaptations to services will ensure these are available to the wider community and not just those with physical disabilities.

2. Provide assistants in health facilities and VCT centres

Providing assistants in health facilities and VCT centres will enable people with physical disabilities to attend and even seek testing without relying on family or friends.

Considerations

Such an arrangement may make people with physical impairments more likely to seek advice and testing because their confidentiality is protected.

3. Orientate people with physical impairments to local HIV services

Local disability organisations could inform people with physical disabilities about services and facilities which are accessible to them. Escorting people with physical disabilities to such services may improve their confidence to access them independently in the future.

Considerations

Where people with physical disabilities are unable to access mainstream services, outreach services could be provided either through a peer education program and/or representatives of HIV organisations.

INTELLECTUALLY DISABLED

1. Organise education and information sessions for “gatekeepers”

Gatekeepers are the major direct focal point for most intellectually disabled individuals. They should receive education to ensure they have a clear awareness and understanding of HIV, and are able to recognise and respond to high risk behaviours in the individual. Representatives from HIV programs should invite care-givers to community education activities.

Considerations


Disability organisations could provide the vital link between carers and HIV organisations.

2. Raise community awareness of their risk and vulnerability

Within the disabled community, it is important to develop DPO networks, so that people with intellectual impairments have people advocating for their rights and protection. Community education campaigns should educate and raise community awareness of the special needs and rights of people with intellectual impairments for protection against sexual abuse and coercion. As gatekeepers may be the perpetrators of such abuse, entire communities should be encouraged to create an environment in which such abuses are recognised and repudiated. This may be done, for example, through principles of community engagement and sensitisation of local police forces (and community leaders) to the needs of sexually abused PWD. (29)

3. Present HIV education messages in simple, single point form

Many intellectually disabled people can learn and understand information if it is not overly complex. Messages for the general population should be presented with appropriate visual cues and with small, simple pieces of information. People with learning impairments are most likely to acquire HIV knowledge when messages are repetitive and consistent in nature.



4. Develop specific HIV messages and services for people with intellectual impairments

People with intellectual impairments may require customised messages which meet their level of cognition. HIV messages may need to be adapted so they are simpler and concrete, such as those utilised in the “Good touch/Bad touch” program developed by Childhelp, Inc. to combat child abuse; visual demonstrations are another useful approach for intellectually-impaired PWD. If there are many people with intellectual impairments in a community, support groups and specialised education sessions could be developed.

Considerations

Developing specialist messages and services for people with intellectual impairments requires increased economic and human resources.

SUGGESTED MODIFICATIONS TO EXISTING PROGRAMS

While HIV programs possess the specialist knowledge and services to prevent and manage HIV amongst the general population, they lack links to the disabled community. In contrast, disability organisations have direct links to PWD and specialist skills in communicating effectively with this group. They, in turn, lack the expertise to effectively convey HIV information and services. The following recommendations for modifying existing HIV and disability programs were derived from the Guidelines Drafting Workshops and the stakeholder feedback meetings held in both states.

MODIFYING HIV PROGRAMS

1. Utilise disability organisations to access PWD

DPOs and other disability organisations are highly motivated towards the welfare of PWD. Their specialist knowledge and ability to engage PWD make such organisations valuable resources and associates for HIV programs. Disability organisations could be recruited to provide disability awareness and sensitisation training to teachers, staff and health professionals within the HIV sector. These individuals can in turn transmit HIV information to the disabled community through direct contact or via appropriate carers and gatekeepers. They can also provide links to the disabled population for specialist HIV services and programs. CBR may provide a framework for the integration of education programs for specific groups of PWD.



2. Train PWD as peer educators

Recruit PWD to act as peer educators for the disabled and wider community. This will facilitate the identification of PWD within that community and improve the relevance and receptivity of messages conveyed.

3. Provide outreach services

Where possible provide outreach services, because many PWD will either be unaware of services or unable to access facilities.

4. Make facilities physically accessible

When building new facilities, HIV organisations should try to ensure that they are physically accessible to PWD. They should also consider making minor adaptations to existing facilities, such as provision of chairs, ramps and railings.⁵

5. Produce HIV information in a variety of formats

Produce educational material in a variety of formats to reach the wider population, which will include PWD.

MODIFYING DISABILITY PROGRAMS (GOVERNMENT and NGO)

1. Create networks with HIV organisations

Links between disability and HIV organisations could provide support and education sessions for disability organisations and their clients/members. Such links may also provide opportunities for disability organisations to sensitise the HIV sector to the needs of PWD.

⁵ Further suggestions of simple ways in which health services can be made more disability-friendly and accessible to PWD are made in *A Health Handbook for Women with Disabilities*. (29) Many of the suggestions are also applicable to men.



2. Provide support for PWD to access HIV information and services

- Offer opportunities for PWD to come together and discuss HIV related issues. Provide facilities and support for HIV educational groups for PWD.
- Train disability providers to offer appropriate HIV materials and education to their clients. For example, a CBR worker may be trained as an HIV educator or to offer life skills workshops and sexual health education in existing disability programs.
- Establish small drop-in centres where PWD can access appropriate HIV educational material, e.g. in the offices of disability organisations, specialist vocational training centres, etc.
- Promote the inclusion of HIV education into the curricula in special schools.
- Find out what HIV services are in the area and help inform PWD about where and how they can access such services. Ensure that this orientation is specific to the needs of individuals and be aware that it may need to be modified according to type and level of disability. For example, it may be necessary to ensure that people with visual impairments know exactly where they can acquire free condoms.

3. Liaise with community and religious leaders

Promote the needs of PWD at the community level with religious organisations and community leaders or groups.



CONCLUSION

The increasing HIV prevalence amongst the general populations in Nagaland and Manipur calls for an “integrated and all-inclusive” response. (3) Addressing the HIV needs of all Indians, including those with a disability, in mainstream HIV responses, is essential from both a public health and human rights perspective. (21) This document provides HIV and disability organisations with practical guidelines which have the potential meet the HIV education and service needs of a large proportion of the disabled population in these states. The majority of the modifications recommended require relatively little additional economic or human resources and have the potential to support the immediate inclusion of PWD in mainstream responses. Longer term strategies, however, should be considered to provide for specialist services which meet the needs of people with disabilities not effectively reached through these mainstream responses.

ADDITIONAL RESOURCES

Those wishing to learn more about the field of disability, and its links to HIV-prevention, may wish to consult the documents, websites and/or organisations listed below. This is not intended as a comprehensive list, but simply a starting point of readily-available sites. Some are international and may be accessed by the internet, while others are based in India.

Free and Downloaded Resources Compiled by International Organisations

HIV/AIDS and Disability Global Survey, Yale University / World Bank.

<http://cira.med.yale.edu/globalsurvey/resources.html>

From their website: *Located at the Yale University School of Public Health through the Center for Interdisciplinary Research on AIDS (CIRA), with funding from the Office of the Advisor on Disability and Development and The Global HIV/AIDS Program of the World Bank, the Global Survey on HIV/AIDS and Disability seeks to understand the impact of the AIDS epidemic on the worlds 600 million men, women and children who live with a disability.*

International Information Support Centre (search resource library)

http://www.ids.ac.uk/sourcsearch/cf/keylists/keylist.cfm?Search=QL_hivdis_AS04&topic

AIDS Alliance HIV/AIDS information

<http://www.aidsalliance.org/sw1280.asp>

Selected India-Based Disability Organisations

Samarthya: *National project for promotion of a barrier free environment for disabled persons*

B-181, Mansarovar Garden, New Delhi-11-15.

Tele/fax (011) 41019389, (M) 09810558321

www.samarthyaindia.com, E-mail: samarthyaindia@yahoo.com

AADI – Action For Ability Development and Inclusion
(formerly Spastics Society of Northern India).

Focus areas: Education; Welfare of the physically and mentally challenged; Rural development.

Contact Person: Ms Nirmal Malhotra.

2, Balbir Saxena Marg, Hauz Khas, New Delhi – 110016

Tel: (011) 26966331 / 26569107 / 26864714. Fax: 26853002.

E-mail: ssni.@del,3.vsnl.net.in

Handicap International India

Ground Floor, 10 Zamradpur Community Centre, Kailash Colony Extension, New Delhi 110048. Tel: (011) 4656 6934 / 935 / 936 / 937

Additional website: http://www.handicap-international.org.uk/page_184.php

Eyeway.org

From website: *This site is a comprehensive source of material that informs, inspires and includes persons with visual impairments. In addition, the site caters to the requirements of parents and guardians, medical professionals, rehabilitation experts and service providers.*

Contact details:

Eyeway.org, Care of: Score Foundation, 125 B, Shahpur Jat, New Delhi 110 049

Tel: (011) 26494582. Fax: (011) 26494581. E-mail: inspiration@eyeway.org

<http://www.eyeway.org/>

Action on Disability and Development

http://www.add.org.uk/index_main.html

AIDS Alliance India (publications on community participation)


<http://www.aidsallianceindia.net/Main/AboutUs.aspx>

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