

TOO FEW TO WORRY ABOUT?

OR TOO MANY TO IGNORE?

**THE EXCLUSION OF PEOPLE WITH DISABILITIES FROM
HIV PROGRAMMES IN INDIA**

FINAL REPORT

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Finally, I sincerely hope that this report can be a catalyst to enabling people with disabilities to achieve their rights of equality of access to HIV information, programmes and services.

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ABBREVIATIONS

AIDS	-	Acquired Immuno-Deficiency Syndrome
AIFO	-	Associazione Italiana Amici di Raoul Follereau
AIHI	-	Australian International Health Institute
APAC-VHS	-	AIDS Prevention and Control Project, Voluntary Health Services
APSACS	-	Andhra Pradesh State AIDS Control Society
CBM	-	Christoffel-Blindenmission
CBR	-	Community-Based Rehabilitation
CINI	-	Children In Need Institute
CMV	-	Cytomegalovirus
DACS	-	District AIDS Control Society
DFID	-	Department for International Development
DLNs	-	District Level Networks
DPOs	-	Disabled People's Organisations
HIV	-	Human Immuno-deficiency virus
HOPES	-	HIV of Positive People Efficiency Society
IDUs	-	Injecting Drug Users
IEC	-	Information, Education and Communication
INGOs	-	International Non-Governmental Organisations
INP+	-	Indian Network of Positive People
ISL	-	Indian Sign Language
KNP+	-	Karnataka Network of Positive People
LCI	-	Leonard Cheshire International
MDACS	-	Mumbai District AIDS Control Society
MSM	-	Men who have Sex with Men
NACO	-	National AIDS Control Organisation
NGOs	-	Non-Governmental Organisations
NPDO	-	Network of Persons with Disability Organisation
PMO	-	Programme Management Office
RDT	-	Rural Development Trust
SACS	-	State AIDS Control Society
SIAAP	-	South India AIDS Action Programme
SLF	-	Stichting Liliane Fonds
SLNs	-	State Level Networks
TANSACS	-	Tamil Nadu State AIDS Control Society
USS	-	Utkal Sevak Samaj
UVYC	-	United Voluntary Youth Council
VCTC	-	Voluntary Counselling and Testing Centre
WHO	-	World Health Organisation

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

EXECUTIVE SUMMARY

Project rationale

Poverty is recognised as a factor that significantly increases vulnerability to HIV. Disability is both a cause and consequence of poverty and people with disabilities are over-represented among the poorest of the poor. Although figures are disputed, it is generally accepted that 6% of India's population - 70 million people - have disabilities.

People with disabilities are a part of every social group. In the context of HIV, this includes high risk and vulnerable groups such as sex workers and their clients, IDUs, MSM, orphans and prisoners. People with disabilities do the same things as everyone else and are no more and no less sexually active than the general population. People with disabilities marry. Some migrate in search of work and some engage in. Some women with disabilities live with men who practice high risk behaviour.

It is commonly and incorrectly assumed that people with disabilities are sexually inactive, unlikely to use drugs or alcohol, and at less risk of violence and rape than non-disabled people. Most organisations working on HIV have not thought to include people with disabilities in their programmes, or do not know how to do this. IEC materials are provided on the assumption that they can be seen, heard and understood which makes them inaccessible to many people with disabilities. Most disability organisations do not yet have HIV on their agenda, or do not know how to access this support.

Despite an estimated number of 320,000 people with disabilities living with HIV in India, most programmes reach only a fraction of that figure, between 0-2%. With 6% of the population not included in HIV programmes, is this too large a section of society to ignore and will this impact upon efforts to slow the spread of HIV?

The purpose of this project was to identify gaps in HIV awareness, prevention, care and support programmes in India. The findings are intended to make the case for HIV planning, policy and practice that is inclusive of people with disabilities. The aim is to identify how the disability sector can be supported engage with HIV, and how the HIV sector can be supported to make their programmes accessible to, and inclusive of, people with disabilities.

The project explored levels of awareness of HIV and perceptions of vulnerability among people with disabilities and how this differs by impairment, sex, age and location by interviewing 521 people with disabilities from 14 states. About 100 organisations (40 working on HIV and 60 on disability) were visited to ascertain what, if any, steps had been taken to include people with disabilities in HIV programmes or, in the case of disability NGOs, to provide or access information on HIV. And where this was not happening, to understand the reasons for this.

The draft research report and aggregated survey findings were presented at a feedback and planning workshop held in Bangalore on 22nd February 2007 for organisations consulted during the research phase. In general, participants felt that the analysis was valid, and the strategies and recommendations relevant, timely and practical. The major recommendation from the workshop was the establishment of one or more disability NGOs as champions of HIV to encourage and support the disability sector to engage with HIV. These nodal NGOs would also train other disability NGOs on how to engage with and include HIV in their work and take up the issue of inclusion of people with disabilities into existing HIV programmes conducted by mainstream NGOs. The development of HIV champions within the disability sector calls for a degree of commitment in terms of time and resources by the HIV sector and some form of joint working group.

Global context

Several international NGOs working on disability are currently looking at how to incorporate HIV into their programmes at an organisational level. In each case, this was after encountering people with disabilities infected and affected by HIV in projects they supported.

A Global Survey on HIV/AIDS and Disability conducted by the World Bank and Yale University in 2004 revealed that people with disabilities were not yet on the radar screen of the HIV sector, despite being vulnerable to all known risk factors, and the paucity of information on the relationship between HIV and people with disabilities. *Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts* were subsequently developed by Yale University (Groce, Trasi & Youasfzai) in 2006. They noted that several questions remained unanswered. Should people with disabilities be included in mainstream programmes or are special initiatives and targeted approaches needed? Will this mean extra expense and if so, where will this come from? The discussion is usually articulated as a choice between doing nothing or implementing expensive, resource-intensive efforts.

The Groce *et al* report argues strongly that inclusion of people with disabilities into HIV programmes cannot wait since the issue is one of basic human rights and public health. The lives of people with disabilities are no less valuable and there can be no justifiable argument to assign them to the bottom of the HIV priority file. Since people with disabilities make up to 10% of the global population, the numbers are simply too large to ignore and continued exclusion runs the risk of hampering efforts to slow the spread of the virus.

The report also suggests three levels of intervention from inclusion of people with disabilities into existing programmes at little or no additional expense, through modifications to existing HIV programmes for greater participation at a low to moderate cost, to outreach efforts that are specifically targeted at people with disabilities which are more expensive.

Research findings

One of the most encouraging findings of this research was the generally overwhelming acceptance by the HIV sector of the case for the inclusion of people with disabilities within their programmes. This research came across several instances of government agencies being approached by disability NGOs to make their IEC materials accessible to people with disabilities and readily agreeing to this. Within the disability sector, general reactions were either that organisations had thought about how to introduce HIV but did not know how or where to access support, or that they hadn't previously thought about HIV but now saw the need to address this.

There are however still a few institutions and organisations who do not subscribe to these views and are uncomfortable with the research assumptions and implications. Some asserted that "people with disabilities don't do those sort of things" while others expressed concern that providing sex education and information on HIV might "corrupt" people with disabilities and encourage them to experiment. Some HIV organisations working with high risk groups felt that because people with disabilities have not been identified as a high risk group, there was no need to include them - a position which ignores the reality that some people with disabilities engage in high risk behaviour.

It has been extremely difficult to gather data on the incidence of HIV among people with disabilities and the degree to which they are being included in, and accessing, HIV programmes as no organisation currently records this information. There is therefore still a need for a more detailed study of the incidence of HIV among people with disabilities and the numbers actually accessing HIV information, services and programmes. One simple method would be to add a box to pro-forma stating whether the person is disabled.

There is no evidence that people with disabilities are a high risk group or that the numbers of people with disabilities living with HIV are higher than their representation within the general population. Equally however, there is no evidence to suggest that their numbers are any less than this. In the absence of evidence to the contrary, it seems logical and cautious to assume that 6% of people living with HIV will be disabled.

Applying NACO's current prevalence rate to the estimated disabled adult population suggests that there are over 313,000 people with disabilities who are HIV positive, while applying the 6% figure to NACO's estimate of 5.412 million people living with HIV gives 324,600 - an average of 319,000. This should mean that up to 32,000 people with disabilities living with HIV have been identified and are being supported in existing HIV programmes. From the anecdotal evidence gathered, nothing even remotely approaching this figure is being achieved. The low numbers of disabled people appearing in HIV programmes and networks are more likely to be an indication of not being reached rather than that they don't exist.

Modes of transmission for people with disabilities are exactly the same as the general population. Disabled men migrate for work and some visit sex workers; some people with disabilities engage in pre- and extra-marital sex; women with

disabilities who are HIV positive have usually been infected by their partners; some women with disabilities work as sex workers; some disabled men have sex with other men; and some are injecting drug users.

Within the HIV movement, several State and District Level Networks of the Indian Network of Positive People have members who are disabled, although estimated numbers were often in single figures or between 1-3% of their membership. Similarly low figures were reported by organisations of people with disabilities. A study in 2000 calculated that 193,607 deaf people in India were HIV positive and yet Deaf Way, a support network for over 3,000 deaf people, know of less than ten.

Among organisations running HIV programmes, a similar picture emerged. Of ten organisations who estimated the number of disabled people living with HIV in their programmes, the average was 1.9%. At least two of these organisations felt this was a result of people with disabilities not being diagnosed, not coming forward, and not being reached. Within the disability sector, several NGOs with disability programmes knew of a few people with disabilities living with HIV, but again, numbers were very low.

The two major reasons for this are the HIV sector's failure to include people with disabilities in its programmes, and lack of awareness of HIV among disabled people. This exclusion is the same attitudinal, institutional and environmental barriers that deny people with disabilities equality of access to all aspects of mainstream development rather than any conscious effort to exclude. Most disability NGOs have not thought to provide or access information on HIV to the people they work with and low levels of awareness of HIV were also common among disability NGO staff. One former DACS staff member commented that he never thought to include people with disabilities in HIV programmes and that nobody had ever suggested this.

One of the principal reasons for the lack of engagement with HIV by the disability sector, and exclusion of people with disabilities from HIV programmes is the lack of contact between the two sectors. Since it is unrealistic to expect the HIV sector to become experts on communication with people with disabilities, and unreasonable to expect the disability sector to become experts on HIV, joint initiatives between the sectors are the most effective strategy to address this gap.

Findings and analysis of individual interviews

As part of this research, a questionnaire designed to ascertain levels of awareness and understanding of HIV among people with disabilities, and their perceptions of vulnerability to HIV was developed from the Global Survey for use with disabled individuals. The survey consisted of four sections looking at background information, awareness of HIV, access to information on HIV, and help and support for disabled people living with HIV.

A total of 521 individual interviews with people with disabilities were conducted and of these, 350 have been inputted and analysed as part of this research. The 350 responses came from 49 NGOs with disability programmes across 14 states. 61% of respondents were from high prevalence states. 55% of respondents were male, 87% were adults and 93% were between 15-45 years. The survey had a strong rural

focus with 93% of respondents living in villages. 95% of interviewees lived at home while 5% were living in disability institutions. 66% of those interviewed had impairments that affected their mobility such as polio or amputation while 14% were blind or partially sighted. A further 7% were deaf or hearing impaired, 5% had intellectual impairments and 3% had mental health problems.

81% of respondents had heard of HIV which, considering that 60% of interviewees lived in high prevalence states, is perhaps not surprising. However, this still means that one-fifth of people interviewed had never heard of HIV and levels of understanding are a cause for concern. Just under half (45%) of those interviewed said they know nothing or very little about HIV.

Three-quarters (73%) of respondents felt that people with disabilities might be at risk of HIV, while two-thirds (64%) thought that they might be at greater risk than non-disabled people. When presented with a series of reasons why people with disabilities might be at risk, no single factor was identified. 12% of respondents felt this was due to lack of information on HIV, while three factors - the inability to develop the social skills to recognise and avoid vulnerable situations, lack of access to HIV prevention programmes, and families not letting people with disabilities participate in HIV programmes - each featured in 10% of responses. 9% of interviewees felt that the fact people with disabilities were as sexually active as the general population meant the same level of risk, while a similar number cited vulnerability to sexual abuse as a factor. The unavailability of IEC materials and information on prevention in alternative formats comprised 8% of responses, while people with disabilities being targeted since they are assumed not to be sexually active and therefore "safer" was noted by 7%.

In terms of access to information, 76% of respondents stated that they had received information on HIV. Of these, 32% identified friends and other people in their communities as their primary source while 25% cited government agencies or NGOs working on HIV. One-fifth cited the NGO they are in contact with, an indication that several disability NGOs are addressing HIV within their programmes. A further 10% gave their school or college while 8% mentioned TV, radio and newspapers. The low numbers acquiring information from the media illustrates their inaccessibility to people with sensory and communication impairments as well as the lower literacy levels of people with disabilities.

Of greater concern, just under half of respondents did not know who to approach or where to go if they wanted to get more information on HIV and only 17% of people with disabilities interviewed had ever asked for such information. Just over one-third knew of NGOs working on HIV awareness programmes in their area - a low figure considering the majority are living in high prevalence states. One-third knew of people with disabilities (probably themselves) who had been able to access information on HIV through programmes aimed at the general population. However, when asked how many people with disabilities in their communities might have been reached by mainstream HIV agencies, 78% felt that only a few had been reached while 19% felt that none had been reached. 81% of respondents felt that the amount of information on HIV reaching people with disabilities was less than that reaching

the general population and as a result, three-quarters felt that understanding of HIV among people with disabilities was less than the general population.

The low numbers of people with disabilities asking for information on HIV (17%) makes the case for mainstream HIV organisations to be more proactive in ensuring the inclusion of people with disabilities in their plans and programmes, particularly as 75% feel they are vulnerable to HIV infection. Several findings on levels of awareness on HIV among people with disabilities and the limited degree of inclusion demonstrate, how to effectively include people with disabilities in mainstream HIV programmes remains an issue.

The last section looked at issues of people with disabilities and their ability to access services on HIV. Only 6% of respondents knew of people with disabilities who had been able to get themselves tested for HIV, possibly a testament to the effectiveness of confidentiality but, more likely, lack of access to VCTCs.

Issues around specific impairments

The ability to receive information on HIV differs by impairment, sex, age, location and other factors. Impairments that affect communication - sight, hearing, speech and intellect - are the most significant.

Approximately 2% of people living with HIV lose their sight through an opportunistic infection cytomegalovirus (CMV). At some stage therefore, it is likely that an NGO working on HIV will encounter people who are visually impaired. Although they may be able to provide HIV-related support, do they know where to refer them for support related to their impairment? Blind men are vulnerable to HIV because many marry quite late as it takes them longer to get established and as a consequence, engage in premarital sex. Unprotected homosexual behaviour in residential institutes was mentioned on several occasions.

Deaf people are excluded because people cannot tell if someone is deaf by looking at them. In general, deaf people have very low levels of body literacy and limited awareness of sexual health. Most deaf children do not go to school and illiteracy levels can be as high as 95%. Only 5% of deaf people in India know Indian Sign Language and the inability to communicate effectively - and therefore to protest and complain - makes deaf women particularly vulnerable to sexual abuse and exploitation.

As with deaf women, people with intellectual impairments are also particularly vulnerable to sexual abuse and exploitation, not only because they are less likely to protest, but also because they are less likely to be believed. Since intellectual impairment is a spectrum, the ability to understand sexuality and HIV will depend on the degree of impairment. For people in the mild to moderate range, many are capable of being sexually active and giving informed consent. Several organisations talked of ex-students who had gone on to get married, particularly in rural areas. Factors which make people with intellectual impairments vulnerable include poor judgement, poor impulse control, social skill deficits, cognitive problems and difficulty in making decisions.

Vulnerabilities around mental illness include temporary lack of control which can make people unmindful of their dress and/or behaviour, while temporary loss of memory means that people are unable to remember if they are abused, and if they do, they are disbelieved. This makes women with mental health problems particularly vulnerable. Since mental health is often associated with destitution, the abuse and rape of women with mental illness living on the streets is a reality.

In general, people with mobility impairments were at no significant disadvantage in terms of their ability to access information on HIV. Men and women with mobility impairments generally know as much (or as little) about HIV as other men and women in their communities. However, accessing HIV services is less straightforward. VCTCs and care and support centres in inaccessible venues with stairs and no ramps or lifts prevent people with mobility impairments from accessing them.

Although there are no communication barriers to prevent people with leprosy from accessing information on HIV, social discrimination means that they are often excluded from community activities, including public information campaigns. Because of this, many people with leprosy still choose to live in their own communities and due to this stigma, sexual partners are often limited to others with leprosy. The combination of a high degree of sexual activity in a small community with multiple partners mean that infections quickly spread.

Issues around gender and disability

The fact that many women with disabilities have had sheltered lives, kept at home by families for “protection,” out of embarrassment, or simply their own limited mobility, means that many have not had the opportunity to acquire the social skills to recognise predatory behaviour and potentially vulnerable situations. Because it is assumed that women with disabilities will not be sexually active, they are not given information on relationships, how to deter predatory behaviour or negotiate safer sex.

People with disabilities and high risk behaviour

As part of this research, NGOs working with “high risk groups” such as sex workers and their clients, Injecting Drug Users (IDUs) and men who have sex with other men (MSM) were also visited. In all cases, it was found that a proportion of the respective NGO’s target group were people with disabilities. Again, this was almost exclusively anecdotal evidence, and estimates quoted were much lower than the 6% figure one would expect. People with disabilities may not be a high risk group, but some people with disabilities engage in high risk behaviour.

Finding women with disabilities in sex work is perhaps not surprising given the connection between disability and poverty. Indeed, given that people with disabilities are more likely to be poorer than non-disabled people, it seems reasonable to assume that the numbers of disabled sex workers would be higher than 6%.

Several NGOs with disability programmes knew of women with disabilities who had turned to sex work in both urban and rural areas. Several NGOs working with sex workers also reported women with disabilities among their target group ranging from 1%-10%. At least two NGOs knew of disabled male sex workers. Some disabled men visit sex workers, with estimates that they make up 2%-10% of sex workers' clientele.

In Manipur, one NGO running a de-addiction centre for female IDUs found that 30 out of 250 female IDUs identified are women with disabilities and that 6 of the 120 women with disabilities they work with are HIV positive.

An NGO working with men who have sex with men (MSM) estimated that about 50 of the 6,000 MSM (0.83%) they are in regular touch with are disabled, including three deaf MSM who have been trained as peer support educators.

Vulnerability within residential institutions for people with disabilities

Gathering hard information on the vulnerability of people with disabilities in residential institutions is extremely sensitive and difficult. However, it is notable that the origins of several disability INGOs' engagement with HIV was a higher incidence of HIV within residential institutions they supported in Africa than in the general population outside. Several incidents were mentioned but how prevalent and representative these are is impossible to tell. Sex education and awareness of what sexual abuse is, can make people more informed and aware of their rights.

Initiatives by disability institutions on sexual health and HIV

Although many institutions working with disabled children conduct sessions on sexuality or sexual health, there is no consistent curriculum or format, nor common source of information. There is a need to provide comprehensive information on sexual health and appropriate behaviour for people with all types of impairments through a holistic sexual health/life skills package, of which HIV is one component. The adaptation of pre-existing materials used in mainstream education would make this task easier and ensure consistency with the non-disabled population.

Initiatives on HIV and disability

Several examples of innovative work on inclusion of people with disabilities in HIV programmes and collaboration between the disability and HIV sectors were identified. These are highlighted as beacons of good practice and sources of advice and support.

Nethrajothi have worked on HIV awareness for visually impaired people in Chennai since 1992. They have conducted HIV awareness programmes in schools for the blind across Tamil Nadu and put material into Braille and on to cassette. They have also implemented a peer support programme where blind people who operate PCOs were given HIV awareness training and supplies of IEC materials and condoms since these places also function as meeting points for other blind people.

Deaf Way in Delhi and Hyderabad have developed a four-day sexual health workshop in Indian Sign Language (ISL) that covers body function, reproduction, relationships, good health and HIV. They hold an average of three workshops per year and since 2002, about 15 workshops have been held around the country for approximately 350 deaf people. Although all courses have been held within the Deaf Way structure to date, they would be happy to run workshops for other organisations.

In January 2005, Mumbai District AIDS Control Society (MDACS) were approached by the Association for Blindness and Low Vision to put their basic IEC materials on HIV into Braille and large print. They readily agreed and copies in Hindi and English Braille and large print were produced and sent to all schools for the blind and disability NGOs in Maharashtra, as well as to every SACS office throughout India. Further copies are available at MDACS.

The Devnar School for the Blind, Hyderabad wanted to ensure that their students had the same information on HIV as their non-disabled peers. Initially they looked for material in Braille and when they couldn't find it, decided to produce it themselves. In 2006, they approached APSACS and asked that if they were to reproduce their IEC material in Braille and send it to schools for the blind in Andhra Pradesh, whether APSACS would pay for this. APSACS readily agreed.

Potential strategies for inclusion of people with disabilities in HIV programmes

- Rights of equality of access to information and services is the most effective argument for inclusion
- Adopt the twin-track approach to inclusion: include people with disabilities in mainstream HIV programmes while at the same time targeting the disability sector
- Proactive engagement - formal and informal, partnerships and joint ventures between the disability and HIV sectors
- Formal engagement between government disability and HIV structures at central and state levels through the inclusion of disability representatives within HIV mechanisms and *vice-versa*
- Similar incorporation and engagement between national and state level organisations working on disability or HIV within the civil society sector
- Establishment of 3-5 disability NGOs as champions of HIV within the disability sector and the formation of some form of joint working group of a few key HIV and disability organisations to achieve this
- Engagement between SACS offices and State Disability Commissions would greatly facilitate inclusion
- Ring-fence a fixed percentage of budgets of HIV organisations for joint disability-HIV initiatives
- Add a question to funding applications asking how the applicant will ensure that people with disabilities are included in the programme for which funding is sought
- Include HIV awareness sessions in training programmes of rehabilitation professionals and special education teachers
- The involvement of people with disabilities who are HIV positive within Positive Speakers programmes raise awareness of their vulnerability as well as addressing stigma

- People with disabilities should receive information on HIV in the same place and at the same time as everyone else in order to avoid further discrimination
- Yale University's three-tiered approach to inclusion of people with disabilities into HIV programmes provides practical advice for HIV organisations and is included as Annexe 3
- Develop similar guidelines on how disability organisations can engage with HIV

Practical recommendations for inclusion of people with disabilities in HIV programmes

- Add an extra box to be ticked alongside sex on pro-forma stating if the person is disabled to monitor inclusion and accessibility
- Identify and contact local DPOs and disability NGOs as sources of local contacts, advice and information on disability
- Identify and train select disability NGOs to provide support on HIV to other disability NGOs and people with disabilities
- Train people with different impairments as HIV peer support workers to work in both mainstream HIV programmes and disability NGOs
- Ask local disability NGOs to conduct disability awareness training for staff of HIV organisations
- Conduct sessions on HIV awareness for staff of disability NGOs
- Advocacy and support: disability NGOs need to be willing to provide/access the technical support to put materials into different formats and support HIV organisations on how to include people with disabilities
- There is no single model for inclusion of people with disabilities, people with different impairments and in different situations require different approaches
- Be diverse and creative in the development of IEC materials and communication techniques
- Have a clear and proactive publicity and dissemination strategy for IEC materials in alternative formats
- Disability institutions should provide a consistent and comprehensive sexual health/life skills package, of which HIV is one component. Make use of pre-existing material used in mainstream education
- Disability institutions need to inform people with disabilities about abuse and exploitation. In order to know whether you are being abused, you first need to know what abuse is

1. PROJECT RATIONALE

According to WHO, 10% of the world's population are disabled and this figure is increasing through population growth, medical advances and the ageing process. The World Bank estimates that 20% of the poorest sections of society are people with disabilities and the UN that 82% of people with disabilities in developing countries live below the poverty line. Poverty is recognised as a significant risk factor in vulnerability to HIV.

Nobody knows how many people with disabilities there are in India. Estimates vary due to differing definitions of disability and questions over the reliability of sample surveys and the national census. The 2001 census calculated that 1.9% of India's population are disabled while the Disability Working Group for the 11th Five Year Plan (2007-2012) recommends 10% as a more realistic figure for planning purposes. The most commonly accepted figure in India is 6% or 70 million people, giving India the largest number of people with disabilities in the world, equivalent to the population of the UK. Whatever the figure, the reality is that people with disabilities represent a significant proportion of India's population.

People with disabilities are part of every social group - class, caste, ethnicity, gender, religious, sexual orientation, etc., and in the context of HIV, are also found within every high risk and vulnerable group - sex workers and their clients, IDUs, MSM, orphans, prisoners, etc.

Men and women with disabilities do the same things as everyone else. They are no more and no less sexually active than any other section of society. Many get married and/or live with partners. Some have sex before and outside marriage, and some have multiple partners. Some migrate in search of work. Some engage in high risk behaviour as sex workers, visiting sex workers or using drugs. Some disabled men have sex with other men (disabled and non-disabled). Some women with disabilities live with men (disabled and non-disabled) who engage in some of these activities.

A statement of the obvious? Apparently not. Despite an estimated number of 320,000 people with disabilities in India living with HIV, most HIV programmes or service providers see only a fraction of the figure, typically between 0%-2%. As their continuing exclusion from sex education and HIV information campaigns demonstrate, it is "commonly and incorrectly assumed - by families, by disability organisations and by NGOs working on sex education and HIV - that people with disabilities are sexually inactive, unlikely to use drugs or alcohol, and at less risk of violence and rape than non-disabled people" (Groce *et al*, 2006).

If 6% of the population are not being included in HIV programmes and services, the question is whether this is too large a section of society to be ignored and how this exclusion will ultimately impact upon efforts to slow the spread of HIV.

People with disabilities are not included in HIV programmes for a range of reasons:

- They are not considered to be sexually active and therefore at little or no risk of HIV infection
- They are not considered a vulnerable group
- Most organisations working on HIV have not thought to include people with disabilities in their programmes, or do not know how to do this
- Programmes and IEC materials on HIV are inaccessible to many people with disabilities
- Many disability organisations do not yet have HIV on their agenda, or do not know how to access this support

Even if people with disabilities are able to access information on sexual health or HIV, this is provided on the assumption that you can see it, hear it and understand it. So if you are blind, if you are deaf, or if you have a learning disability, you will miss most or all of that information. How do you hear a radio campaign, understand a TV information bulletin or a public talk on HIV if you are deaf? How are you counselled about living with HIV if the counsellor can't communicate with you? If you are blind or have low vision, how do you see a poster campaign or a condom demonstration? If you have a learning disability, how do you understand information that is provided in vague or complex terms? If you are unable to walk very far, use crutches or a wheelchair, how do you attend a community awareness session on HIV or visit a VCTC if it is not nearby or not on the ground floor?

1.1 Project purpose

The purpose of this research project was to identify gaps in current HIV awareness, prevention, care and support programmes in India. The findings are intended to make the case for an approach to HIV planning, policy and practice that is inclusive of people with disabilities. The aim is to identify how the disability sector can be supported to engage with HIV, and how the HIV sector can be supported to make their programmes accessible to, and inclusive of, people with disabilities with a series of practical recommendations and strategies to be developed as part of this project.

1.2 Project methodology

Towards this, the project explored levels of awareness and understanding of HIV among people with disabilities in India (including their own risk perception) and how this differed by impairment, sex, age, education level and where they live - in a high or low prevalence state, rural or urban area, in the community or a residential institution. Over 500 people with disabilities from 14 states were interviewed by 52 different NGOs and 350 of these responses have been inputted and analysed.

Approximately 100 organisations working on HIV (40) and/or disability (60) programmes in parts of north, south, east, west and north-east India were visited (Annexe 2) as part of this research to ascertain what, if any, steps HIV organisations have taken to include people with disabilities in their programmes, and what, if any,

steps disability organisations have taken to provide or access information on HIV for the people they work with. The objective was to identify and highlight examples of innovation, good practice and successful inclusion, and in cases where people with disabilities are not yet being included in HIV programmes or accessing information, to understand why this was.

The draft research report and aggregated survey findings were presented at a feedback and planning workshop held in Bangalore on 22nd February 2007 for organisations consulted during the research phase. The purpose of this workshop was to test the research findings, analysis, strategies and recommendations. In general, participants felt that the analysis was valid, and the strategies and recommendations relevant, timely and practical. Participants felt that the *Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts* developed by Yale University to support the HIV sector to become disability-inclusive were practical and thorough and needed no further amendments. However, similar guidelines on how the disability sector can engage with HIV would be a helpful addition.

The major recommendation from the workshop was the establishment of one or more disability NGOs as champions of HIV to encourage and support the disability sector to engage with HIV. These nodal NGOs would also train other disability NGOs on how to engage with and include HIV in their work and take up the issue of inclusion of people with disabilities into existing HIV programmes conducted by mainstream NGOs. The development of HIV champions within the disability sector calls for a degree of commitment in terms of time and resources by the HIV sector and some form of joint working group.

2. GLOBAL CONTEXT

This research comes at a time of growing awareness within the development sector - primarily the disability sector - that people with disabilities are also vulnerable to HIV, and the need to ensure that they are included in HIV programmes.

Several international NGOs working on disability are currently looking at how to incorporate HIV into their programmes at an organisational level, including Christoffel-Blinden Mission (CBM), Stichting Liliane Fonde (SLF), Sense International and Leonard Cheshire International (LCI). In each case, the impetus was encountering people with disabilities infected and affected by HIV in projects they support in Africa. Debates are now centred upon the most appropriate way of addressing this, ranging from making HIV a cross-cutting strategy with dedicated staff, to deciding whether to access support on HIV externally or provide this directly. Within India, disability funder CBR Forum have also been exploring ways of how to encourage their partners to engage with HIV for the last two years.

This research coincided with, and seeks to complement, two similar initiatives in India. One is another DFID-PMO-funded project by the Australian International Health Institute (AIHI) of the University of Melbourne in association with the Emmanuel Hospital Association to develop guidelines for disability-inclusive HIV

programmes and services in Manipur and Nagaland. The other is a broader study on how social exclusion affects marginalised groups such as people with disabilities and *adivasis* from government policies and services in Maharashtra, using health, HIV and education as examples. This project, of which levels of awareness and understanding of HIV among people with disabilities is only one component, is being undertaken by Shodhana Consultancy of Pune for UNICEF Maharashtra.

The first major initiative was a *Global Survey on HIV/AIDS and Disability* conducted by the World Bank and Yale University in 2004. This essentially highlighted the fact that people with disabilities were not yet on the radar screen of the HIV sector despite being vulnerable to all known risk factors, and the paucity of information on the relationship between HIV and people with disabilities. The Global Survey also encouraged further studies in India, Malawi, Zambia, Zimbabwe and Kenya, as well as highlighting earlier studies in the USA, UK, Canada, Rwanda, Uganda and Swaziland.

In their subsequent report, *Guidelines for Inclusion of Individuals with Disabilities in HIV/AIDS Outreach Efforts* (Groce et al, 2006) in response to the Global Survey, it is noted that a number of questions around HIV and disability remain unanswered.

- How can people with disabilities be reached by HIV programmes?
- Should they be included in mainstream campaigns and services, or are special initiatives and targeted approaches needed?
- Will this mean extra expense and if so, where will this come from?

As Groce comments, part of the problem is that the discussion is usually articulated as a choice between doing nothing or implementing expensive, resource-intensive outreach efforts. Calls for inclusion are countered with concerns that HIV programmes and funds are already over-stretched and that funding for disability-specific issues is not available.

The Groce report - and this one - argues strongly that *“inclusion of people with disabilities into HIV programmes cannot wait until all other groups are addressed and that the issue is one of basic human rights and basic public health. The lives of people with disabilities are no less valuable than non-disabled people and there can be no substantive argument that justifies assigning people with disabilities to the bottom of the HIV priority file. Secondly, if people with disabilities are not included now, efforts to slow the spread of the virus or eliminate it will be unsuccessful. People with disabilities are simply too large a proportion of society to ignore.”*

The choice is not simply between inclusion in mainstream programmes or separate outreach initiatives and Groce *et al* suggest three levels of intervention from inclusion of people with disabilities into existing programmes at little or no additional expense, through programmes where modifications are made to existing HIV programmes to ensure greater participation of people with disabilities at a low to moderate cost, to outreach efforts that are specifically targeted at people with disabilities which are more expensive due to the need for specialised knowledge, time and materials. These guidelines are included as Annexe 3 to this report.

This range of intervention strategies enables all HIV organisations to work on the inclusion of people with disabilities in their programmes, while also highlighting the importance of not relying on any single approach - people with disabilities are not homogenous, people with different impairments and in different environments have different needs.

3. RESEARCH FINDINGS

3.1 Overall

One of the most encouraging findings was the generally overwhelming acceptance by the HIV sector of the case for the inclusion of people with disabilities in mainstream HIV programmes. Advancing this argument is pushing at an open door and the overall environment is receptive to, and supportive of, inclusion. The general finding was that most HIV organisations had not previously thought about inclusion of people with disabilities, but immediately saw the need and expressed an openness to ensuring this. This research came across several instances of government agencies being approached by disability NGOs to make their IEC materials accessible to people with disabilities and readily agreeing to this. These include APSACS, TANSACS and Mumbai DACS who have all put information on HIV into Braille and borne the costs of both production and distribution.

Within the disability sector, reactions generally fell into two responses: either that organisations had thought about how to introduce HIV into their programmes but did not know how to do this or where to access support, or alternatively, that although they hadn't previously thought of this, they now saw the need to address this.

There are, however, still a few but significant institutions and organisations within the disability sector who are uncomfortable with the assumptions and implications that people with disabilities are sexually active. At least two state level disability officials commented that "people with disabilities don't do those sort of things" while others expressed concern that providing sex education and information on HIV might "corrupt" people with disabilities and encourage them to experiment. One international disability NGO felt that they because they had never come across a disabled person living with HIV, it was not an issue. Within the HIV sector, some organisations operating in the "high risk group" framework stated that because people with disabilities are not considered high risk, there was no need to include them in their programmes - a position which ignores the reality that some people with disabilities engage in high risk behaviour.

It has been extremely difficult to gather firm data on the incidence of HIV among people with disabilities and the degree to which they are being included in, and accessing, HIV programmes and services as no one has yet thought to collect information in this manner. None of the primary sources contacted in an attempt to get an idea of numbers - VCTCs and NGOs with HIV programmes - record whether the service user or target for information is disabled. Similarly, the positive people's networks do not mention whether the person is disabled in their membership registers. As a result, much of the information gathered in this report is based upon anecdotal information and individual estimates by NGO staff.

Since this research study went for a breadth rather than depth of experience, there is still a need for a more systematic, detailed and in-depth study of the incidence of HIV among people with disabilities and on actual numbers of people with disabilities accessing HIV information, services and programmes.

This is easy enough to do. Since many services and programmes already disaggregate statistics by sex, the addition of one more box alongside this noting whether or not the person is disabled, is a simple and low method of collecting this information that requires no particular expertise. A further box indicating the nature of the impairment or providing options to tick would provide greater levels of information.

There is no evidence that people with disabilities are a high risk group, or that the numbers of people with disabilities living with HIV are higher than their representation within the general population. Equally however, there is no evidence to suggest that their numbers are any less than this. Using the commonly accepted estimate that 6% of India's population is disabled, in the absence of evidence to the contrary, it seems logical and cautionary to assume that 6% of people living with HIV will be disabled. Although the assumption that people with disabilities are no more and no less vulnerable to HIV is reasonable, only hard evidence will sustain this assertion.

Applying NACO's prevalence rate of 0.91% to an estimated disabled adult population of 34.44 million suggests there are over 313,000 people with disabilities living with HIV in India today. Applying the 6% figure to NACO's estimate of 5.412 million people living with HIV gives a similar figure of 324,600. The average of these two estimates is 319,000. Accounting for the fact that 90% of people living with HIV in India do not know they are HIV positive, this should still mean that up to 32,000 people with disabilities living with HIV have been identified and are being supported in existing HIV programmes. From the anecdotal evidence gathered, it is very clear that nothing even remotely approaching this figure is being reached.

Low numbers of disabled people featuring in HIV programmes and within the positive people's networks are more likely to be an indication that people with disabilities are not being reached - thereby highlighting the current inaccessibility of organisations and programmes - rather than that they don't exist.

Modes of transmission for people with disabilities are exactly the same as non-disabled people. Disabled men in rural areas and small towns migrate to urban areas for work and some visit sex workers; some people with disabilities engage in pre- and extra-marital sex; women with disabilities who are HIV positive have usually been infected by their (disabled and non-disabled) husbands; some women with disabilities work as sex workers; at least one disabled woman who is HIV positive was abused within an institution; some disabled men have sex with other (disabled and non-disabled) men; some people with disabilities are injecting drug users.

While it is more common that some people with disabilities become HIV positive, a significant number of people living with HIV have become disabled after becoming HIV positive through opportunistic infections. Two per cent of people living with HIV contract cytomegalovirus (CMV) and become blind. CMV can also effect hearing, intellect and co-ordination. Another opportunistic infection - meningitis - can cause deafness, as can severe reactions to certain drugs. Some people living with HIV are prone to strokes, which can affect mobility, while being diagnosed of HIV can trigger mental illness.

3.2 Invisibility of people with disabilities within the HIV movement

Within the HIV movement, consultations with seven State Level Networks (SLNs) of the Indian Network of Positive People found that many networks have some members who are disabled. In Karnataka, almost all 20 District Level Networks (DLNs) reported people with disabilities living with HIV as members - deaf, blind and mobility impaired - with estimates varying from 1-2 members up to 10% of membership. The Tamil Nadu Network of Positive People estimated that 2-3% of their members are disabled, while the Maharashtra Network of Positive People reckoned 1% of their 6,900 members might be disabled, all with mobility impairments. The Manipur Network of Positive People have several people with disabilities among their 2,000 members but were not sure of the percentage. The Hyderabad Network of Positive People thought that 8 of their 500 members are disabled, including two married woman infected by their husbands and another three who became disabled after HIV infection. The Cuttack DLN in Orissa knew of a few disabled people among their 200 members, while the Positive Women's Network in Chennai said that they very rarely come across women with disabilities and only knew of one women with polio who learned she was HIV positive after her non-disabled husband died. In Kolkata, the Bengal Network of Positive People were not aware of any people with disabilities within their 13 DLNs.

Both Karnataka and Manipur networks reported problems in communicating with members who are deaf, particularly in being able to provide them with information on nutrition, positive living, medication regimes and adherence. In Karnataka, although KNP+ are able to provide HIV-related advice and support to members who have become blind, they are unable to offer any similar support to with regards to their impairment and unsure where to access this.

3.3 Invisibility of people with disabilities within the HIV sector

Among organisations implementing HIV programmes who were consulted, a similar picture of very few people with disabilities identified as HIV positive emerged. Of ten organisations who felt able to estimate the number of disabled people living with HIV in their programmes, the average percentage was 1.9%.

In Namakkal, Tamil Nadu, one of the Districts with the highest incidence of HIV in India, the Positive Living Centre run by HIV Ullor Nala Sangam estimated that 4% (380) of the 9,500 people living with HIV in Namakkal District are disabled, 60% of these visually impaired. Meanwhile, only five (1.9%) of the 260 people identified as HIV positive by Namakkal DACS are disabled - all women infected by non-disabled husbands.

In Anantapur District of Andhra Pradesh, Rural Development Trust were aware of 11 people with disabilities among the 5,550 people identified as living with HIV (nine mobility, two blind and one deaf).

The ART Centre at Sassoon Hospital in Pune estimated that only about 25 of the 2,100 people who come for treatment are disabled and in all but two cases, disability was acquired after HIV infection. These include 15 people with mobility impairments due to strokes, six people with visual impairments caused by CMV, and three people with hearing impairments due to meningitis or a severe reaction to medication. The centre felt the low numbers are a result of people with disabilities not being diagnosed, not coming forward, and not being reached rather than that they don't exist.

The People's Health Organisation, who work with approximately 3,500 sex workers and their clients in Mumbai estimated that 1% of the people they work with are disabled. Of the 400 people living with HIV who have approached the Lawyers Collective in Mumbai for legal advice and support, only four have been disabled. AVERT Society were not aware of coming across any people with disabilities living with HIV, nor any engagement with disability organisations in the course of their work in Maharashtra.

Among NGOs consulted in Kolkata, the Boruka Public Welfare Trust have come across very few people with disabilities who are HIV positive, while none of the 76 people identified as HIV positive in CINI Bandhan's rural programme in South 24 Parganas District in West Bengal are disabled. Again, CINI are in no doubt that there are people with disabilities living with HIV in the areas they work, they are not yet reaching them. Although people with mobility impairments attend HIV awareness sessions in villages, none have ever come to a VCTC for testing.

3.4 Invisibility of people with disabilities living with HIV in the disability movement

Similarly low figures were reported by organisations of and for people with disabilities. The Network of Persons with Disability Organisation of Hyderabad were aware of at least four disabled members who are HIV positive, including a married couple with mobility impairments and a disabled women abandoned by her husband who then turned to sex work.

In 2000, a study "*Exploring the Sexual Vulnerability of Urban Deaf Indians*" applied NACO's 1997 figure on HIV prevalence to the 1991 National Sample Survey Organisation's estimate of 2.5 million deaf adults in India to calculate that 193,607 deaf people were HIV positive. Despite this, Deaf Way, a support network for over 3,000 deaf people in 72 Friendship Clubs across the country know of less than 10 deaf people known to be HIV positive.

3.5 Invisibility of people with disabilities living with HIV in the disability sector

Within the disability sector, several NGOs with disability programmes visited knew of a few people with disabilities living with HIV, but again, numbers were very low. During a talk with ADD India partners in Tamil Nadu, four NGOs knew of women people with disabilities who are HIV positive. Nethrajothi, a Chennai-based NGO knew of eight blind women in Chennai and Tirunelveli who were all infected by sighted partners. Two large NGOs, the National Association for the Blind in Mumbai and the Blind Person's Association, Ahmedabad have not yet come across visually impaired people living with HIV in the course of their work. In the north-east, two out of 52 people with disabilities consulted by AIHI in Manipur and Nagaland were HIV positive. Another Manipur-based NGO, Agent for Social Change have come across one deaf woman who is HIV+.

3.6 Low levels of awareness of HIV among people with disabilities

Several NGOs consulted reported very low levels of awareness of HIV among people with disabilities in rural areas and across all impairments, an observation substantiated in an analysis of the survey data. Both the Association of People with Disabilities, Bangalore and SACRED, Anantapur noted this while conducting interviews in rural areas of Chintamani and Anantapur Districts respectively.

AIHI's research in Manipur and Nagaland found that some people with disabilities had been able to attend HIV awareness programmes aimed at the general population, primarily people with mobility impairments. In Orissa, Utkal Sevak Samaj (USS) Cuttack noticed a few people with disabilities with mobility, visual and hearing impairments attending HIV awareness sessions they conducted in villages although they initially made no special effort to include them.

Inability to attend HIV information sessions or understand what is communicated impacts differently according to impairment and sex. A group consultation with people with disabilities from Torbung, Manipur found that a few men with mobility impairments had been able to attend an HIV awareness session in their village. However, women with disabilities and men with other impairments did not attend. This research also found that in many cases "a little" often means the words "HIV" and/or "AIDS" and nothing else.

A study which included looking at levels of awareness and understanding of HIV among people with disabilities in Maharashtra recently conducted by Shodhana Consultancy reported similar findings. Having interviewed 80 people with disabilities in three Districts, they found that men and women with mobility impairments know as much (or as little) about HIV as non-disabled men and women in their communities since as long as locations are physically accessible, there are few other barriers to communication and understanding. This distinction between sexes is highlighted because gender disparities are the primary barrier in the case of mobility impairments. Women with mobility impairments know less about HIV and sexual health than men with the same impairment.

Shodhana Consultancy also found that although visually impaired people might know less about HIV, they are often vocal enough to ask for information. Elsewhere however, other visually impaired people told stories of attending community awareness sessions on HIV where they sat through condom demonstrations that they were not able to see. Since they were usually too embarrassed to ask to touch the condom and the organisers did not think to give them one to handle, they often left sessions knowing a little about HIV and that a condom can provide protection, but what it is, what it looks like and what to do with it was entirely dependent on the accompanying commentary.

Hearing impaired are among the least aware of disabled people. The Torbung group in Manipur said that although the two deaf people in their village also attended a workshop on HIV, with no effort to make materials or communications accessible, their knowledge remained at zero.

3.7 Why aren't people with disabilities included in HIV programmes?

The two major reasons are the HIV sector's failure to include people with disabilities in its programmes, and lack of awareness of HIV among disabled people. The exclusion of people with disabilities is of course not a result of any conscious effort to exclude, but simply the attitudinal, institutional and environmental barriers that deny people with disabilities their rights of equality of access to all aspects of mainstream development. This inaccessibility of HIV information and programmes means that people with disabilities remain unaware of the risks and therefore don't ask for information or access to services.

Most disability NGOs have not thought to provide or access information on HIV to the people with disabilities they work with. Indeed, low levels of awareness of HIV were as common among many disability NGO staff as they were among the people they worked with. Organisations such as the Freedom Foundation in Bangalore who provide training inputs on HIV for other NGOs noted that they had never been asked to provide this for a disability NGO.

Inaccessibility is not just about information, but also physical access to programmes and communication with programme personnel. If HIV programme staff are unable to communicate with people with disabilities, not comfortable in dealing with them, or do not perceive of them as sexually active, it is unlikely that they will ever reach them. One former DACS staff member in Tamil Nadu now working with a disability NGO commented that he never thought to include people with disabilities in HIV programmes and that nobody within his office had ever suggested this.

For someone with a speech or hearing impairment, inability to communicate with an HIV service provider would be a further deterrent to engagement. How can confidentiality be maintained if the disabled individual has to bring an interpreter or guide (if they are blind) with them?

Low levels of literacy also prevent many disabled people from accessing printed literature. Since fewer people with disabilities go to school than non-disabled children, literacy levels are much lower. According to UNDP, globally it is as low as 3% among disabled men and 1% in women with disabilities. Similarly, people with disabilities whose impairments and/or families keep them at home are likely to know less than someone who is able to interact regularly with their community.

Other reasons why some people with disabilities who might be aware of HIV do not avail of HIV services may well be the same as non-disabled people, including misplaced confidence that “it can’t happen to them” or not wanting to know for fear of the social and personal implications if they test positive.

3.8 The case for engagement between the disability and HIV sectors

One of the principal reasons for the lack of engagement with HIV by the disability sector, and exclusion of people with disabilities from HIV programmes is the lack of contact between the two sectors. Although the concept of cross-cutting sectors such as gender has made some inroads, the tendency within the development sector is to work in compartmentalised sectors. Of approximately disability and HIV 100 organisations consulted as part of this research, in most cases there was no or very little interaction with the other sector. This was even true within organisations implementing both disability and HIV programmes.

Yet mutual engagement and joint collaboration is the only way to overcome this. Since it is unrealistic to expect the HIV sector to become experts on communication with people with disabilities, and unreasonable to expect the disability sector to become experts on HIV, joint initiatives between the sectors - of which several examples were identified and are highlighted later - are the most effective strategy to address this.

In Hyderabad, membership organisations of people with disabilities (NDPO) and people living with HIV (HOPES) provide a good example of how collaboration ensures that people with disabilities living with HIV are able to benefit from the services of both organisations. Also in Hyderabad, LEPRAs are an excellent example of a disability NGO that has engaged with HIV in a big way. There is a considerable degree of interaction and overlap between LEPRAs in both leprosy and HIV programmes, and they are also actively involved with both the disability and HIV movements in the state.

4. FINDINGS AND ANALYSIS OF INDIVIDUAL INTERVIEWS

As part of this research, a questionnaire was designed to ascertain levels of understanding and awareness of HIV among people with disabilities, and their perceptions of vulnerability to HIV. The questionnaire was developed from the Yale University-World Bank Global Survey used in 2003-4 and adapted for use with disabled individuals. The survey consisted of 25 questions with four sections intended to look at background information, awareness of HIV among disabled people, access to information on HIV, and help and support for disabled people living with HIV respectively. Approximately 50 NGOs with community-based disability programmes participated in the survey, with their frontline personnel conducting structured and individual one-to-one interviews with disabled people they were already familiar with. Although the vast majority of interviews were conducted directly with people with disabilities, 22 (6%) were carried out indirectly with the help of a carer in the case of communication difficulties.

All questions had an option to state “do not know” or “no response” to ensure that no question was overlooked. For the purpose of this analysis, such responses have been omitted while calculating percentages.

The decision to base the questionnaire on the Global Survey was taken in the interests of enabling complementarity with other studies internationally and to allow for a comparison on HIV awareness among disabled people between different countries. An alternative approach would be to make use of similar studies that have surely been conducted within India to look at awareness and understanding of HIV among the general population and then compare these. Many of the questions from the questionnaire used in this research could also be asked of non-disabled people in order to assess comparative levels of awareness, understanding and perceptions of vulnerability between people with disabilities and the general population. The questionnaire, with aggregated responses, is therefore attached as Annexe 1 to provide opportunities for this.

4.1 Background information

A total of 521 individual interviews with people with disabilities were conducted and of these, 350 have been inputted and analysed as part of this research. The 350 responses came from 49 NGOs with disability programmes across 14 states. Of these, 60% came from the four south Indian states, followed by the north-east (Manipur, Meghalaya and Assam) at 14% and eastern India (West Bengal and Orissa) with 13%. North Indian states (Uttar Pradesh, Bihar and Jharkhand) made up 10% and western India (Maharashtra and Madhya Pradesh) comprised 3% of the total. 61% were from high prevalence states and the spread was determined by the engagement of CBR Forum partners and the researcher’s own contacts. With the majority of respondents living in high prevalence states, the expectation would be of higher levels of awareness of HIV.

In terms of demographics, 55% of respondents were male, 87% were adults and the remaining 13% were students in full time education. 93% were between 15-45 years, 6% were over 45 and 1% under 15 years. 64% were unmarried and 43% had never been to school. The survey had a strong rural emphasis with 93% of respondents living in villages. 95% of interviewees lived at home while 5% were living in disability institutions.

66% of those interviewed had impairments that affected their mobility such as polio or amputation while 14% were blind or partially sighted. A further 7% were deaf or hearing impaired, 5% had intellectual impairments and 3% had mental health problems. The residual 10% had other impairments such as cerebral palsy, epilepsy, multiple impairments and other conditions. There was no one with autism or leprosy among the 350 interviews that were analysed.

4.2 Awareness of HIV among people with disabilities

81% of respondents had heard of HIV which, considering that 60% of interviewees lived in high prevalence states, is perhaps not surprising. However, this still means that one-fifth of people interviewed had never heard of HIV. Although the numbers of people with disabilities aware of HIV is at one level encouraging, the degree of understanding is a cause for concern. When asked how much people understood about HIV, 26% knew the words "HIV" and/or "AIDS" but little else, and 19% knew nothing at all. A further 31% said they knew a little about the causes of HIV, while 22% said they knew enough to know the risks and how to protect themselves. In essence, just under half (45%) have stated they know nothing or very little about HIV. Lack of knowledge is exacerbated by lack of interaction: very few respondents (4%) knew of anyone in their area living with HIV and only 14% knew of anyone suspected to have died from an AIDS-related illness.

Three-quarters (73%) of respondents felt that people with disabilities might be at risk of HIV, while two-thirds (64%) thought that they might be at greater risk than non-disabled people. When presented with a series of reasons why people with disabilities might be at risk, no single factor was identified. 12% of respondents felt this was due to lack of information on HIV, while three factors - the inability to develop the social skills to recognise and avoid vulnerable situations, lack of access to HIV prevention programmes, and families not letting people with disabilities participate in HIV programmes - each featured in 10% of responses. 9% of interviewees felt that the fact people with disabilities were as sexually active as the general population meant the same level of risk, while a similar number cited vulnerability to sexual abuse as a factor. The unavailability of IEC materials and information on prevention in alternative formats comprised 8% of responses, while people with disabilities being targeted since they are assumed not to be sexually active and therefore "safer" was noted by 7%. A further 6% felt that medical procedures some people with disabilities (such as haemophiliacs) made them vulnerable, while the fact that some are also IDUs was cited by 5% of respondents. Another 5% felt that the fact that many disability institutions do not let their residents participate in HIV/AIDS programmes made them vulnerable while a further 4% felt that living in an institution was a risk factor in itself, possibly another indication of the existence of exploitation and/or abuse within institutions.

Out of 176 people responding to the question whether there was anything about the type of impairment they have that makes people less aware and/or more vulnerable to HIV, 75% of these identified impairments that affect communication and understanding. In response to a similar question whether there were particular issues that make women and girls with disabilities more vulnerable than disabled men or non-disabled women, 77% of interviewees agreed, in most cases attributing this to the double impact of gender and disability inequality *“families do not give permission to disabled females to attend HIV awareness programmes. They think it is not necessary”* and *“disabled females are more sexually abused.”*

4.3 Access to information on HIV

In terms of access to information on HIV, an encouragingly high figure of 76% of respondents stated that they had received information on HIV and from a range of sources. Of these, 32% identified friends and other people in their communities as their primary source while 25% cited government agencies or NGOs working on HIV. One-fifth (19%) of those interviewed cited the same NGO they are currently in contact with as their principal source of information on HIV, an indication that several disability NGOs are addressing HIV within their programmes. A further 10% gave their school or college while 8% mentioned media such as TV, radio and newspapers. The low numbers acquiring information from the media illustrates their inaccessibility to people with sensory and communication impairments as well as the lower literacy levels of people with disabilities.

Of greater concern, just under half (49%) of the respondents did not know who to approach or where to go if they wanted to get more information on HIV. Indeed, only 17% of people with disabilities interviewed had ever asked for information on HIV. Just over one-third (36%) knew of NGOs working on HIV awareness programmes in their area - a low figure considering the majority are living in high prevalence states. However, a surprising two-thirds (68%) stated they were aware of efforts by mainstream HIV organisations to include people with disabilities in their awareness campaigns.

One-third (37%) knew of people with disabilities (which may well be themselves) who had been able to access information on HIV through programmes aimed at the general population. However, when asked how many people with disabilities in their communities might have been reached by mainstream HIV agencies, 78% felt that only a few or some had been reached while 19% felt that no disabled people had been met. Consequently, 81% of respondents felt that the amount of information on HIV reaching people with disabilities was less than that reaching the general population. As a result of this inability to reach people with disabilities and/or communicate with them effectively, three-quarters (74%) felt that understanding of HIV among people with disabilities would be less than the general population.

These figures highlight a couple of issues. The low numbers of people with disabilities asking for information on HIV (17%) makes the case for mainstream HIV organisations to be more proactive in ensuring the inclusion of people with disabilities in their plans and programmes, particularly as 75% of people with disabilities feel they are vulnerable to HIV infection. There is some discrepancy between the fact that only 36% of people with disabilities (115 respondents) say they

are aware of NGOs working on HIV awareness in their area, while a much larger 68% (146 people) say they are aware of efforts by mainstream HIV agencies to include people with disabilities in their programmes - a statement that contradicts other findings. If this is correct, then again it serves to demonstrate the openness of HIV organisations to the inclusion of people with disabilities. However, as several findings on their levels of awareness and degree of inclusion demonstrate, knowledge of how to effectively include people with disabilities in mainstream HIV programmes remains an issue. The fact that only one-third of respondents knew of people with disabilities who had been able to access HIV programmes aimed at the general population further emphasises this point.

4.4 Help and support for people with disabilities living with HIV

The last section looked at issues of people with disabilities and their ability to access services on HIV. In line with earlier questions about awareness of people living with HIV, only 6% of respondents knew of people with disabilities who had been able to get themselves tested for HIV. The low figure is either a testament to the effectiveness of confidentiality or, more likely, lack of access to VCTCs.

Experience in other parts of the world has shown that people with disabilities are often diagnosed as HIV positive later than non-disabled people for a range of reasons, including lack of awareness of causes and symptoms, inaccessibility of services and communications issues, as well as more common reasons such as fear of finding out. 12% of respondents said they knew of people with disabilities who had such experiences. The low numbers of people answering yes to this question (30) probably make the response a reliable indicator.

The last question looked at public disapproval and judgmentalism within the local disability community as a deterrent to asking for information on HIV. Asked whether disabled individuals might be reluctant to ask for information because the disability community is small and where word quickly gets around, 16% of respondents said they had not heard of this happening. This relatively low figure is helpful in indicating the declining stigma in people wanting to inform themselves on HIV and again makes the case for the inclusion of people with disabilities in mainstream HIV programmes.

5. ISSUES AROUND SPECIFIC IMPAIRMENTS

Clearly, the ability to receive information and inform oneself on HIV, and methods of providing information differs by impairment, sex, age, location and other factors. Part of this research was to look at some these factors in more depth. The intention was to try and understand the particular issues, impact and implications of specific impairments in relation to HIV. The most significant issue is impairment, followed by sex.

Inevitably, impairments that affect communication - sight, hearing, speech and intellect - are the most significant since information is provided on the assumption that it can be seen, heard and understood. However, every impairment comes with its own set of issues. Organisations with experience of working with people with these impairments are valuable sources of further advice and support.

5.1 Visual Impairment

It is estimated that 1.4% of India's population are blind, more than the official numbers of people living with HIV. At the same time, it is estimated that 2% of people living with HIV lose their sight through an opportunistic infection, cytomegalovirus (CMV). At some stage therefore, it is likely that an NGO working on HIV will encounter people who are visually impaired.

One of the social factors observed by Nethrajothi in Chennai that make blind men vulnerable is that many marry quite late in life because it takes them longer to get established in terms of finding a steady job and saving money. As a consequence, many blind men engage in premarital sex. Further, many blind and partially sighted people are still schooled in residential institutes and instances of homosexual behaviour between adolescent males were reported in several interviews.

Although there are clearly accessibility issues around the ability to see printed literature, billboard campaigns and practical demonstrations without an accompanying commentary, much of this is fairly easy to overcome. Putting material into audio-formats such as on to CD or cassette, use of radio and TV (as long as it is accompanied by a descriptive narrative) are all options, although it is important to recognise that not all visually impaired people may be able to afford such assets. The transformation of printed word into spoken word is relatively inexpensive, but care is needed to ensure clarity, accuracy and detail in describing accompanying pictures, charts or diagrams. Tactile charts are simple to make by affixing different widths of string around outlines and other details, and these posters can still be used for sighted or mixed audiences.

Translation of HIV material into Braille has been the most common example of adaptation of IEC materials in India to date with NGOs and SACS/DACS working together in Andhra Pradesh, Tamil Nadu and Mumbai. However, only 40% of visually impaired people know Braille and this number is declining. Another factor to

consider is which Braille to use. As a transliterated language, Braille can be transcribed into Hindi, English or a local language. The need is to ascertain which is the most common form of Braille used locally and if necessary, be prepared to make different copies. In Maharashtra, basic information on HIV was first produced in Hindi Braille, then English and next Marathi.

For people who are partially sighted, large print versions is another option that has been adopted by Mumbai DACS. For visually impaired people who are IT literate and with access to software, screen-reading programmes such as JAWS enable them to have the contents of a web-site or file read out automatically.

Practical demonstrations, such as how to use a condom require detailed descriptions and the opportunity for visually impaired people to feel visual aids. Giving someone a condom will be far more effective than simply a description. Use of realistic and life size models are also helpful. Most people develop their knowledge of what the opposite sex looks like through pictures and photographs. Someone who is blind from birth will not have had that opportunity.

When conducting an awareness session in a community, find out before starting by asking and observing (people may feel shy to say) if there is anyone present who cannot see or has limited vision. If there is someone who is partially sighted, make sure that they can see what is being shown by ensuring they are close enough and the place is well lit.

5.2 Hearing Impairment

Deaf people are generally excluded from everyday life because people are not aware they are deaf - you cannot tell by looking. Since ability to communicate is the most important factor in the acquisition of knowledge, there are particular considerations in terms of deaf people and their vulnerabilities. Ability to communicate also depends on when they became deaf. Someone who became deaf after they learnt to talk (post-lingual deafness) will be at a greater advantage in terms of speech skills and the ability to lip-read than someone who was born deaf (pre-lingual deaf). Communication also depends upon the degree of deafness: someone who is hard of hearing but able to acquire and use a hearing aid will be at a greater advantage than someone who is completely deaf.

In general, deaf people have very low levels of body literacy (systems, function, differences, changes, etc.) and a similarly limited awareness of sexual health. This study heard of instances of young deaf women becoming pregnant and whose understanding of the body was so limited that they had no idea that having sex could lead to pregnancy, which they instead thought was caused by eating certain foods or tying a *mangalsutra*.

Poor levels of body literacy are a result of the inaccessibility of subjects such as human biology and reproduction within the school curriculum. Although most deaf children do not go to school, those who do, usually attend regular schools where teachers are not been given the training, time or resources to communicate effectively and as a result, much of the curriculum passes them by. Although some deaf children attend schools with specialist training and facilities for deaf children, in

most cases, these only go up to 7th Standard whereas subjects such as human biology, reproduction and sex education are covered later. The ability to learn effectively - in any subject - is dependent upon the communication skills between teacher and student. The outcome is high levels of illiteracy among deaf people - as high as 95%.

Inability to communicate - and therefore to protest and complain - makes deaf women particularly vulnerable to sexual abuse and exploitation. Organisations in contact with deaf women in Andhra Pradesh, Delhi, Karnataka, Maharashtra and Manipur all expressed this concern, in most cases based upon specific instances.

Although most deaf people in India communicate with each other by Sign Language, in 95% of cases, these are individual or local form of gestural communication - finger spelling, pidgin Sign, manual codes, visual-gestural combinations or mime. Only 5% of deaf people in India know Indian Sign Language (ISL), the majority of these in the north.

From Delhi and Hyderabad, Deaf Way conduct sexual health workshops for deaf people in ISL in response to demand and when resources permit. In the absence of contacts with the HIV sector, they have had to develop their own materials independently. They find the two main barriers to communication are low levels of literacy and limited knowledge of ISL. Although both can be overcome to a certain degree through extensive use of visual aids and mime, Deaf Way also invite hearing companions of deaf people who are familiar with their individual gestures to translate.

Although there are no physical barriers to prevent deaf people from attending public sessions on HIV, they generally get left out because people cannot tell if someone is deaf by looking at them. The only way is to ask the audience before beginning a session. For people able to who lip read, ensuring that the speaker's face is well lit, in direct line with the lip reader and speaking clearly all help in better communication.

5.3 Intellectual Impairment

In common with deaf women, people with intellectual impairments, learning disabilities and developmental delay are particularly vulnerable to sexual abuse and exploitation, not only because limited communication skills make them less likely to be able to protest and complain, but also because they are less likely to be believed. Again, NGOs working in Andhra Pradesh, Delhi, Karnataka, Maharashtra and Manipur all expressed this concern.

Because intellectual impairment is a spectrum and may be accompanied with other impairments, issues around vulnerability and ability to understand about sexuality and HIV will depend on the degree of impairment. For those in the severe to profound spectrum, the major concern of parents is vulnerability to sexual abuse. That concern is real - several organisations knew of incidents and in most cases, the family kept quiet out of shame and fear of social repercussions.

For people with mild to moderate intellectual impairment, many are capable of being sexually active and giving informed consent. Indeed, several organisations talked of ex-students who had gone on to get married. It is not uncommon for people with mild to moderate intellectual impairment in rural areas to get married since awareness is lower and acceptance higher.

However, there are also many factors that make people with intellectual impairments vulnerable, including poor judgement, poor impulse control, social skill deficits, cognitive problems and difficulty in making decisions.

People within the mild to moderate spectrum are able to understand information and advice on sexuality in varying levels of detail according to the degree of impairment. There are also issues around short attention spans and the ability to retain information. One NGO in Anantapur District reported that when a woman with mild intellectual impairment got married recently, they decided to provide her with information on family planning. Although there was scepticism that she would be able to understand, they found this was possible when they used simple language and terminology. Another NGO in Chennai found that every three months they had to remind a woman with mild intellectual impairment who they knew to be sexually active to insist on condom use.

No NGO consulted in the course of this research had yet come across someone with an intellectual impairment who was known or suspected to be HIV positive. However, given the exposure to abuse among the severe to profound spectrum, and the fact that many in the mild to moderate sector have relationships, this is again more likely to be failure to reach them. Certainly, Parivaar, the National Federation of Parent's Associations have no doubt that there are people with intellectual impairments living with HIV, it is just that they have not as yet encountered any.

For the NGO providing information on HIV, it is important to ensure that people with mild to moderate intellectual impairments are also included in community programmes. The key is simple language and patience. A Delhi-based NGO, Jan Madhyam, has developed a booklet on relationships and sexuality for young people with intellectual impairments.

5.4 Mental Illness

People with mental health problems can become HIV positive in the same way as other people can, while being diagnosed as HIV positive can also trigger mental illness. As with visual impairment, it is probable that any NGO working with people living with HIV will eventually encounter people with mental health problems.

Vulnerabilities around mental illness include temporary lack of control which can make people unmindful of their dress and/or behaviour, while medication to control certain symptoms can in some cases increase libido and make men sexually aggressive. Temporary loss of memory means that people are unable to remember if they are abused, and if they do, they are disbelieved. All these factors make women with mental health problems particularly vulnerable.

Mental illness is often associated with destitution and women with mental health problems living on the streets are perhaps most at risk. One organisation working with mentally ill women reported that 70% of women they see have been sexually assaulted, which in most cases means they have been raped. Over the last four years, they have identified an average of 10 mentally ill women as HIV positive per year (2.7%). Since only one test is conducted, missing the window period probably means that the actual number will be higher.

The ability to absorb information will depend upon the degree of mental illness, stage of recovery and efficacy of medication. Several residential institutions who work with mentally ill people provide information on safer sex as they near the period for release. For an HIV NGO working in the community, there is no reason why people with mental illness should not be included.

5.5 Mobility Impairment

In general, it was found that people with mobility impairments were at no significant disadvantage in terms of their ability to access information on HIV other than physical access. Men with mobility impairments generally know as much (or as little) about HIV as anyone else in their community. If the non-disabled population know very little about HIV, then people with mobility impairments will be the same. In Tamil Nadu, ADD India found that people with mobility impairments occasionally asked questions about HIV which people with other impairments did not.

Even if community awareness workshops are held in inaccessible locations, the range of media tools used to disseminate information (TV, radio, newspapers, etc.) and the absence of barriers to communication mean people with mobility impairments are able to learn as much as anyone else. Gender inequality means that disabled men will be more aware and have more opportunities to socialise than women with disabilities, and therefore in terms of HIV information, the need is to consider the gender dimension rather than impairment in such cases. However, accessing HIV services is less straightforward when physical presence is required. VCTCs and care and support centres that are in distant locations and/or inaccessible venues with stairs and no ramps or lifts will prevent people with mobility impairments from accessing such services.

5.6 Leprosy

Although there are no communication barriers to prevent people with leprosy from accessing information on HIV, social discrimination means that they are often excluded from community activities, including public information campaigns. Because of this, many people with leprosy still choose to live in their own communities. This research did not come across any instance of HIV awareness campaigns being conducted in these communities. Several NGOs working with people with leprosy in Karnataka, Andhra Pradesh and Orissa were aware of some who are also HIV positive.

Continued discrimination against people with leprosy is a major factor in terms of vulnerability to HIV. Many people with leprosy live in their own communities and because of stigma, their sexual partners are often limited to other people with leprosy. According to at least one NGO working on leprosy, there is a relatively high

degree of sexual activity in leprosy communities with multiple partners. In such a closed environment, infections quickly spread and prevalence can become higher than among the general population outside.

A similar scenario prevails within leprosy rehabilitation centres where people go to be treated, where rest and regular dressing of wounds is the main treatment. Away from their families and communities, social norms can be relaxed, while staying in an environment with other people who have the same impairment and with a lot of time on their hands, there is again believed to be a relatively high degree of sexual activity.

5.7 Cerebral Palsy

The Spastics Society of Tamil Nadu and Vidya Sagar in Chennai knew of women with cerebral palsy who have gone on to get married, mostly to non-disabled men. The Spastics Society of India, Mumbai also reported that many ex-students have gone on to get married, in their case more men than women. Since 60-70% of people with cerebral palsy have only co-ordination difficulties with no accompanying intellectual impairment, there are no particular issues around their ability to understand sexual health and HIV and therefore no reason not to provide information on sexual health and HIV.

5.8 Autism Spectrum Disorder

As with intellectual impairment, the ability to understand and use information depends on the degree of ASD. Autistic people in the mild to moderate spectrum are capable of learning and several NGOs visited knew of autistic people who had gone on to get married and are presumably sexually active. As an impairment related to social skills, there are however issues related to the inability to rationalise. Although many people with autism are able to understand the difference between good or bad touch as a method of preventing abuse or abusing others, they are often unable to apply discretion to advice. As such, it is difficult for an autistic child to understand that while it is OK for a parent to touch a certain part of the body, it is not acceptable for anyone else to do so. The message received is that either everyone or no one can touch you.

5.9 Deaf-Blindness

According to Sense International and the Helen Keller Institute, deaf-blind people are extremely vulnerable to abuse and exploitation because of the difficulties of communication and ability to access information. Abuse does happen but is generally unreported and some centres use the "good touch, bad touch" methodology to make people aware of abuse. Methods of communication used are finger spelling directly on to the palm and tactile Sign Language.

6. ISSUES AROUND GENDER AND DISABILITY

Exclusion and marginalisation on the basis of sex and impairment are two common forms of discrimination. A disabled woman therefore suffers the double discrimination and multiple impact of both forms of inequality. The implications of this in terms of HIV is that women with disabilities - particularly those with speech, hearing and intellectual impairments - are more vulnerable to sexual exploitation and abuse than men with disabilities or non-disabled women.

The fact that many women with disabilities have had sheltered lives, kept at home by families for “protection,” out of embarrassment, or simply their own limited mobility, means that many have not had the opportunity to acquire the social skills to recognise predatory behaviour and potentially vulnerable situations. Because it is assumed that women with disabilities will not be sexually active, they are not given information on relationships, how to deter predatory behaviour or negotiate safer sex.

A further factor is the perception that women with disabilities are likely to have fewer opportunities for relationships than non-disabled women. The outcome is that some disabled women are therefore more vulnerable to overtures and with that, reduced negotiating powers and increased vulnerability to exploitation.

The social imperative to get daughters married, combined with the fact that women with disabilities are generally considered less eligible as marriage partners means that many are married off to any man willing to accommodate them. In many cases, women with disabilities living in rural areas become second or third wives. The resultant low self-esteem combined with negligible knowledge of sexual health severely diminish their ability to negotiate safer sex.

7. PEOPLE WITH DISABILITIES AND HIGH RISK BEHAVIOUR

As part of this research, NGOs working with “high risk groups” were also consulted, including those working with sex workers and their clients, Injecting Drug Users (IDUs) and men who have sex with other men (MSM). In all cases, it was found that a proportion of the respective NGO’s target group were people with disabilities. Again, this was almost exclusively anecdotal evidence and estimates quoted were much lower than the 6% figure one would expect and again, this makes the case for more detailed studies. People with disabilities may not be a high risk group, but some people with disabilities engage in high risk behaviour.

Finding women with disabilities in sex work is perhaps not surprising given the connection between disability and poverty. In the absence of employment opportunities or safety networks, women with disabilities are particularly vulnerable to being forced into sex work. Indeed, given that people with disabilities are more likely to be poorer than non-disabled people, it seems reasonable to assume that the numbers of disabled sex workers would be higher than 6%.

Several NGOs with disability programmes knew of women with disabilities who had turned to sex work in the absence of alternatives. NPDO Hyderabad told of a disabled woman who discovered she was HIV positive after her husband died and with no source of income, went into sex work. The Manipur Network of Positive People knew of several women with disabilities whose husbands had died of AIDS-related illnesses forced to turn to sex work. RDT Anantapur mentioned a disabled woman with a mobility impairment who periodically goes to Bangalore for sex work. The Blind Person's Association knew of five visually impaired sex workers in Ahmedabad while AIFO also knew of several women with leprosy engaging in sex work. Neither is this an urban phenomenon. While interviewing people with disabilities in rural Karnataka, one NGO found that several women with disabilities were involved in sex work.

Several NGOs working with sex workers also reported women with disabilities among their target group. In Bangalore, Agni Raksha estimated that 30 out of the 300 female sex workers they work with (10%) have disabilities, the majority of them mobility or hearing impairments. In Maharashtra, two out of 12 sex workers interviewed (16%) by Shodhana Consultancy were disabled (one hearing and one intellectually impaired), while in Orissa, one of the 25 sex workers USS Cuttack works with (4%) is mobility impaired. In Tamil Nadu, Arogya Agam were aware of at least six disabled sex workers while another knew of six women recovering from mental illness who engage in sex work. In Kolkata, Durbar Mahila Samanwaya Committee were aware that some of the 20,000 sex workers they work with are disabled, but were unable to give an estimate of numbers.

As with the non-disabled population, disabled sex workers are not exclusively female and at least two NGOs working with male sex workers in Bangalore and Mumbai knew of disabled male sex workers.

Some disabled men also visit sex workers. Staff of one NGO in rural Karnataka thought that men with disabilities probably made up 10% of sex workers' clients while sex workers in Maharashtra estimated that disabled men made up 2% of their clientele. In Orissa, several men who visit sex workers in USS's targeted intervention programme are also disabled.

In Manipur, the United Voluntary Youth Council (UVYC) run a de-addiction centre for female IDUs at Torbung. In the course of their work, they have come across people with disabilities who use drugs and of 250 female IDUs identified, 30 of these (12%) are women with disabilities, mainly with mobility and hearing impairments. Within UVYC's disability programme, six of the 120 women with disabilities they work with (5%) are also HIV positive. The reasons women with disabilities give for taking drugs are the same as other women: escape from the ongoing conflict and security situation, as a release from domestic problems, and easy availability.

In Mumbai, the Humsafar Trust, a health-oriented NGO for men who have sex with men (MSM) estimate that about 50 of the 6,000 MSM (0.83%) they are in regular touch with are disabled. One MSM with a mobility impairment is a public speaker for Humsafar, while after coming across a group of deaf men cruising at a railway station, three deaf MSM were subsequently trained as peer educators who now work

with a group of 15 other deaf MSM. In general, men with mobility and visual impairments find it harder to access cruising sites because of their lack of physical mobility or vision and are obliged to develop contact other MSM through friends or contacts.

8. VULNERABILITY WITHIN RESIDENTIAL INSTITUTIONS FOR PEOPLE WITH DISABILITIES

Gathering hard information on the vulnerability of people with disabilities in residential institutions is of course extremely sensitive and difficult. However, it is notable that the origins of several disability INGOs' engagement with HIV was a higher incidence of HIV within residential institutions they supported in Africa than in the general population outside.

Staff of at least one residential home talked of several instances of abuse or high risk behaviour between residents where the tendency was to ignore and/or cover up such incidents since people were too embarrassed and unsure of how to deal with it. In another case, one NGO became aware of sexual abuse of mentally ill women as well as homosexual behaviour with and among male inmates in institutions, but their proposal to conduct sessions on sexuality in order to create awareness of abuse and appropriate behaviour was rejected because it was felt that it would "corrupt" people.

One NGO who conducted a session on HIV within a residential school for blind boys was approached by a student afterwards and asked for condoms because homosexual activity between blind students was unprotected. Similar behaviour was reported in other residential institutes for blind boys.

How prevalent and representative such instances are, it is of course hard to tell and awareness of HIV is in many ways irrelevant in cases of sexual abuse. Nevertheless, awareness of sexual abuse and sex education can make people more informed, aware and assertive of their rights, and less tolerant of abuse and exploitation.

9. INITIATIVES BY DISABILITY INSTITUTIONS ON SEXUAL HEALTH AND HIV

Although many institutions working with disabled children - across all types of impairment - conduct sessions on subjects such as sexuality, sex education and sexual health, there is as yet no consistent curriculum or format, nor any common source of information. It also seems that coverage of sex-related information is mainly conducted by large scale educational institutions for disabled children in metropolitan cities.

In most cases, sex education starts around the time of puberty in order to cover subjects such as menstruation and masturbation, and this is then augmented in subsequent years. Topics covered include relationships, body literacy, reproduction, sexual health, intercourse, safe sex, family planning, STDs and RTIs. Several

institutes also provide pre-marriage counselling. However, there are still gaps: although several institutions commented that several of their ex-students had gone on to get married, not all of them covered family planning.

HIV has been introduced more recently by several organisations, including the Blind Persons Association of Ahmedabad, the Spastics Society of India in Mumbai, Vidya Sagar and the Spastics Society of Tamil Nadu in Chennai. In some cases, HIV is an integral part of sex education programmes while in others, it is a separate, stand-alone subject. In the absence of contact with the HIV sector, institutions rely on their own materials and format for HIV awareness.

Awareness of sexual abuse has also been introduced by several institutions, some at an early stage and across the full range of impairments. The “good touch, bad touch” methodology is the most common approach followed because it is simple enough to be understood by children with most types of impairment (with the exception of autism). Wherever possible, most organisations prefer to conduct sessions in mixed-sex groups with opportunities for single-sex groups or individual discussion offered.

There is a need for disability institutions to provide comprehensive information on sexual health and appropriate behaviour for people with all types of impairments. Although there is a need for discretion according to age and individual circumstances, there is also a need to provide a consistent and holistic sexual health/life skills package, of which HIV is one component. Adaptation and use of pre-existing materials used in mainstream education (such as the *Life Skills Modules* which are part of the Adolescence Education Programme developed by the Ministry of Human Resource Development, NACO and UNICEF) would not only make this task easier, but also ensure a consistency with what is being provided in the mainstream sector.

10. INITIATIVES ON HIV AND DISABILITY

In the course of this research, several examples of organisations providing information on HIV and/or including people with disabilities in their programmes were identified - many of these collaborative ventures between government agencies and NGOs. These are reported here as examples of good practice and for further information.

10.1 Nethrajothi, Chennai

Nethrajothi, formerly known as AIDS Action for the Blind, have worked on HIV awareness for visually impaired people since 1992 and are the earliest known example. Started by a group of blind and sighted people involved in the education of blind students, the origins were a concern that blind men were particularly at risk because they engaged in high risk behaviour with minimal information. The two main reasons were that because many blind men tend to marry late, many engage in premarital sex, and the incidence of homosexual behaviour in residential institutes for the blind.

They began by translating a booklet *AIDS: What You Should Know* into Braille in 1993, and worked with the South India AIDS Action Programme (SIAAP) in Chennai. Since then, Nethrajothi have conducted a series of HIV awareness programmes in schools for the blind across Tamil Nadu which included putting material into Braille and on to cassette with funding from SIAAP, AIDS Prevention and Control Project, Voluntary Health Services (APAC-VHS) and Tamil Nadu SACS (TANSACS). They have also worked with the state branch of the National Federation of the Blind.

Nethrajothi have also implemented an innovative peer support programme whereby blind people who operate PCOs were given HIV awareness training and supplies of leaflets and condoms since these places also function as meeting points for other blind people.

They are currently fundraising for an HIV awareness and prevention programme with 3,500 blind people in Chennai, Coimbatore, Tiruchi and Madurai using the same combination of IEC campaigns in schools for the blind alongside training of blind PCO owners as peer support workers.

Because Nethrajothi have only been able to secure short-term and one-off funding to date, they have not been able to work on a long term and continuous basis. As a result, awareness campaigns in schools happen in alternate years and IEC materials that are put into Braille and cassette, once exhausted, are not able to be replaced. As a targeted intervention to reach blind people, the programme is an excellent initiative that provides scope for replication with people with other impairments. However, the provision of information on HIV to blind people needs to be provided continuously, as an integral part of HIV programming and not as an “add on” when funds permit.

The Nethrajothi example is possibly the best example identified because it has used a range of techniques - Braille, audio-cassette and talks to provide information, engagement with the disability movement, and application of the peer support strategy to reach blind people in the community, not just those in educational institutions.

10.2 Deaf Way, Delhi and Hyderabad

Between 1998-2000, the Macarthur Population Programme funded a research programme - Project Signpost - to explore deaf adults' sexual behaviour and vulnerability to HIV involving three groups of deaf people, two schools for deaf children and one workshop of deaf women in Delhi, Mumbai and Chennai. The report *Exploring the Sexual Vulnerability of Urban Deaf Indians* found above average (compared with the general population) levels of sexual abuse of deaf women and children, average levels of sexual activity, and well below average levels of knowledge about the body, anatomy, functions, sexual and reproductive health. The main reason was attributed to the fact that the majority of deaf schools only go up to 7th Standard and if students wish to continue studies, they have to then enter the

mainstream system. In theory, deaf students are then able to access the regular school curriculum which covers biology and sex education, but in reality this depends on the ability of the student and teacher to communicate with each other. Using (1999) NACO statistics of the estimated incidence of HIV among the general population and applying this to the estimated number of deaf people in India, the study calculated there were 193,607 deaf people in India were living with HIV.

In response, Deaf Way developed a four-day workshop in Indian Sign Language (ISL) *Relationships and Health* - a sexual health curriculum that covers body function and systems, reproduction, maintaining good health and relationships, and HIV. The curriculum was designed by accessing information from the internet and making it accessible to deaf people by using ISL, PowerPoint, slides, overheads, video, flip-charts, mime and role play. Eight deaf people were trained as trainers and five are still active in Delhi and Hyderabad.

Deaf Way hold an average of three workshops per year which are organised in response to requests from Friendship Clubs. Most workshops are self-financing and a maximum of participants pay Rs200 for the full four days. Most are aged between 16-40 and although some are married and parents, Deaf Way find that their knowledge and understanding is often as limited as unmarried participants. Since starting in 2002, about 15 workshops have been held to date in Delhi, Punjab, Andhra Pradesh, Maharashtra, Tamil Nadu and Kerala and approximately 350 deaf people have received the training. With only 5% of deaf people in India familiar with ISL, some participants with limited ISL skills are also invited in the expectation that they will pass on their newly acquired information to other deaf friends using local gestures. Translation from ISL to local gestures, captioning, mime and role play are other methods used to promote understanding. Although all courses have been held within the Deaf Way structure to date, they would be happy to run workshops for other organisations.

As with Nethrajothi, Deaf Way courses are not dependent on any single form of communication but are creative - and therefore more inclusive - by using a full range of communication techniques.

10.3 Mumbai DACS-Association for Blindness and Low Vision, Mumbai

In January 2005, Mumbai District AIDS Control Society (MDACS) were approached by the Association for Blindness and Low Vision to put their basic IEC materials on HIV into Braille and large print. MDACS readily agreed and 10,000 copies in Hindi large print and 5,000 in Hindi Braille were produced by the Helen Keller Institute, Mumbai. A year later, this time at MDACS initiative, a further 10,000 large print copies in English and 5,000 in English Braille were also produced. MDACS are now considering whether to produce further copies in Marathi Braille and large print.

Once produced, MDACS sent copies to all schools for the blind and all known disability NGOs throughout Maharashtra, as well as to every SACS office throughout India for their information. Further copies are available at MDACS free of cost. It will be important to regularly publicise their existence because if people forget they exist or are unaware of this, they will stop asking for it.

The MDACS example is an excellent example of the openness of DACS/SACS offices to the inclusion of people with disabilities in their programmes. Clearly, it would not have been possible to distribute the material to all NGOs working on disability in Maharashtra without getting this information from the State Disability Commission or disability NGOs familiar with the state scenario. The MDACS example demonstrates two factors for success: the importance of a clear distribution and dissemination strategy and the value of engagement with the state disability structures.

10.4 Devnar Foundation for the Blind-APSACS, Hyderabad

The Devnar Foundation run a School for the Blind in Hyderabad and felt it important that their adolescent students had the amount of information on HIV as their non-disabled peers. Initially they looked for material in Braille that they thought would be readily available and when they realised it wasn't, decided to produce it themselves.

In 2006, they approached Andhra Pradesh SACS (APSACS) and asked them for copies of IEC materials distributed to all mainstream schools under the Adolescence Education Programme. They then asked APSACS that if Devnar was to reproduce the most relevant material in Braille and send it to all 50 schools for blind children in Andhra Pradesh, whether APSACS would pay for the production and distribution costs. APSACS immediately saw the need and readily agreed.

The two manuals are a Frequently Asked Questions Booklet for Students "*Growing Up in a World with HIV/AIDS*" and the narrative from an accompanying "*Flip Chart: Teaching Aid for the Classroom*" for blind teachers. The two publications are part of four materials that comprise the NACO/APSACS Adolescence Education Programme. Two copies of the student's booklet and teacher's flip chart were sent to all 50 schools for blind children in Andhra Pradesh. Copies are available at Devnar Foundation and APSACS, who are open to producing information in other formats in order to make their material accessible for disabled people with other impairments.

The example from Andhra Pradesh highlights the importance and benefits of cross-sectoral collaboration. By approaching APSACS with the offer to provide whatever technical support was required (in this case translation into Braille and Braille printing), APSACS job was much easier. The ability to either provide the necessary technical support, or know where to access this, makes the request much more likely to be approved.

10.5 Other Initiatives

In 2002-03, **YRG-CARE** conducted a study within five schools for deaf and blind students in **Chennai** and found that levels of awareness of HIV was extremely low while some of the students were sexually active. In July 2003, they then conducted a two-day training programme on HIV, sex and sexuality for 15 teachers from the St. Louis Institute for the Deaf and Blind and Dr. MGR School for Speech and Hearing Impaired, both in Chennai. However, this was a one-off initiative and has not been repeated in these or other schools.

Gujarat AIDS Awareness & Prevention Unit (GAP) ran an HIV awareness programme in **Ahmedabad** over a two year period that included blind PCO owners as peer support workers in the same way as Nethrajothi in Chennai.

As reported earlier in this report, several disability INGOs are considering how to address HIV in their programmes. For disability NGOs using CBR as their main strategy, the debate is to what degree other non-disability subjects can and should be covered within the remit of a CBR programme. In **Orissa, Pratibandhi Kalyan Kendra** have been covering subjects such as family planning and safe sex within their CBR programme for some time. They have recently added HIV awareness to this which includes IEC materials. Sessions on HIV for mobility and visually impaired people are conducted in groups while people with hearing impairment are briefed individually using lip reading and gestures. PKK have not yet come across any people with disabilities who are HIV positive.

11. POTENTIAL STRATEGIES AND PRACTICAL RECOMMENDATIONS FOR INCLUSION OF PEOPLE WITH DISABILITIES IN HIV PROGRAMMES

11.1 Potential Strategies

- In the absence of firm data on numbers of people with disabilities living with HIV, rights of equality of access to information and services on HIV is a more effective argument for inclusion. Lack of statistics or low numbers provide a justification not to include people with disabilities or to allocate fewer resources to this
- Adopt the twin track approach to inclusion: include people with disabilities in mainstream HIV programmes while at the same time, targeting the disability movement and sector
- Inclusion is only achievable by proactive engagement - formal and informal, partnerships and joint ventures between the disability and HIV sectors to develop and maintain disability and HIV perspectives in the respective sectors
- Formal engagement between government disability and HIV structures at central and state levels through the inclusion of disability representatives within HIV mechanisms and *vice-versa*, for example:
 - The Office of the Chief Commissioner for Persons with Disabilities within the National Council on AIDS and/or the National AIDS Committee
 - NACO representation within the Central Co-ordination Committee and/or Central Executive Committee of the Persons with Disabilities Act, 1995
 - A disabled person with experience of advocacy in the national and/or international arena within the Country Co-ordinating Mechanism for AIDS, TB and Malaria as a Civil Society Representative
 - A disabled person with experience of working on disability issues within SACS Advisory Panels
- Similar incorporation and engagement between national and state level organisations working on disability or HIV within the civil society sector
- The establishment of 3-5 disability NGOs as champions of HIV within the disability sector to advocate for engagement with HIV within the disability sector, to provide training and support to enable this, and to support mainstream HIV programmes to become inclusive of people with disabilities
- The formation of some form of joint working group of a few key HIV and disability organisations to achieve this
- Formal and informal engagement between SACS offices and State Disability Commissions would greatly facilitate the inclusion of people with disabilities and disability organisations in HIV information, programmes and services

- Ring-fencing a fixed percentage of annual budgets of both government agencies and NGOs working on HIV for joint disability-HIV initiatives (preferably 6% or at the very least, in line with the National Planning Commission guidelines for budget provision) would enable a more proactive approach to funding
- For funders of HIV programmes, adding a question to applications asking how the applicant will ensure that people with disabilities are included in the programme for which funding is sought would greatly promote inclusion. Adding the same question in subsequent reporting formats and monitoring this would ensure it
- Include HIV awareness sessions in training programmes of rehabilitation professionals and special education teachers
- The Positive Speakers strategy used by the Positive People's Networks are a highly effective way of reducing social stigma and discrimination. The inclusion of people with disabilities living with HIV into these public speaking programmes would also raise awareness of the vulnerability and existence of people with disabilities with HIV
- Wherever possible, people with disabilities should receive information on HIV in the same place and at the same time as the rest of their community in order to avoid further stigma and discrimination, unless there is a natural environment in which to provide this. Institutions for people with disabilities are one such natural environment
- Yale University's three-tiered approach to inclusion of people with disabilities into existing programmes to targeted interventions is a helpful and practical model and is included as Annexe 3 to this report
- Develop similar guidelines on how disability organisations can engage with HIV

11.2 Practical Recommendations

- In order to monitor whether disabled people are accessing services and being included in HIV programmes, adding an extra box to be ticked alongside sex is a simple and low cost method to collect information. A further box stating the type of impairment (hearing, visual, mobility or intellectual) will provide more information and requires no specialist skills to identify. As a rough guide, if the numbers of people with disabilities contacted is less than 6% of the total, the organisation is not matching the demographic profile
- Identify and contact local DPOs and disability NGOs. DPOs in particular can be a valuable source of local contacts, advice and information on disability and alternative communication techniques. However, be aware that not all people with disabilities are members of DPOs
- Identify select disability organisations locally on the basis of their reach, target group and/or engagement with specific impairments, and train them as nodal agencies to provide awareness, training and support on HIV to other disability organisations and people with disabilities
- Train people with different impairments as HIV peer support staff to inform and support other people with disabilities on HIV awareness and information. Ensure that disabled peer support staff are working both in mainstream HIV programmes as well as within disability NGOs
- Ask local disability organisations to conduct disability equality/awareness training workshops for staff of HIV organisations. Similarly, conduct sessions on HIV awareness for staff of disability NGOs. Doing these on a reciprocal basis can make this a no cost exercise.
- As well as advocating for inclusion in, and access to, HIV programmes, the disability sector needs to be willing to provide the technical support required to put materials into different formats and to support the HIV sector on how to include people with disabilities
- There is no single model for ensuring the inclusion of people with disabilities in HIV programmes. People with different impairments and in different situations require different approaches
- This calls for diversity and creativity in the development of HIV IEC materials and communication techniques. Both the most common forms of alternative formats - Braille and Indian Sign Language - have limitations: only 40% of visually impaired people use Braille (and the number is declining) while only 5% of deaf people know Indian Sign Language. Large print versions, audio-cassettes and CDs are alternatives to Braille, although many talking libraries are now replacing cassettes with CDs. Be aware that not all blind people may be able to afford such assets. Tactile charts, full-scale replicas and allowing people to feel objects such as condoms are other methods of ensuring better communication with visually impaired people. Use of captioning, mime and a family member or friend familiar with an individual deaf person's own form of gestures as an interpreter can

augment communication with deaf people who cannot lip read. Use of simple terms, repetition and/or pictures and photographs are helpful in enabling people with intellectual impairment to understand

- Having a clear and proactive publicity and dissemination strategy for IEC materials and communications methodologies in alternative formats is as important as the initial openness to producing material. Knowing the target audience - where to send materials and where to hold awareness sessions and follow up sessions is essential
- Disability institutions need to provide comprehensive information on sexual health and appropriate behaviour for people with disabilities with all types of impairments. Although many do provide inputs on a range of topics, there is a huge variation in subjects covered and amounts of information. There is also a need to provide a consistent and holistic sexual health/life skills package, of which HIV is one component. The adaptation and use of pre-existing material used in mainstream education would ensure a consistency in what is being provided
- As well as providing basic information for life skills, it is also essential to inform people with disabilities about abuse and exploitation. In order to know whether you are being abused, you first need to know what abuse is

REFERENCES

Gopinath, C. & Patil, S. (2000) *Exploring the Sexual Vulnerability of Urban Deaf Indians*, Macarthur Population Programme, Mumbai

Groce, N. (2004) *HIV/AIDS and Disability: Capturing Hidden Voices*, *The World Bank and Yale University Global Survey on HIV/AIDS and Disability*, Yale School of Public Health, New Haven

Groce, N., Trasi R. & Yousafzai, A. (2006) *Guidelines for Inclusion of Individuals with Disabilities in HIV/AIDS Outreach Efforts*, Yale University

Annexe 1

**SURVEY ON HIV AND DISABILITY:
QUESTIONNAIRE FOR DISABLED PEOPLE
AGGREGATED RESPONSES**

Number of people interviewed	350	
Location		%
Andhra Pradesh	103	29
Kerala	41	12
Manipur	40	11
Tamil Nadu	31	9
Karnataka	29	8
Orissa	25	7
West Bengal	22	6
Bihar	15	4
Jharkhand	14	4
Assam	5	1
Madhya Pradesh	5	1
Maharashtra	5	1
Meghalaya	5	1
Pondicherry	5	1
Uttar Pradesh	5	1

PART 1
BACKGROUND INFORMATION

Date of completing form	
Name of person interviewed (optional)	
Name of organisation through which contact was made	
Location (village/town/city, district, state):	
Male/female	M-191 (55%), F-159 (45%)
High or low prevalence state	H-213 (61%), L-137 (39%)
Age (Under 15, 15-45, 45 plus)	U-15-5 (1%), 15/45-324 (93%), 45+ 21 (6%)
Disabled person	328 (94%)
Carer of a disabled person (state relationship)	22 (6%)
Working/studying/unemployed	W -178 (51%), S - 47(13%), U- 125(36%)
Married/single	M-127, S-223
Rural or urban-based	R-325 (93%), U-25 (7%)
Living at home/with relatives	334 (95%)
Live in an institution	16 (5%)

1. What is your impairment (or that of the person you care for)?

Orthopaedic	232 (66%)
Visual: blind/partially sighted/low vision	50 (14%)
Hearing: deaf/hard of hearing	26 (7%)
Cerebral Palsy	4 (1.1%)
Intellectual: learning disability/mental retardation	17 (5%)
Mental Illness	11 (3%)
Autism	0 (0%)
Epilepsy	1 (0.3%)
Leprosy	0 (0%)
Haemophilia	1 (0.3%)
Multiply Handicapped	3 (0.9%)
Other (please describe)	5 (1.4%)

2. Did you go to school?

Yes	145 (46%)	No	173 (54%)
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No response - 32

2a. Did you go to a regular school or a special school for disabled children?

Regular	138 (51%)
Special	15 (6%)
Didn't go to school	116 (43%)
No response	81

2b. What standard did you study up to?

PART 2
AWARENESS OF HIV/AIDS AMONG DISABLED PEOPLE

3. Have you ever heard of HIV and/or AIDS?

Yes	272 (81%)	No	62 (19%)
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No response - 16

3a. If yes, what do you understand about HIV and/or AIDS?**4. How much would you say you understand about HIV/AIDS?**

A lot	6 (2%)
Enough to know the risks and how to protect myself	72 (22%)
A little: what it is, causes, risks, etc.	99 (31%)
The words "HIV/AIDS," but little else	84 (26%)
Nothing at all	62 (19%)
Other (please explain)	2
No response	22

5. What ways do you know how people can become infected by HIV?**6. Do you think that disabled people might be at risk of HIV/AIDS?**

Yes	152 (73%)	No	55 (27%)	Don't know	127
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No response - 16

7. Do you think that disabled people might be at greater risk of HIV/AIDS than non-disabled people?

Yes	114 (64%)	No	65 (36%)	Don't know	141
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No response - 30

8. Why do you think disabled people might be at risk of HIV/AIDS?*(Tick as many as appropriate)*

They are as sexually active as the general population	131 (10%)
Vulnerable to sexual abuse	125 (9%)
Disabled people are targeted by others as they are assumed not to be sexually active and therefore "safer"	98 (7%)
Many disabled people have not been able to develop the social skills to avoid vulnerable situations	146 (11%)
Drug usage	65 (5%)
Medical procedures they undergo	84 (6%)
They live in an institution	61 (5%)
Lack of information concerning HIV/AIDS	177 (13%)
No access to HIV prevention programmes	144 (11%)
Prevention programmes are not in a language/format that can be understood	113 (8%)
Families will not let them participate in HIV/AIDS programmes	139 (10%)
The institution they live in will not let them participate in HIV/AIDS programmes	64 (5%)
Other (please explain):	14
No response	60

9. Is there anything particular about the type of disability you have that makes people with that disability less aware of, or more vulnerable to HIV/AIDS?**9a. Are there any specific issues that might make disabled women/girls less aware of, or more vulnerable to HIV/AIDS? If so, what are these?****10. Do you know of any disabled people in your area who:****a. are living with HIV or AIDS?**

Yes	12 (4%)	No	313 (96%)
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No response - 25

b. have died from an AIDS-related illness?

Yes	44 (14%)	No	274 (86%)
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No response - 32

11. If there are people (disabled or non-disabled) who have died from, or are infected with, HIV/AIDS in your area, how have others in the community responded?

HIV/AIDS is not discussed	57 (37%)
It is said that they died from something else	50 (33%)
Stigma/prejudice against those who are infected	46 (30%)
Other (please explain)	10
No response	187

PART 3
ACCESS TO INFORMATION ON HIV/AIDS

12. Have you ever received any information on HIV/AIDS?

Yes	219 (76%)	No	71 (24%)
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No response - 60

12a. If yes, what type of information did you receive?

General information on HIV/AIDS	164 (34%)
Safe Sex	115 (24%)
Sexually Transmitted Diseases	104 (21%)
Drugs	66 (14%)
Other topics relevant to HIV/AIDS (Please describe)	35 (7%)
No response	156

13. If so, who provided this?

The same NGO who has supported us before	102 (19%)
Another NGO that works on HIV/AIDS	62 (12%)
School/college	51 (10%)
Government agency	71 (13%)
Other people in my community	74 (14%)
Family	30 (6%)
Friends	94 (18%)
Others (please explain)	42 (8%)
No response	101

14. If you wanted to get information/more information about HIV/AIDS, would you know where to get this from?

Yes	167 (51%)	No	161 (49%)
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No response - 22

14a. If so, where and/or who from?**15. Have you, or any other disabled people you know ever asked for information, advice or support on HIV/AIDS from an organisation?**

Yes	53 (17%)	No	266 (83%)
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No response - 31

15a. If so, what was asked for?**15b. Were they helpful?**

Yes	71 (40%)	No	107 (60%)
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No response - 172

15c. If they were helpful, what did they do that made it helpful for disabled people?

16. Are you aware of any organisations in your area that are informing people about HIV/AIDS?

Yes	115 (36%)	No	202 (64%)
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No response - 33

17. Are you aware of any efforts by organisations to include disabled people in information programmes on HIV/AIDS?

Yes	146 (68%)	No	70 (32%)
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No response - 134

18. Do you know if any disabled people in your community have ever received information on HIV/AIDS through programmes aimed at the general population?

Yes	118 (37%)	No	205 (63%)
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No response - 27

- 18a. If yes, how many disabled people in your community do you think were reached?

None	35 (19%)
Few	99 (53%)
Some	47 (25%)
Most	5 (3%)
All	0 (0%)

No response - 164

- 18b. If yes, what type of information was received?

General information on HIV/AIDS	132 (41%)
Safe Sex	81 (25%)
Sexually Transmitted Diseases	65 (20%)
Drugs	35 (11%)
Other topics relevant to HIV/AIDS (Please describe)	7 (2%)
No response	192

19. Do you think the amount of information on HIV/AIDS reaching disabled people is:

Less than that reaching the general population	182 (81%)
Equal to that reaching the general population	37 (17%)
More than that reaching the general population	5 (2%)
Don't know	126

20. Do you think disabled people's understanding of HIV/AIDS will be:

Less than the general population	159 (74%)
The same as the general population	53 (25%)
More than the general population	3 (1%)
Don't know	135

PART 4
HELP AND SUPPORT FOR DISABLED PEOPLE LIVING WITH HIV/AIDS

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

Yes	9 (6%)	No	153 (94%)	Don't know	188
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- 22. Do you know of any disabled people who were not able to be tested for HIV, or had trouble getting tested because of:**

Inaccessible clinics	72 (33%)
No one willing to treat them	72 (33%)
No Sign Language translation	43 (20%)
Other difficulties (please explain)	31 (14%)
No response	196

- 23. Do you know any disabled people who could not access care and support programmes for people living with HIV/AIDS because of their disability?**

Yes	30 (10%)	No	283 (90%)
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No response - 37

- 23a. If yes, please describe:**

- 24. Disabled people are sometimes diagnosed with HIV/AIDS much later than non-disabled people: because they don't recognise the symptoms; because they're afraid and don't know much about HIV/AIDS; or because HIV/AIDS clinics are inaccessible and/or unable to communicate with disabled people. Have any disabled people you know had any such experiences?**

Yes	30 (12%)	No	219 (88%)
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No response - 101

- 25. Because the disabled community is often small, there may be additional reluctance by disabled individuals to ask about HIV/AIDS for fear of "word getting around." Have you ever heard of this happening?**

Yes	51 (16%)	No	259 (84%)
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No response - 40

Annexe 2
Organisations Visited: August 2006-January 2007
Disability organisations

1. Deaf Way, Delhi
2. Nav Prerna, Delhi
3. Business Community Foundation, Delhi
4. SCORE Foundation, Delhi
5. CBR Forum, Bangalore
6. ADD India, Bangalore
7. Basic Needs, Bangalore
8. Amici di Raoul Follereau, Bangalore
9. Christoffel-Blinden Mission, Bangalore
10. Association of People with Disabilities, Bangalore
11. Mitra Jyothi, Bangalore
12. Leonard Cheshire International, Bangalore
13. Parivaar, Bangalore
14. Banjara Academy, Bangalore
15. Seva-In-Action, Bangalore
16. Samarthyaa, Bangalore
17. Spastics Society of Karnataka, Bangalore
18. Jan Madhyam, Delhi
19. Society for Child Development, Delhi
20. Academy for Severe Handicaps and Autism, Bangalore
21. SACRED, Anantapur
22. Devnar School for the Blind, Hyderabad
23. Stichting Liliane Fonde, Hyderabad
24. Network of Persons with Disability Organisation, Hyderabad
25. Deaf Way, Hyderabad
26. Montford Community Development Services, Chennai
27. Cheshire Home, Chennai
28. The Banyan, Chennai
29. Spastics Society of Tamil Nadu, Chennai
30. Ability Foundation, Chennai
31. Vidya Sagar, Chennai
32. Vazhndhu Kaatuvom, Chennai
33. ADD India, Tamil Nadu, Tiruchi
34. Anjali, Kolkata
35. Antara, Antargram, West Bengal
36. Subhi Association of Women With Disabilities, Subhi, West Bengal
37. Shanta Memorial Rehabilitation Centre, Bhubaneswar
38. Protibandhi Kalyan Kendra, Bhubaneswar
39. Council for Anti-Poverty Action & Rural Volunteers, Imphal
40. Sanchar, Kolkata
41. Blind Person's Association, Ahmedabad
42. Sense International, Ahmedabad
43. Helen Keller Institute, Mumbai
44. National Association for the Blind, Mumbai
45. Spastics Society of India, Mumbai
46. Ali Yavar Jung National Institute for the Hearing Handicapped, Mumbai

HIV organisations/organisations implementing HIV programmes

47. Karnataka Network of Positive People, Bangalore
48. SAMRAKSHA, Bangalore
49. Freedom Foundation, Bangalore
50. Karnataka Health Promotion Trust, Bangalore
51. New Entity for Social Action, Bangalore
52. International HIV/AIDS Alliance, Delhi
53. Christian Medical Association of India, Delhi
54. Human Resources Development Network, Delhi
55. Catholic Hospitals Association of India, Hyderabad
56. HIV of Positive People Efficiency Society, Hyderabad
57. APAC-Voluntary Health Services, Chennai
58. SAATHII, Chennai
59. South India AIDS Action Programme, Chennai
60. Tamil Nadu Network of Positive People, Chennai
61. YRG CARE, Chennai
62. Positive Women's Network, Chennai
63. Indian Network of Positive People, Chennai
64. HIV Ullor Nala Sangam - HUNS, Namakkal
65. Arogya Agam, Aundipatti, Tamil Nadu
66. INSA India, Bangalore
67. Bengal Network of Positive People, Kolkata
68. CINI Bandhan, Pailan, West Bengal
69. GOAL, Kolkata
70. Boruka Charitable Trust, Kolkata
71. Concern Worldwide, Bhubaneswar
72. Committee for Reproductive Health Rights, Bhubaneswar
73. Utkal Sevak Samaj, Cuttack
74. Manipur Network of Positive People, Imphal
75. Network of Maharashtra by People Living with HIV/AIDS, Pune
76. ART Centre, Sassoon Hospital, Pune
77. Lawyers Collective, Mumbai
78. AVERT Society, Mumbai
79. Humsafar Trust, Mumbai
80. People's Health Organisation, Mumbai

Organisations with disability and HIV programmes

81. ActionAid Karnataka, Bangalore
82. Bangalore Multipurpose Social Service Society, Bangalore
83. Agni Raksha, Bangalore
84. Rural Development Trust, Anantapur
85. LEPRa, Hyderabad
86. Emmanuel Hospital Association, Delhi
87. Nethrajothi, Chennai
88. ActionAid West Bengal, Kolkata
89. LEPRa, Bhubaneswar
90. Agent for Social Change, Imphal
91. United Voluntary Youth Council, Torbung
92. Shodhana Consultancy, Pune
93. Indian Network of NGOs on HIV/AIDS, Ahmedabad

SACS & DACS offices

94. Andhra Pradesh - APSACS, Hyderabad
95. Manipur SACS, Imphal
96. Mumbai DACS, Mumbai

Annexe 3: Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts

Table 1: Low or no-cost modifications to existing programmes

N.E. Groce, R. Trasi & A.K. Yousafzai

Strategy	Purpose of strategy & cost implication	Suggested activities	Examples of suggested activities	Check Points: Examples of questions that should be asked
Type 1	Individuals with disability are reached by the same AIDS education messages and services as are members of the general public	<p>1. Use materials already available to the general public, incorporating simple adaptations to ensure accessibility by all</p> <p>2. Ensure that AIDS educational outreach and services available to the general population include individuals with disability</p>	<p>1.1 Depicting individuals with visible disability (a wheelchair user, or a blind person who uses a cane) in AIDS posters and billboards that are produced. Include examples of individuals with disability in published materials</p> <p>2.1 Moving HIV/AIDS education, testing, and service delivery programmes, as well as drug, alcohol, and domestic violence programmes to accessible meeting places</p>	<p>1.1.1 Are persons with disabilities depicted in posters, billboards & etc. – especially those which are intended to show that all types of people are at risk?</p> <p>1.1.2 Are there disabled individuals in the stories and vignettes used to illustrate HIV/AIDS issues?</p> <p>1.1.3 If you are including individuals with disability, do they represent all members of the disabled population: (i.e. a blind person from a local ethnic or minority group; a teenaged chair user from a rural area etc.)?</p> <p>2.1.1 Is the place where you are holding your programme accessible for people with physical impairments, does the venue require people to walk long distances?</p> <p>2.1.2 Do people with physical impairments need to take public transport? Is such transportation handicap accessible? Is such transportation affordable?</p> <p>2.1.3 Can you hold the meeting at street level, rather than the second floor of a building? In the courtyard of the building if step block entry into the building for some?</p>
Cost	Little or no additional cost	<p>3. Inform AIDS educators, outreach workers, and clinical and social service staff about challenges faced by individuals with disabilities & disability issues</p> <p>4. Establish a partnership with local DPOs to educate AIDS outreach workers about disability issues</p>	<p>2.2 Making sure that individuals with disability in the community are aware of the AIDS activities being offered and know that they are invited to attend</p> <p>3.1 Making simple adaptation in AIDS prevention interventions to ensure that messages are understood by people with disabilities</p> <p>4.1 Partner with local NGOs to make sure presentations and language used are as inclusive as possible</p>	<p>2.2.1 Have field staff invited the disabled people from the area or encouraged them to participate in the programme's activities?</p> <p>3.1.1 Did you pass around a condom so the blind individuals in the community could feel what a condom is?</p> <p>3.1.2 Is your prevention message simple enough and repeated enough times that it can be understood or memorised by intellectually disabled individuals?</p> <p>3.1.3 Does it contain euphemisms and analogies that might add to the complexity of the message?</p> <p>3.1.4 Are disabled people aware where resources such as condoms and HIV testing are available? Are such places accessible?</p> <p>3.1.5 If there is someone who needs to lip read, have you made sure they know they can sit in front of the presenter?</p> <p>4.1.1 Have you called upon local disabled people's organisations (DPO) for support in reaching people who cannot otherwise be reached?</p>

Annexe 3: Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts

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

Groce, Trasi & Yousafzai

Strategy	Purpose of strategy & cost implication	Suggested activities	Examples of suggested activities	Check Points
Type II	Adaptations are made to AIDS outreach campaigns to ensure that individuals with disability are included as members of the general public	<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>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>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 programme 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 Counselling and Testing Centre?</p>
Cost	Low to moderate cost	<p>3. Establish a partnership with local disabled peoples' organisations (DPOs) and identify training needs</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>3.1.1 Are members of the HIV outreach team in contact with DPOs for guidance and oversight to ensure they understand disability issues & 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>

Annexe 3: Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts
Groce, Trasi & Yousafzai

Table 3: Moderate to higher cost disability-specific programmes targeting the harder-to-reach individuals

Strategy	Purpose of strategy & cost implication	Suggested activities	Examples of suggested activities	Check Points
Type III	Disability-specific adaptations are made to existing materials and new materials are developed to reach individuals with disability outside the bounds of the general public, targeting harder to reach individuals and populations	1. Develop disability specific outreach efforts	1.1 Train/hire AIDS educators and staff to specialise in issues related to serving specific disabled populations 1.2 Working in collaboration with local DPOs, CBR staff and others, identify all the hard-to-reach population with disabilities and identify a local strategy for reaching these individuals with disability	1.1.1 Is sex education available in special schools for disabled children? 1.1.2 When disabled children are integrated into the regular classroom, are they allowed to sit through sex education classes or are they sent out of the room because teachers do not think they need this information? 1.1.3 When there are special programmes for street children, are disabled children and adolescents included? (remember 30% of all street children are disabled). 1.1.4 Does your organisation run special training session for sub-groups within the disability community? By type of disability? 1.1.5 Do have sessions that would attract individuals with similar life experiences and concerns to meet, discuss and become empowered? For example, do you hold special outreach sessions for individuals who are deaf? Women with disability? Disabled adolescents? 1.2.1 Do you know how many individuals with disability live in your area? 1.2.2 Do you know how many of these are being reached by AIDS outreach efforts? 1.2.3 Have you assessed what their knowledge, attitudes and practices about HIV/AIDS are in comparison with the surrounding non-disabled population?
Costs	Moderate to higher cost	2. Train disability advocates to be AIDS educators specifically for the disability community 3. Develop new materials to use in outreach efforts	2.1 Develop and test training curriculum with people from different disabled groups 3.1 Adapt or develop new materials, media and training sessions for individuals with disability who are not being reached through general inclusion or minor adaptations listed in Types I & II above	2.1.1 Is there a native Sign Language user who could be trained to reach the deaf community? 2.1.2 Is there an individual with intellectual impairments who could provide information to peers? 3.1.1 Do you have programmes that are simple, straightforward and use basic language and lots of pictures to describe sex, sexuality and HIV/AIDS for individuals who are intellectually disabled? 3.1.2 Do you have training videos either in Sign Language or captioned for Sign Language users available to the deaf community? 3.1.3 Do you have sessions for deaf individuals where discussion can be carried out in Sign Language? 3.1.4 Do you have a Sign Language interpreter available for clinics/hospitals to ensure privacy for deaf patients as well as to explain HIV testing as well as complicated regimes of AIDS drugs and follow-ups programmes? 3.1.5 Do you provide disability-specific information about issues related to HIV/AIDS – (i.e.: domestic violence, substance abuse or sexual decision making among young people)?

