

PREVENTING HIV/AIDS AMONG PERSONS WITH DISABILITIES



*A Hand Book for Policy Makers, Healthcare Providers and
Care Givers of Persons with Disabilities*

Prepared By
DAMIAN O. IVOM

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ABBREVIATION

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
ASCEND	Association for Comprehensive Empowerment of Nigerians with Disability
AZT	Zidovudine
BCC	Behavioural Change Communication
C&S	Care and Support
CAHD	Community Approaches to Handicap in Development
CCD	Centre for Citizens with Disabilities
CDD	Centre for Disability and Development
CHBC	Community Home Based Care
DPLHA	Disabled People Living with HIV/AIDS
DPOs	Disabled people Organisation
ECR	Expanded Comprehensive Response
FHI	Family Health International
GFATM	Global Fund to Fight AIDS Tuberculosis and Malaria
HAART	Highly Active Antiretroviral Therapy
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
ID	Compact Disc
IDA	International Development Association
IDU	Injecting Drug Users
IEC	Information Education and Communication
MAARDEC	Mobility Aid and Appliances Research and Development Centre
MCH	Maternal and Child Health
MSM	Men Who have Sex with Men
NAC	National AIDS Council
NGOs	Non-Governmental Organisations
NY	New York
OVC	Orphan and Vulnerable Children
PABA	People Affected by AIDS
PLHA	People Living with AIDS
PMTCT	Prevention of Mother-to-Child Transmission
RHRU	Reproductive Health Research Unit
STI	Sexually Transmitted Infection
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children Fund
US	United States
VCT	Voluntary Counseling and Testing
WHO	World Health Organisation

INTRODUCTION

HIV/AIDS has become one of the major challenges facing mankind since its inception in the early 1980's. Reducing HIV/AIDS among vulnerable population, especially persons with disabilities cannot be ignored if the virus is to be reduced and mitigated within the general population. Mitigating its impact among persons with disabilities is a monumental task that requires the input of governments, International Agencies, Healthcare workers, Caregivers, Non-governmental Organizations, Disabled people organizations and individuals.

Currently, little is known about HIV/AIDS and disability. Only a few studies have estimated prevalence and no prevalence data exist for any disabled populations from sub-Saharan Africa, Asia, Europe, Central and South America, or the Caribbean. However, a growing number of stories from disability advocates worldwide point to significant unreported rates of infection, disease, and death. Over the past decade there have been a handful of articles on HIV/AIDS pilot programmes and interventions for intellectually disabled adults or services for deaf adolescents.

Over the years policy makers including stakeholders from different sectors – public, private and NGOs has not deem it fit to integrate and include persons with disabilities into HIV/AIDS programmes. This has resulted in persons with disabilities' activists and DPOs to advocate and champion their own course. With the slogan "nothing for us without us" by disability groups all over the globe, different agencies including government, funding agencies, International NGOs, private establishments and even local NGOs has begun to include and integrate persons with disabilities into their development programmes that will enhance the standard of living of persons with disabilities who are infected and affected with the virus. But unfortunately, the issues of HIV/AIDS have been at the back drop as regards effective and adequate mainstreaming of persons with disabilities. While some countries has started to integrate persons with disabilities into their HIV/AIDS programmes there is still a lot to be done especially in developing countries. If HIV/AIDS is to be reduced in the general population, persons with disabilities as a matter of urgency should be included in the policy and programmes of activities that will enhance the reduction of the virus in the general population. With a good percentage of persons with disabilities into the general population, their continued neglect by some stakeholders could cause a big setback in the quest for a free HIV world.

However, one cannot but advocate for better programmes where persons with disabilities should be able to have access to VCT centres, care and support, information about prevention methods and strategies.

Reaching out to persons with disabilities and integrating them into the activities of HIV, prevention and mitigation will help in ensuring that the spread and impact is drastically reduced.

This handbook therefore, looks at various methods of preventing HIV/AIDS within persons with disabilities and how they can be reached and integrated into HIV/AIDS programmes and activities, so as to cause a reduction within its communities and in the general population.

This publication is premised on the fact that many programmes and activities on HIV/AIDS have never been taking into cognizance the inclusion of persons with disabilities. This publication will help and guide policy makers, healthcare workers, NGOs, Caregivers and members of the public on how to integrate persons with disabilities in decision making programmes and activities that will help in reducing the spread and impact of HIV/AIDS among them.

This handbook cannot give all the needed guide in HIV/AIDS prevention within the disabilities communities but, would help in enhancing its reduction. We therefore urge you to make a good use of what you have gotten from this handbook for the benefit of persons with disabilities in your community in particular and members of the public in general.

CHAPTER 1: FACTS ABOUT HIV/AIDS AND PERSONS WITH DISABILITIES

According to World Health Organization (WHO), 10% (600 million) 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 persons with disabilities and the UN that 82% of persons with disabilities in developing countries live below the poverty line. Poverty is recognized as a significant risk factor in vulnerability to HIV.

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

Disability is often addressed as a medical concern. While some individuals with disability do have health issues and rehabilitation needs, there is a growing realization that the greatest problems they face are social inequity, poverty, and lack of human rights. Indeed, the United Nations has clearly stated that one can be both disabled *and* healthy. Strikingly little is known about HIV/AIDS within disabled populations. Only a handful of prevalence studies, all from North America, have been published. However, findings from these studies raise serious concerns. For example, a small survey from the United States reported an HIV infection rate among deaf individuals twice that of the surrounding hearing population.

In the early 1990s, infection rates among institutionalized schizophrenic women in two urban hospitals were between 5% and 9%. Collins *et al.* report that AIDS is now the leading cause of mortality among women with psychiatric illness in New York City. There are few comparable studies on HIV prevalence rates among disabled populations in the developing world. Mulindwa, using STDs as a proxy for potential HIV exposure, conducted a study on Uganda and found that 38% of women and 35% of men with disability reported having had an STD at one time.

In India for example, an estimated number of 320,000 people with disabilities are 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).

Persons 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 not more and not 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.

Moreover, the AIDS epidemic may increase disability rates. The disabling effects of AIDS on previously non-disabled individuals are well established, but other sequels have received less attention. For example, in-utero exposure to the HIV virus can cause significant developmental delays. There is only a limited, though often innovative, group of articles and small-scale reports on AIDS education and intervention strategies for disabled populations. While there is no large body of research, anecdotal evidence from disability advocacy groups points to significant and unreported rates of HIV infection, disease, and death. Indeed, the extent of the problem in sub-Saharan Africa prompted Johnson to state unequivocally that efforts to provide rehabilitation services to disabled populations "are no longer possible" unless HIV issues are addressed.

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

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

Facts and figures on HIV/AIDS and disability

Do you know?

It is estimated that 1 in 7 deaf persons has substance abuse problems, compared with 1 in 10 in the hearing population (J. Peinkofer, HIV Education for the Deaf: A Vulnerable Minority, 1994).

According to the VIP Peers Program in Rochester, NY, **the incidence of alcohol abuse within the deaf community is estimated to be at 35% as compared to 12%-14% incidence among the general population** (S. Kennedy and C. Bucholz, HIV and AIDS Among the Deaf, 1995).

The National Coalition on Deafness and HIV/AIDS **estimate that 7,000 deaf people in the United States are infected with the virus and/or full blown AIDS**, and there have been 700 deaths so far. These figures are loosely based on mathematical formulas of deafness ration per general population in the USA (one out of ten people), and the number of deaf (200) on the NAMES QUILT Project (S. Kennedy and C. Bucholz, HIV and AIDS Among the Deaf, 1995).

Estimates of HIV-positive deaf run from 7,000 to as high as 26,000 (in the United States). (D. Van Biema, AIDS, 1994).

The deaf students had significantly lower scores on the HIV/AIDS Knowledge Index than the hearing students in a study involving 34 deaf undergraduates at Gallaudet University and 46 hearing undergraduates at the University of Maryland Baltimore (K. Heuttel and W. Rothstein, HIV/AIDS Knowledge and Information Sources Among Deaf and Hearing College Students, 2001)

70% of 204 deaf and hearing impaired adolescents surveyed did not realize that HIV and AIDS can not be contracted by giving blood; 46% were unaware that people who are not gay can get AIDS; and 43% were unaware that all gay people do not have AIDS. In addition, 62% thought that married people can not get AIDS (J. Luckner and B. Gonzales, What Deaf and Hard of Hearing Adolescents Know and Think About AIDS)

None of the 19 learning disabled men interviewed reported bringing condoms to a sexual encounter or any suggestion that they had negotiated their use (D. Thompson, The Sexual Experiences of Men with Learning Disabilities Having Sex with Men- Issues for HIV Prevention, 1994).

A study on HIV among the mentally ill reported an infection rate in three inpatient, psychiatric hospitals in New York City that was double the rate in the general population in that same city (H. Goodman, Infection and the Severely Mentally Ill Patients: Risky Behaviours and Risk Reduction, 1991).

Arnie Jackson and Virginia Wadley found that **30% of the [472] sexually active women in their study were not using birth control after becoming disabled by a spinal cord injury** (A. Jackson and V. Wadley, Women's Reproductive Health After SCI, 1999).

A national survey of disabled women showed that the prevalence of emotional, physical, and sexual abuse was not significantly different between a sample of 439 women with a variety of physical disabilities and 421 women with no disabilities. In both groups of women, 62% reported having experienced some type of abuse in their lifetime; about 52% reported experiencing physical or sexual abuse. There was, however a significant difference in the duration of the abuse, with **women with disabilities experiencing all three types of abuse for significantly longer periods of time than did women without disabilities** (M. Nosek et. al, The Investigation of Abuse and Women With Disabilities, 2001).

In a survey of 201 physically disabled persons, low discussion rates with health care providers were reported for sexuality (28.4%), STD's (14.4%), contraception (17.9%), and reproductive choices (9.5%). (M. Branigan et. al, Perceptions of Primary Healthcare Services Among Persons with Physical Disabilities. Part 2: Quality Issues, 2001).

A study on HIV and Mental Illness reports that mentally ill persons appear less likely than the general population to be in a monogamous relationship, engage more often in high risk behaviours, use condoms inconsistently, and are ambivalent regarding both abstinence and reducing the risk of infection with a sexual partner (J. Cates and G. Bond, AIDS Knowledge, Attitudes, and Risk Behavior Among People with Serious Mental Illness, 1994).

CHAPTER 2: OVERVIEW OF HIV/AIDS IN THE GENERAL POPULATION

Every day, over 6800 persons become infected with HIV and over 5700 persons die from AIDS, mostly because of inadequate access to HIV prevention and treatment services. The HIV pandemic remains the most serious of infectious disease challenges to public health. Nonetheless, the current epidemiologic assessment has encouraging elements since it suggests:

- the global prevalence of HIV infection (percentage of persons infected with HIV) is remaining at the same level, although the global number of persons living with HIV is increasing because of ongoing accumulation of new infections with longer survival times, measured over a continuously growing general population;
- there are localized reductions in prevalence in specific countries;
- a reduction in HIV-associated deaths, partly attributable to the recent scaling up of treatment access; and
- a reduction in the number of annual new HIV infections globally.

Examination of global and regional trends suggests the pandemic has formed two broad patterns:

- generalized epidemics sustained in the general populations of many sub-Saharan African countries, especially in the southern part of the continent; and
- epidemics in the rest of the world that are primarily concentrated among populations most at risk, such as men who have sex with men, injecting drug users, sex workers and their sexual partners.

Sub-Saharan Africa remains the most seriously affected region, with AIDS remaining the leading cause of death there.

The estimated number of deaths due to AIDS in 2007 was 2.1 million [1.9–2.4 million] worldwide, of which 76% occurred in sub-Saharan Africa. Declines in the past two years are partly attributable to the scaling up of antiretroviral treatment services. AIDS remains a leading cause of mortality worldwide and the primary cause of death in sub-Saharan Africa, illustrating the tremendous, long-term challenge that lies ahead for provision of treatment services, with the hugely disproportionate impact on sub-Saharan Africa ever more clear. HIV incidence (the number of new HIV infections in a population per year) is the key parameter that prevention efforts aim to reduce, since newly infected persons contribute to the total number of persons living with HIV; they will progress to disease and death over time; and are a potential source of further transmission.

Global HIV incidence likely peaked in the late 1990s at over 3 million new infections per year, and was estimated to be 2.5 million (1.8 - 4.1 million) new infections in 2007 of which over two thirds (68%) occurred in sub-Saharan Africa. This reduction in HIV incidence likely reflects natural trends in the epidemic as well as the result of prevention programmes resulting in behavioural change in different contexts.

A final conclusion concerns the quality and nature of strategic information relating to the pandemic and the effects of our programmes. Increased investments in interventions for HIV prevention, treatment and care are showing results but also greatly increase the complexity of the epidemic and analysis of its trends. The analyses reported here cannot adequately define the impact of specific interventions or programmes. This will require special studies in local areas, including direct assessments of HIV incidence, mortality, programme effectiveness and the burden of HIV infection, disease and death in children.

As the resources committed to AIDS and other major health problems continue to increase, more emphasis is required to strengthen systems to collect and analyse data and to improve the quality of such data to strategically guide programming. Despite the challenges and limitations inherent in data collection of this nature, the resources made available to the global AIDS response have enabled the quality of information and our understanding of the HIV pandemic to be superior to many other global disease estimates.

In addition to the declines in new infections in **sub-Saharan Africa** between 2001 and 2007, the estimated annual number of new HIV infections decreased in **South** and **South-East Asia** from 450,000 (150 000–800 000) in 2001 to 340 000 (180 000–740 000) in 2007, and in **Eastern Europe** from 230,000 (98 000–340 000) in 2001 to 150,000 (70 000–290 000) in 2007. The difference in the number of new infections in **Eastern Europe** is due mainly to the slower growth of the HIV epidemic in the **Russian Federation**, the country with the largest epidemic in that region and where new infections increased steeply in the late 1990s before peaking in 2001. Annually reported (rather than estimated) new infections in the **Russian Federation** have been growing again in recent years, but at a lower rate than at the turn of the century. The 92 000 (21 000–220 000) adults and children estimated to be newly infected with HIV in **East Asia** in 2007 represent an increase of almost 20% over the 77 000 (49 000–130 000) people who acquired HIV in 2001. **Oceania** also saw an increase in estimated new infections—from 3800 (3000–5600) in 2001 to 14 000 (11 000–26 000) in 2007. In the **Caribbean, Latin America, the Middle East and North Africa, North America and Western Europe**, the numbers of new HIV infections in 2007 remained approximately stable.

These regional incidence figures can mask the fact that the actual number of persons living with HIV may be increasing; for instance in Eastern Europe, the total number of persons with HIV increased nearly 150% between 2001 and 2007.

Also in individual countries, such as Viet Nam and Indonesia, the prevalence of HIV is growing. Women living with HIV Similar increases occurred in the estimated total numbers of new infections in men and women between 2001 and 2007—the ratio of women to men remaining stable globally. The estimated 15.4 million (13.9–16.6 million) women living with HIV in 2007 numbered 1.6 million more than the 13.8 million (12.7–15.2 million) in 2001. For men, the 15.4 million (14.3–17.0 million) estimated to be living with HIV in 2007 compared with 13.7 million (12.6–15.2 million) in 2001. In **sub-Saharan Africa**, almost 61% of adults living with HIV in 2007 were women, while in the **Caribbean** that percentage was 43% (compared with 37% in 2001).

The proportions of women living with HIV in **Latin America, Asia** and **Eastern Europe** are slowly growing, as HIV is transmitted to the female partners of men who are likely to have been infected through injecting drug use or during unprotected paid sex or sex with other men. In **Eastern Europe** and **Central Asia**, it is estimated that women accounted for 26% of adults with HIV in 2007 (compared with 23% in 2001), while in **Asia** that proportion reached 29% in 2007 (compared with 26% in 2001).

HIV/AIDS is the leading cause of death in sub-Saharan Africa. More than 18 million Africans have died, more than 12 million African children have been orphaned because of AIDS, and another 28 million Africans are living with the virus today, the vast majority of them in the prime of their lives as workers and parents. Life expectancy is dropping, family incomes are being decimated, and agricultural and industrial efficiency is declining because of the epidemic. African nations and the international community have recognized how disastrous the epidemic is to the African continent, and have concluded that past efforts to wage war against the virus have failed because: (i) there was insufficient commitment and leadership to fight the epidemic among nations both inside and outside the continent; (ii) the war was being waged with too few human and financial resources; (iii) those programmes that were effective, often undertaken by civil society organizations, were rarely scaled up; (iv) resources were not reaching communities; and (v) programmes were too narrowly focused on the health sector. A new strategy has been developed by African countries and the donor community to wage war more effectively.

It is based on:

- Defining national HIV/AIDS prevention, care, treatment and mitigation strategies and implementation plans through a participatory process;
- Establishing National AIDS Councils (NACs) at the highest level of government, with broad stakeholder representation from the public and private sector and civil society;
- Empowering stakeholders from the village to national level with money and decision-making authority within a multisectoral framework; and
- Using exceptional implementation arrangements such as channeling money directly to communities and civil society organizations and contracting out many administrative functions.

CHAPTER 3: FACTORS RESPONSIBLE FOR THE SPREAD OF HIV/AIDS AMONG PERSONS WITH DISABILITIES

Being disabled can make a person more vulnerable to HIV infection. Persons with disabilities and their caregivers and families, need information on sexuality, sexual health and HIV which is appropriate and enable them to take action.

Persons 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

Risk Factors

Individuals with disability are at significant risk of becoming HIV infected. A lot of factors are responsible for the spread of HIV/AIDS among persons with disabilities. Studies conducted in most countries of the world noted that being disabled and HIV positive has been a big threat for the disabled community and found that a lot of factors are responsible for this spread:

Poverty

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

Lack of education

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

Lack of information and resources to ensure 'safer sex'

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

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

- a. There has not been a great deal of research in this area, but what studies do exist and the responses we have elicited through the survey show that individuals with disability are up to three times more likely to be victims of physical abuse, sexual abuse, and rape.
- b. Most individuals with disability have little or no access to police, legal counsel, and courts for protection
- c. Should sexual abuse/rape occur, individuals with disability have less access to medical interventions, including psychological counseling and prophylactic care, than their non-disabled peers.

Substance abuse

- a. Survey responses, as well as limited information from the literature, report drug abuse among select groups studied (the deaf and women with physical disabilities) at rates significantly higher than the general population.
- b. Most of this information is from the developed world. Virtually nothing is known about this from developing countries, other than information provided by the Global Survey. These results indicate that substance abuse exists and is a problem. It has been proven that most people who take drugs stand a very chance of contracting HIV.

Disabled AIDS Orphans

- a. Children with disability orphaned because of their parent's death through AIDS – whether they themselves are HIV+ or not –
 - i. Require extra care (feeding, toileting, etc.) from already overburdened caregivers with many other children to care for.
 - ii. Are more likely to be malnourished, neglected, institutionalized and abandoned.
 - iii. More like to become illiterate/lack basic education

Access to and Affordability of Care if Individuals with disability become HIV+

- a. Health care facilities are often physically inaccessible (stairs, lack of sign language interpreters, etc.)
- b. Health care is unaffordable for the impoverished disabled.
- c. Health care professionals are unaware of the needs of individuals with disability, and routinely deny disabled individuals access to HIV testing, AIDS care, and place a lower priority on disabled individuals with AIDS when scarce AIDS drugs and services need to be rationed.
- d. Allied services, such as drug and alcohol programs, domestic violence intervention programs, and places where condoms are distributed and where AIDS education materials are available are also inaccessible and non-inclusive.

Stigma

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

Reasons Persons with Disabilities Are Not Being Reached

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

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

Subgroups at Still Higher Risk

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

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

Disabled members of ethnic and minority populations:

1. Are marginalized within their own societies as well within the larger, national society
2. Have lower levels of education, employment, and access to disability programs
3. Are less likely to be reached by national AIDS education and outreach
4. Face “triple discrimination” if they are women

CHAPTER 4: STRATEGY FOR HIV/AIDS PREVENTION

Potential Strategies

- In the absence of firm data on numbers of persons 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 persons 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 federal and state levels through the inclusion of disability representatives within HIV mechanisms and *vice-versa*, for example:
 - o The Office of the Chief Commissioner for Persons with Disabilities within the National Council on AIDS and/or the National/state Agency for the Control of AIDS as the case may be.
 - o A disabled person with experience of advocacy in the national and/or international arena within the Country Co-coordinating Mechanism for AIDS, TB and Malaria as a Civil Society Representative
 - o A disabled person with experience of working on disability issues within NACA's 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 NACA's offices and State Disability Commissions or state ministries of social development would greatly facilitate the inclusion of persons 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.
- Include HIV awareness sessions in training programmes of rehabilitation professionals and special education teachers.
- The Positive Speakers strategies 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.
- Develop similar guidelines on how disability organisations can engage with HIV.

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
- Develop similar guidelines on how disability organisations can engage with HIV
- Persons with disabilities should be taught more about family planning as so many of have too many children and they are so poor, the children don't go to school but end up begging on the streets.

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 Sign Language - have limitations. 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.

Recommendation for DPOs

- DPOs should initiate HIV & AIDS and reproductive health programmes that will focus on issues like STIs, Family planning, prevention, care, support and mitigation for the disabled people. The disabled people should coordinate the HIV&AIDS programs. All disabled people should be encouraged to participate.
- Through a participatory and consultative process involving people with disabilities, DPOs should formulate HIV & AIDS policies that will enable the implementation of HIV & AIDS programmes for their membership and staff.

- DPOs should educate their members on the existing policies on HIV&AIDS, reproductive health and disability. Resources permitting, the policies should be translated to local languages.
- DPOs should implement empowering programs for the disabled people to enable them deal with social, economic and cultural factors that pre dispose them to HIV & AIDS infection, we recommend to adopt the STAR (stepping stones and reflect) programme to empower people with disability.
- DPOs should mainstream HIV & AIDS and disability issues in their advocacy programmes e.g. advocating for HIV & AIDS information written in brail, counseling in sign language at VCT Centers and Hospitals and disabled people to be part of the advocacy teams for funding raising for HIV &AIDS programs.
- DPOs should initiate training of disabled people in HBC, counseling in sign language, peer education and orphan care etc. The disabled people should be encouraged to participate in the existing Home based care programs with in their communities than starting a special HBC program for the disabled people unless it is with in an institution. During the trainings, non-disabled people should be trained on how to care for the disabled people within a home-based care program.

Type of actions to include disabled people in HIV/AIDS prevention and care

	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>

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 novels</p> <p>2.2 Making AIDS materials available for the blind in inexpensive cassette formats</p> <p>2.3 Making AIDS materials available for the deaf through visual formats</p> <p>2.4 Making meeting places accessible to individuals with physical impairments through inexpensive infrastructure modifications</p> <p>3.1 Developing a Training of Trainers curriculum with relevant topics to train AIDS outreach workers about disability 3.2 Train individuals with disability to be AIDS educators for the whole community</p>	<p>1.1.1 Is the captioning of AIDS announcements clear and in simple language – remember many deaf individuals have low literacy levels 1.1.2 Are there specific terms in local Sign Language for discussing HIV/AIDS? 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? 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? 2.2.3 Is there a local programme specifically targeting the blind? 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? 2.4.1 Have you looked into building ramps at meeting halls (e.g. ramps can be made of mud, stone, bamboo, wood). 2.4.2 Have you talked to local officials about building a ramp into the local HIV clinic or Voluntary Counseling and Testing Centre?</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? 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>
Cost	Low to moderate cost			

<p>Type III</p> <p>Costs</p>	<p>Disability-specific adaptations are made to existing materials and new materials are developed to reach individuals with disability outside the bounds of the general public, targeting harder to reach individuals and populations</p> <p>Moderate to higher cost</p>	<p>1. Develop disability specific outreach efforts</p> <p>2. Train disability advocates to be AIDS educators specifically for the disability community</p> <p>3. Develop new materials to use in outreach efforts</p>	<p>1.1 Train/hire AIDS educators and staff to specialise in issues related to serving specific disabled populations</p> <p>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</p> <p>2.1 Develop and test training curriculum with people from different disabled groups</p> <p>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</p>	<p>1.1.1 Is sex education available in special schools for disabled children?</p> <p>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?</p> <p>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).</p> <p>1.1.4 Does your organisation run special training session for sub-groups within the disability community? By type of disability?</p> <p>1.1.5 Do you 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?</p> <p>1.2.1 Do you know how many individuals with disability live in your area?</p> <p>1.2.2 Do you know how many of these are being reached by AIDS outreach efforts?</p> <p>1.2.3 Have you assessed what their knowledge, attitudes and practices about HIV/AIDS are in comparison with the surrounding non-disabled population?</p> <p>2.1.1 Is there a native Sign Language user who could be trained to reach the deaf community?</p> <p>2.1.2 Is there an individual with intellectual impairments who could provide information to peers?</p> <p>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?</p> <p>3.1.2 Do you have training videos either in Sign Language or captioned for Sign Language users available to the deaf community?</p> <p>3.1.3 Do you have sessions for deaf individuals where discussion can be carried out in Sign Language?</p> <p>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?</p> <p>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)?</p>
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CHAPTER 5: MOTHER TO CHILD TRANSMISSION OF HIV/AIDS

Mother-to-child transmission (MTCT) of HIV remains a major public health problem worldwide, especially in resource-constrained countries, home to more than 95 percent of all people living with HIV/AIDS (PLHA). Heterosexual intercourse is the most common mode of HIV transmission in resource-constrained countries, which results in large numbers of infected women, who then transmit the virus to their babies. In 2001, an estimated 800,000 infants and children (2,200 per day) acquired HIV infections, more than 90 percent of them in sub-Saharan Africa, and the majority (90-95 percent), from their mothers.

The rate of MTCT has been reduced to less than two percent among HIV-infected women in developed countries. But rates remain high in resource-constrained countries, particularly in sub-Saharan Africa, where the vast majority of HIV-infected women of childbearing age live. In the absence of any intervention, rates of MTCT are 25 to 45 percent in resource-constrained countries, compared to 15 to 30 percent in the industrialized world. Transmission occurs during pregnancy, labor and delivery, and breastfeeding. In non-breastfeeding populations, an estimated 65 percent of perinatal infections occur late in pregnancy and during labor and delivery. These high rates are largely due to poor access to prevention interventions, including HIV voluntary counseling and testing (VCT), replacement feeding, selective caesarean section and antiretroviral drug therapy.

A comprehensive approach to preventing HIV infection in infants and young children especially children with disabilities has four components:

1. preventing HIV infection among disabled women of childbearing age
2. preventing unintended pregnancy among HIV-positive disabled women
3. preventing MTCT during pregnancy, labor and delivery, and breastfeeding
4. providing care and support for HIV-infected disabled women, their infants and families.

Based on current scientific knowledge and collective international experience, a comprehensive package to reduce MTCT for women with disabilities should include these interventions:

Improved availability, quality and use of maternal and child health services

Functioning and adequate maternal and child health (MCH) services are the foundation of any intervention to prevent MTCT irrespective of disability or not. But MCH services in most resource-constrained countries face managerial, financial and human resources constraints. Even where they are available, these services are not fully used by those who would most benefit. In many resource-constrained countries, fewer than half of births are supervised by appropriately trained personnel. Effective implementation of MTCT programs requires upgrading the infrastructure and essential services of existing MCH facilities. Efforts are also needed at the community level to improve health-seeking behaviours and increase the use of MCH services.

HIV voluntary counseling and testing (VCT)

VCT is a critical intervention to help women with disabilities evaluate their options for infant feeding, future pregnancy and HIV prevention, including MTCT. VCT is an important entry point to prevention and care services and a critical component of MTCT interventions, since women must know their HIV status to access and benefit from these interventions. But in most resource-constrained countries, VCT services are still underdeveloped; where they are available, persuading pregnant women who are disabled to use them remains a challenge due to stigmatization and discrimination. Ways to improve acceptability of VCT for persons with disabilities must be explored. Routinely offering VCT has good potential for success.

Antiretroviral therapy

The presence of high maternal viral load is one of the strongest predictors of MTCT. Administering antiretroviral drugs during pregnancy and around delivery has proved to significantly reduce the risk of MTCT, especially among non-breastfeeding women:

- The Pediatric AIDS Clinical Trials Group in 1994 demonstrated that zidovudine (AZT) administered to the mother from 14 weeks of gestation, and to the child during the first seven days after birth, reduced the risk of MTCT among non-breastfeeding mothers by two-thirds.
- Two similar studies conducted in Côte d'Ivoire and Burkina Faso among breastfeeding mothers demonstrated a 37 percent reduction in MTCT.
- A study in Uganda demonstrated a 47 percent reduction in MTCT following a single dose of nevirapine to the mother at onset of labor and to the baby within 72 hours after birth.
- The combination of AZT and lamivudine in a short-course regimen also has been shown to reduce MTCT.

While the long-course AZT regimen is too costly for most people in resource-constrained countries, the various short-course regimens appear more feasible and affordable. Efforts are underway in many resource-constrained countries to implement these regimens.

Infant feeding options

Avoiding breastfeeding has proved effective in preventing postnatal MTCT whether a disabled woman or not. Exclusive breastfeeding is also believed to be associated with lower risk than mixed feeding. But formula feeding and exclusive breastfeeding both present a challenge in resource-constrained countries: Although formula feeding is not readily affordable and presents the risk of infection and diarrhea, achieving exclusive breastfeeding is not easy because of beliefs and practices related to infant feeding. A recent study suggests that HIV-infected mothers who breastfeed experience higher mortality than those who do not. Although WHO maintains that these findings do not warrant changes in current infant feeding guidelines, the results underscore the importance of providing adequate care and support to disabled mothers as part of the effort to prevent MTCT.

Safer delivery practices

Elective caesarean section, before rupture of membranes, has been demonstrated to have a more protective effect against MTCT than vaginal delivery. But caesarean section has limited applications in resource-constrained settings for women with disabilities where access even to emergency obstetric care is limited, and the procedure is associated with increased rates of maternal morbidity and mortality. Health care providers should avoid invasive obstetrical practices – such as artificially rupturing membranes, episiotomies, fetal scalp monitoring and other conditions increasing contact between the fetus and maternal secretions – as these may increase the risk of transmission. Good obstetric care for all women, with attention to basic infection prevention guidelines, will reduce the risk of MTCT and vertical transmission of HIV in the health care setting.

Care and support

It is important to organize and provide care and support to help mothers with disabilities maintain their health, both for their own and their families' benefit. Prolonging the parent-child relationship has direct implications for child development and survival, regardless of the child's own HIV serostatus. Identifying and strengthening referral systems contributes significantly to meeting the long-term prevention, care, and support needs of HIV-infected mothers, their children and families.

Other interventions

Other MTCT prevention options – including vaginal disinfection, vitamin A supplementation, passive and active immunization – have been proposed but not yet proven to be effective. Vaginal disinfection was shown to reduce infant morbidity and mortality, and vitamin A supplementation reduces the risk of low birth weight, severe pre-term birth, and small size for gestational age at birth. Immunization reduces the chances of the unborn baby not be affected by any form of birth deformity.

CHAPTER 6: VOLUNTARY COUNSELING AND TESTING FOR PERSONS WITH DISABILITIES

Many approaches to HIV prevention and care require that people know their HIV status. High-quality VCT enables and encourages people to access appropriate care services and is an effective HIV prevention strategy. Many countries are responding to the call for improved VCT services, but few have developed services specifically for persons with disabilities. Experience has identified the following barriers to VCT specifically for persons with disabilities:

- Availability and acceptability of VCT services, including legal issues (disclosure and consent)
- Worries about confidentiality and pressure by health staff to notify partners and parents
- Inaccurate risk perception
- Fear of being labeled and stigmatized by families, friends and communities
- Perceptions of the consequences of living with HIV
- Inadequate responses from health care providers, including counselors, to effectively meet the HIV prevention, care and support needs of youth
- Reluctance to seek testing if post-test support systems and medications are unavailable
- Cost of services and waiting time
- Accessibility to VCT Centres
- Fear of discrimination by health care providers

Despite these barriers, most persons with disabilities in countries with high HIV prevalence want to know their HIV status. Persons with disabilities desire to know their status, coupled with the crucial role that they play in the fight against HIV/AIDS, make the presence of disabled-friendly VCT services critical. VCT for persons with disabilities is needed because:

- There are more persons with disabilities today than ever before: 600 million persons with disabilities the world over.
- Persons with disabilities account for a significant percentage of all new HIV infections worldwide.
- In many developing countries, customs demand that a woman remarries as soon as she loses her husband. This has contributed significantly to the spread of the virus in the general population.
- In most African countries, many people believe that having sex with a virgin will cure HIV virus. With this belief a lot of HIV infected persons go to disabled women believing most disabled women are virgins. Most persons with disabilities are especially vulnerable to HIV infection due to emotional and developmental factors, low condom use, biological and social vulnerabilities, sexually transmitted infections, poor health-seeking behavior, and alcohol and substance abuse.

Countries are urged to develop services to respond to persons with disabilities-specific needs – either all in one service or through referral networks and linkages among providers.

The specific HIV-related issues of persons with disabilities include assertiveness and negotiation skills; risk-taking; alcohol and other substance abuse; STIs; contraception; condoms and barriers to their use; sexual and familial relationships; discrimination; abuse and violence, including rape; pregnancy and fertility; disclosure; inaccessibility of health facilities; myths associated with disability and HIV treatment. Some of these may be met through counseling, while others may require comprehensive health education and opportunities for life skills training. To address these needs, disability-friendly services should have the following characteristics:

- Full participation of persons with disabilities in decision-making, planning and delivery of services
- Community mobilization to increase understanding of persons with disabilities health needs
- disability education through community outreach and clinic-based educators
- Designated “disability-friendly corners” at clinics and freestanding VCT sites
- Health providers trained in disability-friendly approaches to communication and counseling
- Confidentiality, including suitable accommodations that ensure discretion for issues of consent and disclosure
- Integration with other post-test health and psychosocial support services
- Adequate supplies of condoms, IEC materials and drug
- Use of sign language experts for hearing impaired persons
- IEC materials translated into brails for virtually impaired persons
- Accessible health facilities

Counseling persons with disabilities about HIV is challenging. It is important to be non-judgmental, to establish rapport and to instill hope in persons with disabilities, particularly those who test positive. Here are some key issues to be considered when implementing VCT for persons with disabilities:

- There are no instant prescriptions for providing VCT to persons with disabilities. “Learning by doing” is effective.
- VCT services should be made available outside of formal health settings.
- A range of innovative service delivery models can be applied, depending on the context. These models may include freestanding sites, mobile services or outreach models. The model chosen must ensure adequate cost consideration to guarantee sustainability.
- VCT is most effective as part of an integrated delivery system where related psychosocial, spiritual and medical services are immediately available to persons with disabilities who seek VCT. This requires identifying or strengthening care and support services and referral networks.
- VCT must be accessible and affordable for all categories of persons with disabilities.

- It is important to facilitate supportive policy development — including age of consent — for access to VCT, clinical and psychosocial care and follow-up support for persons with disabilities.
- Sites must be adequately staffed with high quality counselors with supportive attitudes and practices towards persons with disabilities.
- Services should ensure access to medical care and condoms.
- There is great need for pre-marital counseling.
- Program planner must encourage and promote VCT for couples who are both disabled, as couples counseling helps in assessing risk and planning risk-reduction. It is also cost-efficient.
- Persons with disabilities have concerns about confidentiality, disclosure of test results and consent issues. Program planners must address legal and ethical issues, including age of consent, coercion, disclosure and mandatory testing.
- Persons with disabilities have different needs from one another.
- VCT services should consider the particular vulnerabilities of disabled women.

Persons with disabilities should be stakeholders in disability-friendly VCT services, rather than only recipients. They should help plan, implement and evaluate services designed for them. They can help as:

- Educators (not counselors)
- HIV-positive speakers
- Participants in community mobilization
- Leaders of post-test associations and other support groups
- Members of service planning and design teams

Scaling up for an Expanded and Comprehensive Response to HIV/AIDS

An expanded and comprehensive response (ECR) to the HIV/AIDS epidemic is the goal of HIV programming globally. Many pilot projects and small-scale projects in several countries have shown that key technical approaches can reduce transmission. But to have the greatest impact on the epidemic, we must now go beyond pilot and demonstration projects to increase coverage and quality at local, regional and national levels for persons with disabilities.

To date, a limited technical approach has resulted in a lack of programming that addresses the broad range of HIV prevention, care and support services at high levels of coverage. However, the goal of achieving coverage with comprehensive interventions is becoming more attainable with the addition of such new funding sources as the Global Fund for AIDS, Tuberculosis and Malaria (GFATM). Nevertheless, HIV/AIDS programming globally for persons with disabilities has suffered from limited financial resources, weak accountability and oversight systems, undeveloped technical and management skills, poorly functioning support systems (such as logistics and training) and lack of widespread community, private sector and civil society involvement and not including persons with disabilities into HIV/AIDS programming. While many successes have been achieved in the general population, there will be no increased scale across a continuum of high-quality services unless several elements work together to form a working system to integrate HIV/AIDS into disability community.

Scaling up as a working system

To overcome the limits of absorptive capacity en route to an expanded and comprehensive response for persons with disabilities, there must be progress in several complementary areas by: 1) promoting ECR as both a vision and an attainable goal, which will include persons with disabilities and other vulnerable groups; 2) building the institutional foundations for expanding both coverage and technical areas to this group of persons; 3) developing technical and programmatic capacity in HIV/AIDS at multiple levels, including accessibility support functions; 4) increasing DPOs involvement and multi-sector participation; and 5) creating knowledge and applying lessons from the effort as implementation experience accumulates.

To scale-up through ECR for persons with disabilities, it is necessary to use a programming and implementation framework that considers increased scale, scope and quality of service across a continuum of HIV prevention, care and support services. It also must include the important dimensions of systems development and community capacity development, the building blocks behind expanded and comprehensive programming for HIV/AIDS. Key elements include:

Good governance. The foundation for a scaled-up response is good governance. Countries and donors alike are increasingly taking responsibility to ensure effective oversight, coordination and transparency in their HIV/AIDS programs, enabling broad participation on critical issues, increasing access and empowerment. But problems remain, and change will be required in the legal, policy and resource development areas using good governance principles and skilled leadership practices.

Technical and programmatic capacity building in HIV/AIDS. To achieve a scaled-up response, it is necessary, but not sufficient, to train service providers in the various prevention, care and support interventions. These include behavior change communication, voluntary counseling and testing for HIV, prevention of mother-to-child transmission, community and home-based care, clinical management and treatment, persons with disabilities, and orphans and vulnerable children. In addition, national and local efforts must work together to integrate these interventions into a well-functioning program. Three important steps are key:

1. **Replicate a district and community action planning process** around the scaling-up framework and provide support at increasingly higher levels of the system. Implementation and monitoring are best achieved through a **local network of providers** who coordinate, make referrals and support community efforts through partnerships.
2. **Ensure effective project management to link funds from a variety of sources** into an integrated program.
3. **Strengthen national scale support functions** such as logistics, human capacity development, finance, monitoring and evaluation to reach disabled community.

Increased community and multi-sector involvement Services need to be built on a foundation of partnership and open communication across sectors (public, NGO and private) and across development areas (such as health, education, agriculture,

1. commerce, youth and gender). It is necessary to articulate a technical and programming vision relevant for multiple levels in a country, including national, regional, district and community. They contribute to and sustain a culture of facilitation to work simultaneously at community and service provider levels.
2. **Learning from experience.** Any effort to achieve scale and increase the range of services available will benefit from hard-won “lessons learned” elsewhere. Knowledge transfer should support learning from experience, especially in the dynamic environment surrounding the HIV/AIDS epidemic and disability. New technologies and networks are now available to create communities of practice around critical areas. The scale-up framework should include a learning framework that will help structure knowledge to be applied to problems encountered during scale-up.
3. **“Big Bang” or patchwork?** It is not likely that scaled-up programs will suddenly appear as the result of a master plan from above. Rather, it is more likely that victories will occur in fits and starts, and larger, more comprehensive responses will flourish district by district, supported by caring communities and provider organizations. Fragmented programs, multiple funding options and political constraints diminish the chances of smoothly ramping up even the most successful vertical interventions.
4. **Increased community and multi-sector involvement;** Services need to be built on a foundation of partnership and open communication across sectors (public, DPO, NGO and private) and across development areas (such as disability, health, education, agriculture, commerce, youth and gender). It is necessary to articulate a technical and programming vision relevant for multiple levels in a country, including national, regional, district and community. They contribute to and sustain a culture of facilitation to work simultaneously at community and service provider levels.
5. **Learning from experience;** Any effort to achieve scale and increase the range of services available will benefit from hard-won “lessons learned” elsewhere. Knowledge transfer should support learning from experience, especially in the dynamic environment surrounding the HIV/AIDS epidemic. New technologies and networks are now available to create communities of practice around critical areas. The scale-up framework should include a learning framework that will help structure knowledge to be applied to problems encountered during scale-up.
6. **“Big Bang” or patchwork?** It is not likely that scaled-up programs will suddenly appear as the result of a master plan from above. Rather, it is more likely that victories will occur in fits and starts, and larger, more comprehensive responses will flourish district by district, supported by caring communities and provider organizations. Fragmented programs, multiple funding options and political constraints diminish the chances of smoothly ramping up even the most successful vertical intervention

CHAPTER 7: CONDOM USE

Condom use has been an effective prevention of pregnancy and HIV/AIDS/STI for decades. It has been proved that condom is 85% effective if properly used. To effectively mitigate the impact of HIV/AIDS and other sexually transmitted diseases it will be mostly advised that persons with disabilities adequately make use of condom (both male and female).

Pregnancy prevention

The female condom is an effective contraceptive if used consistently and correctly. Within the first year of consistent and correct use, about 5 percent of women relying on the female condom will have an unintended pregnancy, compared to 3 percent for male condoms and 6 percent for both spermicides and the diaphragm. When use is not always correct or consistent, the unintended pregnancy rate has been estimated at 21 percent for the female condom, compared to 14 percent for the male condom.

These rates are based on the largest and most comprehensive study of effectiveness of the female condom, which was initiated in 1990. The study involved 328 participants in the United States, Mexico and the Dominican Republic and measured six-month gross cumulative pregnancy rates. To adjust the findings to 12-month pregnancy rates, researchers used the relationship of pregnancy rates at six and 12 months for the diaphragm, cervical cap and sponge. Calculating 12-month pregnancy rates is more complicated than simply doubling six-month rates.

Other smaller and single-country studies have found somewhat better effectiveness rates. A 1992 study from the United Kingdom involving 106 women for various lengths of time (a total of 441 months of observation) reported a 12 month pregnancy probability of 15 percent with typical use. A 1998 study from Japan found a six-month pregnancy rate of 1 percent when used consistently and correctly and 3 percent under typical use. In Japan, the male condom is the predominant method of family planning. The familiarity of using male condoms may have contributed to higher effectiveness rates with the female condom.

STI prevention

Laboratory studies have found the device impermeable to various sexually transmitted infections (STIs), including HIV. In theory, the female condom should protect against STIs in human contact as well, but more research is needed to confirm its effectiveness. Because the outer ring partially covers the external genitalia, the female condom may provide more protection against genital ulcer infections, such as herpes and chancroid, than the male condom. Using female condom contraceptive effectiveness data and mathematical modeling, a study estimated that perfect use of the female condom might reduce the annual risk of acquiring HIV by more than 90 percent among women who have intercourse twice weekly with an infected male.

One human study has found that the female condom protects against trichomoniasis, the most common curable STI in the world. One hundred and four women who had been previously diagnosed and treated for trichomoniasis were offered a female condom. Those who said they would use the device consistently were put in the “user” group; the others were put in the control group. None of the 20 women who used the female condom consistently for 45 days became re-infected, compared to 15 percent re-infected among those in the user group who used it inconsistently (5 of 34) and 14 percent re-infected among those who used no protection (7 of 50).

A study in Thailand suggests that the availability of the female condom lowers STI rates. Those with access to both male and female condoms (249 sex workers) had an incidence of 2.8 STIs per 100 women per week. Those with access only to male condoms (255 sex workers) had 3.7 STIs per 100 women per week. The study measured gonorrhea, chlamydial infections, trichomoniasis and genital ulcers over 24 weeks. While the difference between 2.8 and 3.7 suggests that the availability of the female condom lowers STI infection rates, the results were not statistically significant. Low overall rates of STIs already existed at these sites, due to their participation in the 100 percent male condom program in Thailand.

In contrast, a study among 1,600 women in a community intervention trial in rural Kenya suggests that the availability of the female condom, along with the male condom, does not affect STI rates, compared to the availability of only the male condom. At both control and intervention sites, about 24 percent of the women had gonorrhea, chlamydia or trichomoniasis at baseline. After 12 months, the rates of these STIs had declined to 18 percent in both intervention and control sites.

The female condom is considerably more expensive than the male condom. Like the male condom, the female condom is currently approved for only one use.

If the female condom can be used safely more than once, the cost of each use would decline even if the price of the device itself remained unchanged. Establishing the safety of reusing the device could increase access in resource-poor countries. Although reuse of the female condom is discouraged, this practice has been reported in a number of countries.

A consultation of experts convened by the World Health Organization (WHO) and the United Nations Programme on HIV/AIDS (UNAIDS) in June 2000 concluded that data were insufficient to advise on the safety of reuse. In view of the potential risks during washing or subsequent use, the consultation recommended that all female condoms be disinfected before washing. A draft protocol for disinfecting, washing, drying, storing and re-lubricating the female condom was developed and is currently being evaluated.

Structural integrity

Studies have found that the device remains structurally sound after repeated washing and reuse. In a study by FHI, the structural integrity of the female condom remained well above the standards of the female condom manufacturer, after a single act of intercourse or after up to 10 washes with or without bleach disinfection. Four laboratory tests compared the test condoms with new female condoms (seam tensile strength, water leakage, air burst and tear propagation). More than 300 condoms were washed after a single act of vaginal intercourse, and about 1,000 unused female condoms were washed in the laboratory. The washing procedure used mild soap in warm water and rinsing, followed by pat-drying of both sides of the condom with a towel.

The Reproductive Health Research Unit (RHRU), University of Witwatersrand, in South Africa, has also studied the structural integrity issue. RHRU found that the device remained sound after multiple washings in the laboratory. Then, in an RHRU study among women who used the same female condom up to seven times, washing and drying did not seriously affect the structural integrity of the device. In the study, if a condom remained structurally sound after one use and wash, the woman could volunteer to use and wash another new device two times. If that condom remained structurally sound after two washings, she could receive a new condom that could be used and washed up to three times. This process continued for up to seven uses. Disinfection was not part of the washing protocol. All of the used condoms surpassed standards set by the U.S. Food and Drug Administration for seam tensile strength and air burst, indicating the devices remained structurally sound. However, five holes were detected across all cycles, three of which were detected by the subjects. The holes were not associated with an increasing number of uses and washes.

The reuse protocol drafted by the WHO-UNAIDS consultation requires disinfection before each wash. Preliminary findings from a WHO-funded study to test the structural integrity of condoms repeatedly disinfected in bleach and washed indicate that the female condom can be used up to seven times and remain structurally sound. Study results are expected to be published in 2001.

Safety and re-infection

Preliminary findings from another FHI study indicate that multiple disinfection and washings of the female condom do not harm the vaginal wall, cervix or penis. The study is comparing the experience of 40 couples who use five devices one time each with 40 couples who use one device five times, with at least a 12-hour wait between uses. The study is using colposcopy to examine the vaginal wall and cervix at baseline and after the last use, to see if washing, disinfection and re-lubrication make a woman more susceptible to infection by causing lesions or other changes. With nearly half of the couples having completed the protocol, only one vaginal reaction has occurred, and that was with a single-use couple.

Before reuse can be recommended, research needs to demonstrate that sexually transmitted pathogens including HIV can be removed effectively from the device after use by a simple disinfection and washing procedure. WHO is funding such a laboratory study, which will explore the minimum bleach soak necessary to ensure safety.

Female Condom Acceptability and Sustained Use

Women may be able to negotiate use of the female condom more easily than the male condom, giving them potentially more power to protect themselves in a sexual relationship. But the female condom must be acceptable to both men and women in order to be used consistently and correctly, thus providing effective protection against sexually transmitted infections (STIs) and pregnancy.

Studies conducted in more than 40 countries in Africa, Asia, Latin America, Europe and North America have found good initial acceptability of the device by individuals with varying sexual histories, ages, social situations and economic status. A recent review by the World Health Organization of 41 acceptability studies indicated that the degree of acceptance varies widely, from 41 percent to 95 percent of study participants. Determining which initial acceptors sustain female condom use over time requires more research. Research indicates: ...counseling helps overcome women's initial difficulties in using the device, directing promotion campaigns to men and providing women with negotiation skills are important to overcome men's resistance to use, and over time, use tends to become concentrated among a subset of women or couples with high motivation to use it.

Initial acceptability

Since the female condom is a new method, initial interest and demand has to be generated. Various aspects of the method attract potential users. Women and men report that, compared to a male condom, the female condom is less likely to slip or break, more durable, and less disruptive of sexual spontaneity and intimacy. A woman can put it in place well before intercourse occurs, which can give her more personal control. After ejaculation, the male partner need not hurry to withdraw fearing that the condom will slip off inside the vagina. Men report that the female condom is more comfortable than the male condom, neither diminishing sexual sensation nor constricting the penis.

On the other hand, women complain that the device is too long -- its outer ring hangs outside of the body. Some report that the rings are uncomfortable and that it is unattractive. Men and women have complained about noise during use and excessive lubrication. The female condom may carry the stigma of being used only in short-term, casual relationships for disease prevention, and hence be associated with promiscuity. While some women report initial trouble correctly placing the device, training people to use it can increase acceptability.

Among the many acceptability studies, recent UNAIDS-supported research in Costa Rica, Indonesia, Mexico and Senegal found that women who introduced the female condom into a relationship reported it allowed them to communicate more successfully about safer sex. In a study involving 377 women in the Dominican Republic, Mexico and United States, about four of every five women liked the device and said they would recommend it to others.

Sustained use

Researchers are seeking to understand which types of users, called “market segments” by some, are most likely to continue using the female condom. In Zambia and Zimbabwe, mass marketing campaigns and some educational support have made the female condom available in urban areas. A year after the Zimbabwe campaign began, a survey of more than 1,600 people at retail outlets concluded that single women and men with partners outside of marriage seemed to benefit most from the female condom introduction. After six months in the Zambia campaign, a random sample of 1,570 persons at 52 retail outlets found that those who had already discussed the female condom with a partner were more likely to use it in the future.

Among 900 women provided with both male and female condoms at STI clinics in the U.S., after six months, 8 percent had used only the female condom. Another 73 percent had used both the male and female condom; about a third of those used 10 or more female condoms. The researchers concluded that women at risk of STIs find the female condom acceptable, with many using either the male or female condom consistently over time.

Two studies among women at high risk of HIV infection indicated successful sustained use. A study in Zambia found that the devices were used in one quarter of coital acts at three, six and 12 months. In a study among sex workers in Thailand, some 250 women offered both male and female condoms used female condoms in 12 percent of all sexual acts, a level that continued for the entire six-month study period.

CHAPTER 8 CARE AND SUPPORT

Being disabled and living with HIV/AIDS is a condition that requires adequate attention. Caring for persons with disabilities who are living with HIV/AIDS can be very tasking and demanding. Care for an individual with disability who is living with the virus should be holistic to ensure that these individuals are not traumatized.

More than 15 years of experience in the HIV epidemic have produced many effective HIV prevention and care strategies. Many pilot projects and small-scale projects in several countries have demonstrated key technical approaches that can reduce transmission and address care and support needs, but unfortunately persons with disabilities has not been taken into consideration. But to have the greatest impact on the epidemic, we must now go beyond pilot and demonstration projects to create programs with increased coverage and quality at local, regional and national levels to include persons with disabilities.

HIV/AIDS interventions targeting individuals with disabilities in some countries have achieved some success. But individual behavior is profoundly influenced by broader contextual factors, including social norms, service and facility accessibility and public policy. To be successful and sustainable, interventions must take place at multiple levels so that they can best: influence individual, community and societal norms; improve the health infrastructure; and alleviate structural and environmental constraints to HIV prevention and care. We must tailor program design and implementation to local conditions, appropriate to the stage of the epidemic, responsive to host country and donor needs, and targeted to meet strategic objectives.

The interventions within comprehensive prevention care and support should reinforce each other and should not be implemented in isolation on persons with disabilities. Only by combining key technical strategies can we meet the needs of the family and the community and make the greatest impact on the epidemic. Depending on the goals of the program, various combinations of technical strategies will be used to address different segments of the population, since one component may be most effective when bolstered by another. Availability of a wide range of care and support interventions further increases demand for services, helps de-stigmatize and normalize HIV through improved community acceptance of DPLHA and their families, and increases opportunities for HIV prevention among both HIV-positive and HIV-negative people.

The number of persons with disabilities and families living with HIV/AIDS who need care and support services is continuously increasing in some communities. This poses tremendous challenges to the health care and community systems that are coping with and responding to the pandemic in the general population. HIV/AIDS patients already occupy a large proportion – often more than half – of the hospital beds in heavily affected countries. Given the chronic but clinically manageable nature of HIV and the number of new infections (now approximately 16,000 per day), demand for care and support at institutional, community and family levels will only increase in the foreseeable future. At the same time, efforts to provide appropriate care at all levels is hampered by the lack of human, technical and financial

resources; continuing high levels of stigma; and the fact that most people living with HIV/AIDS (PLHA) do not know they are infected.

Synergy between prevention and care: Experience and research in implementing community-based prevention and care programs has shown that a synergistic approach promotes community acceptance of HIV, reduces stigma, and encourages PLHA to practice preventive behaviours and seek relevant care and support not only in the general population but also in disabled community. VCT for HIV is an important entry point for both prevention and care, as well as for reducing stigma and discrimination for persons with disabilities. Involving persons with disabilities who are living with the virus in designing and implementing prevention, care and support programs will be instrumental to the quality and sustainability of such programs. Examples include workplace education by a PLHA employee, discordant couple counseling, disability-targeted VCT programs, and post-test associations linked to care services.

Comprehensive needs of people and families living with HIV/AIDS: The needs of PLHA and their families can be categorized into four connected areas: medical needs, such as treatment information and treatment; psychological needs, such as emotional support; socioeconomic needs, such as welfare provisions, help in the household, and orphan support; and human rights and legal needs, including access to care and protection against violence and discrimination. Interventions to respond to these needs are interrelated and reinforce each other. For example, HIV therapy is better adhered to if patients are able to cope with their HIV status and feel supported. Over the years, relevant responses have been developed in these domains, resulting in comprehensive care and support services. When they are built on existing structures, such services have proven effective, efficient, and sustainable if the various providers complement each other's activities.

Continuum of care: The types of services that DPLHA need change as their illness progresses. Providing comprehensive care across a continuum – from home and community to institutional services – will ensure that the specific needs of clients and their families are met. A continuum of care is built around a network of resources and services that provide care and support to the ill person and the family caregiver. The goal is an affordable, comprehensive range of services in various settings, including the home, community projects, clinics, and hospitals. Effective referral systems have been developed to ensure that people living with and affected by HIV can benefit from the variety of services at the community and institutional levels throughout the course of infection and disease.

Medical and nursing care: DPLHA need medical services and nursing care that will reduce HIV morbidity and mortality and improve their quality of life as much as possible. Such services include: appropriate diagnosis, treatment and prevention of tuberculosis (TB) and other opportunistic infections and HIV-related illnesses; provision and management of highly active antiretroviral therapy (HAART); palliative therapies; and possibly traditional and alternative remedies. All other illness associated with persons with disabilities should equally taken consideration when

caring for persons with disabilities. Although, the capacity of health care systems and available human and financial resources will determine the choice of interventions and the quality of medical care among and within countries, minimal standards can be put in place and monitored.

Psychological support: HIV/AIDS is often associated with a range of psychological complications that must be addressed throughout all stages of HIV infection. Psychological support is critical for helping individuals, couples, and families affected by HIV cope with their fears and emotions. Being disabled and living with HIV/AIDS could be so devastating. The psychological trauma is so intense that disabled persons living with HIV/AIDS hardly disclose their status or even care to go for VCT. I believe there should be double support for a disabled person living with HIV/AIDS. This will help the infected persons to not only come out from HIV psychological trauma but, also from being disabled trauma. HIV voluntary counseling and testing (VCT) provides the bulk of initial psychological support. It also links individuals, couples and families to follow-up psychological support and other support services. These might include legal, welfare, and spiritual support within communities; DPO support groups; appropriate medical services for early management of TB and other opportunistic infections; and interventions to reduce mother-to-child transmission of HIV. In addition, VCT has proven important in promoting safer sexual behavior, thus preventing HIV transmission and enabling PLHA to disclose to (and involve their) significant others. Where VCT has become a regular service integrated into health and community systems, it has helped normalize HIV/AIDS and decrease the stigma attached to the disease.

Socioeconomic support: DPLHA and their families are confronted with additional challenges throughout the course of infection and recurrent episodes of illness. These include isolation, loss of income, medical and transport expenses, funera costs and the unmet needs of orphaned children for education, shelter, nutrition, clothing, and other necessities. With some external support and the involvement of DPLHA, families, community leaders, DPOs, volunteers, government agencies, nongovernmental and religious organizations, and existing social networks can care for family members and adequately support children and spouses in the home. Home care programs are cost-effective and sustainable when there is strong community support for running them, reinforced by quality medical and social services from nearby facilities. Major challenges remain in scaling up, income generation, and meeting nutritional needs of the rapidly increasing number of affected families and orphans.

Care for the caregivers: Caring for anyone with a serious chronic illness is a physical and emotional challenge for even the most dedicated caregivers more especially when the person is physically challenged in one way or the other. This is particularly true for nurses, counselors, volunteers, and caregivers in the home who provide the bulk of care for DPLHA. These caregivers also need support to help them do their jobs well, avoid burnout and remain free of infection. Regular social events, better recognition, incentives, peer support, access to post-exposure prophylaxis, and additional training opportunities are some of the ways to address caregivers' support needs.

The main technical elements of a comprehensive strategy for individuals, families and communities are:

Prevention	Care, Treatment, Support and Mitigation	
<ul style="list-style-type: none"> • Behavior change communication (BCC) for risk reduction • Condom promotion and availability • STI management • Voluntary counseling and testing (VCT) for HIV • Prevention of mother-to-child-transmission (MTCT) • Blood safety and universal precautions • HIV prevention for injecting drug users • Stigma reduction 	<ul style="list-style-type: none"> • Stigma reduction • VCT • Psychosocial support for affected (as well as infected) family members • Palliative and respite care • Educational support for children • Legal support • Nutritional support • Home and community-based care • BCC for health care providers, patients, families, communities 	<ul style="list-style-type: none"> • Disease management with antiretrovirals (ARV) • Clinical management of opportunistic infections and HIV-related illnesses • Tuberculosis prevention and control • Interventions for orphans and other vulnerable children • Micro-enterprise and income generation • Community preparation

The following example shows how technical elements can complement and reinforce each other:

Voluntary counseling and testing (VCT) for HIV is recognized as an effective, pivotal strategy in AIDS prevention, care and support. VCT provides benefits for those who test positive as well as for those who remain negative. But quality programs and services must be in place before individuals can truly benefit from VCT. Promoting VCT for behavioral change as a prevention strategy alone will not work if services or referrals are unavailable after test results are provided. Using VCT to identify HIV-positive individuals without then trying to promote behavior change for prevention – sexual risk reduction counseling or preventing MTCT, for example – does not make full use of the strategy.

Intervention	Program Goal	Necessary Programs and Services
VCT for HIV	<ul style="list-style-type: none"> • High quality, accessible, acceptable, utilized VCT services 	
Promote behavioral change (reduced risk behavior)	<ul style="list-style-type: none"> • Behavior change communication • Supportive environment and policies 	
	<ul style="list-style-type: none"> • Availability of prevention commodities (condoms, needles, syringes) 	
	<ul style="list-style-type: none"> • Quality STI services and other reproductive health services 	

• Outreach to particularly vulnerable groups	
• Post-test support groups	
• Stigma alleviation	
Referral for care and support across a continuum	• Medical, nursing, home care or respite care services, palliation, and nutritional support
• Providing ARVs as appropriate (e.g., stage of infection, MTCT program, etc)	
• Prophylaxis and treatment for common infections (bacterial and tuberculosis)	
• Post-test support groups	
• Stigma alleviation	
Entry point for addressing affected family members	• Couple/family HIV counseling and testing • Counseling on parent-child communication regarding disclosure
• Succession planning/referral to legal and social support	

CHAPTER 9: BEHAVIOURAL CHANGE COMMUNICATION OF HIV/AIDS

Behavior Change Communication (BCC) is an interactive, community-driven process to develop tailored messages and approaches using various communication channels to develop positive behaviours; promote and sustain individual, community and societal behaviour change; and maintain appropriate behaviours. Before they can reduce their risk and vulnerability to HIV, persons with disabilities and communities must understand the urgency of the epidemic. They must be given basic facts about HIV/AIDS, taught a set of protective skills and offered access to appropriate services and products. They must also perceive their environment to be supportive of changing or maintaining safe behaviours. As HIV is primarily a sexually transmitted infection (STI), this requires national and community discussions on sex and sexuality, rape, risk, risk settings and risk behaviours. It also means dealing at the national and community levels with the resulting stigma, fear and discrimination. The HIV/AIDS epidemic forces societies to confront cultural ideals – and the practices that clash with them. BCC is vital to this process and can set the tone for compassionate, responsible interventions. It can also produce insights into the broader socio-economic impacts of the epidemic. BCC is most effective when integrated into an overall program.

The Strategic Role of Behaviour Change Communication. BCC has many different, related roles to play in HIV/AIDS programming for persons with disabilities and the general population. Effective BCC should:

- **Increase Knowledge.** BCC should ensure that people have the basic facts in a language, visual medium or other media that they can understand and relate to. Effective BCC should motivate audiences to change their behaviours in positive ways.
- **Stimulate Community Dialogue.** Effective BCC should encourage community and national discussions on the underlying factors that contribute to the epidemic, such as risk behaviours, rape, risk settings and the environments that create these conditions. BCC should create a demand for information and services, and should spur action for reducing risk, vulnerability, discrimination and stigma.
- **Promote Advocacy.** Through advocacy, BCC can ensure that policy makers and opinion leaders approach the epidemic seriously. Advocacy takes place at all levels, from the national down to the local community level and to DPOs.
- **Reduce Stigma and Discrimination.** Communication on HIV/AIDS should address stigma and discrimination and attempt to influence social responses to them.
- **Promote Services for Prevention Care and Support.** BCC can promote services that address STIs, orphans and vulnerable children (OVC), voluntary counseling and testing (VCT) for HIV, mother-to-child transmission (MTCT), support groups for disabled people living with HIV/AIDS (DPLHA), clinical care for opportunistic infections, and social and

- and economic support. BCC can also improve the quality of these services by supporting providers' counseling skills and clinical abilities.

The Goals of Behavior Change Communication

BCC strategies in HIV/AIDS aim to create a demand for information and services relevant to preventing HIV transmission, and to facilitate and promote access to care and support services. Some specific BCC objectives include:

- Increasing the adoption and continued use of safer sex practices
- Promoting visits to clinics treating STIs and opportunistic infections, including tuberculosis
- Increasing the demand for VCT, for MTCT prevention services, and for OVC care and support
- Increasing the adoption and continued use of safer drug-injecting practices
- Stimulating dialogue and discussion on risk, rape, risk behavior, risk settings and local solutions
- Reducing stigma and discrimination for those persons with disabilities living with HIV/AIDS
- Including brail and interpreters for visual and hearing impaired persons

Essential Steps to Develop a BCC Strategy

The following steps incorporate careful analysis, feed-back and redesign throughout the entire process. **Step 1:** Identify the problem based on the overall program goals. **Step 2:** Segment target populations. **Step 3:** Engage in formative research. **Step 4:** Identify behavior change goals. **Step 5:** Seek consensus from stakeholders. **Step 6:** Design communication plan, including objectives, overall theme, specific messages and outlets for dissemination. **Step 7:** Pre-test and revise. **Step 8:** Target communication to specific groups. **Step 9:** Implement the plan. **Step 10:** Monitor and evaluate it. **Step 11:** Seek feedback and revise appropriately.

Lessons Learned. Experience in carrying out BCC interventions has shown that:

- BCC should be integrated with overall program goals and specific objectives. BCC is an essential element of HIV/AIDS prevention, care and support programs, providing critical links with other program components.
- BCC should be linked to policy initiatives and service provision.
- BCC should encourage individual behavior change and also help create environmental conditions that facilitate personal risk reduction.
- Formative assessment or audience research must be conducted to better understand the needs of persons with disabilities and the barriers to behavior change that its members face.
- All BCC in HIV/AIDS should help reduce stigma and discrimination.
- The target population and the related community should participate in every phase of BCC development to ensure delivery of consistent message — and to avoid use of conflicting ones.

- Using a variety of communication channels is more effective than relying on any one. For example, peer education should be promoted by mass media, interpreters should be employed, messages should be incorporated into brails, counseling and other approaches.
- Pre-testing is essential for developing effective BCC materials.
- Program planners should incorporate monitoring and evaluation at the start of any BCC program.
- Programs should state specific objectives for change after exposure to the communication. These might be changes in actual behavior or shifts in the precursors to behavior change (such as in knowledge, attitudes or concepts).
- Because society-wide change is slow, program planners will not see changes achieved through BCC overnight.

Conclusion

BCC strategies must be based on overall program goals and objectives targeting specifically for persons with disabilities. They must move beyond individual communication products to a careful use of many different interventions, products and channels for a broad community approach. A BCC strategy that is woven into the overall program and based on sound formative assessment can influence community discussion, social norms, and — when services and commodities are in place — individual and community behavior. Those who plan and implement HIV/AIDS programs should develop strategic approaches that view BCC not as a collection of different, isolated communication tactics, but as a framework of linked approaches that function as part of an integrated, ongoing process.

CHAPTER 10: CONTROL OF SEXUALLY TRANSMITTED INFECTIONS

More than 300 million new cases of curable sexually transmitted infection (STI) occur each year, with a global distribution much like that of HIV. Each new infection not only increases HIV transmission risk but also carries the potential of other serious complications, including fetal loss, stillbirth, infertility, ectopic pregnancy and severe congenital infections. Syphilis alone, when present during pregnancy, results in fetal loss in a third of cases, and half the surviving infants suffer congenital disability.

There are a few large-scale interventions that demonstrate the potential impact of STI control on HIV transmission. In less than five years, Thailand reduced the incidence of curable STI by more than 80 percent through a comprehensive effort that included both improved STI treatment and targeted promotion of condom use in commercial sex establishments (100 percent condom policy). HIV prevalence, which had been increasing rapidly, began to fall during this period. Through sustained application of these interventions, Thailand stabilized HIV transmission early and averted a far more extensive epidemic.

There is also evidence that more limited STI interventions can reduce HIV transmission. In rural Mwanza, Tanzania, improving the case management of STI through the syndromic approach in clinics reduced the incidence of new HIV infection by 40 percent. In contrast, the mass antibiotic treatment of the sexually active population at nine-month intervals in Rakai, Uganda, neither reduced most curable STI nor lowered the rate of HIV transmission. We attribute these differences mainly to the stage of the epidemic and the underlying prevalence of curable STI and high-risk behavior in the population.

Experience in STI control programming teaches us that reducing high rates of STI requires a comprehensive strategy of both prevention and management. This includes such well-known aspects of STI control as ensuring effective diagnosis and treatment, encouraging treatment adherence and partner treatment and avoiding re-infection. But it is equally important to pay attention to who uses existing clinical services and who does not. Even the most technologically advanced services will have little impact on STI prevalence if there is poor access to those services. One of the greatest challenges in STI control is making sure that effective services reach the people most frequently exposed to infection and who have the most frequent opportunities to pass on infection to others.

The most effective components of STI control for reducing STI prevalence include:

- **Communication strategies** to promote services, improve symptom awareness and STI treatment-seeking behavior, and promote and provide adequate supplies of condoms.

- **Efficient, effective STI management in clinics accessible and acceptable to the majority of the population**, including services for adolescents and young adults. The goal is to maximize the proportion of such encounters that are effectively managed (no “missed opportunities”) while avoiding costly over-treatment

in settings with low STI prevalence. Local priorities must determine the appropriate balance between sensitive approaches for identifying infection and avoiding over-treatment, still a central issue in STI control.

• **Interventions targeted at populations with the greatest risk of acquiring and transmitting STI.** Outreach and peer education among high transmission networks are the foundations of targeted interventions. Preventive and curative services for individuals in these networks go hand-in-hand. Individuals are more receptive to condom use and other prevention messages when they are delivered with quality, non-judgmental curative services (“prevention-care synergy”).

- **Improved STI management in important informal sector outlets** (e.g., pharmacies where many people, especially male bridging groups, seek treatment).
- **Screening or presumptive treatment of the most important core and bridging groups** as short-term measures to reduce STI prevalence.
- **Selective implementation of more focused disease control measures** designed to rapidly reduce the prevalence of specific STI and/or their complications may include the elimination of congenital syphilis, enhanced control of genital ulcer disease or the elimination of infectious adult syphilis or chancroid.
- **Improved reliability and relevance of surveillance and evaluation data**, including laboratory data to guide control efforts and measure progress.
- **Addressing structural changes to modify underlying conditions that facilitate STI transmission.** Examples include providing family housing for migrant workers to reduce the demand for commercial sex, and promoting “safe house” rules in brothels where the pressure to use condoms comes from the management rather than individual sex workers.

STI case management is an important, but not the only, component of STI control. The syndromic approach endorsed by WHO/UNAIDS has become the standard of care in many countries for managing the most common STI syndromes. By directing treatment against the common causes of easily identified syndromes, primary health care workers can achieve high cure rates without the delay and cost incurred with laboratory workups. Syndrome algorithms also reduce treatment failures and re-infection by stressing the importance of treatment adherence, condom use and partner treatment. Syndromic management is most effective and cost-effective for syndromes such as urethral discharge and genital ulcer disease, although in many countries herpes is becoming the most common cause of genital ulcers. The approaches now used to manage vaginal discharge syndromes in women are less accurate; better combinations of syndromic and laboratory diagnosis and screening are needed. For now, more sensitive and costly approaches can be adapted for populations with relatively high prevalence and exposure, while treating the more common vaginal pathogens may be more cost-effective in lower-risk populations. As simpler, more affordable and accurate diagnostics become available, STI case management guidelines recommending combinations of

syndromic and laboratory diagnostic methods will become feasible under field conditions.

CHAPTER 11: MAINSTREAMING DISABILITY INTO HIV/AIDS

In the field of mainstreaming of disability and/or HIV/AIDS in development cooperation activities, the aim is to adapt activities in order to take into account the impact of these two issues, as well as other factors that increase the vulnerability towards disability and/or HIV/AIDS. In other words, we must react to social context changes that cause phenomena like disability and HIV/AIDS. We have already evoked most of these contextual issues elsewhere in this publication: the close link between poverty on the one hand, and disability and HIV/AIDS on the other; the importance of prevention; the vulnerability of people with disabilities, and particularly women, towards the AIDS virus.

In this chapter, we will describe some essential steps that must be continuously enforced. Mainstreaming on the level of activities is a continuous process along which we pass through every phase of the project cycle. A concrete activity or project includes a planning phase, an implementation phase, regular evaluations and adjustments. After each change of activity or orientation the cycle begins again. Here, we'll go into further details on the different steps advised to give a place to disability and/or HIV/AIDS within the organization. More precisely, the next phases are also important when mainstreaming other diversity factors:

1. Training and capacity building
2. View on the local situation
3. Project with indirect attention towards disability and/or HIV/AIDS
4. Fitting in the project cycle and procedures

Training and capacity building

Although throughout developing countries, disability and HIV/AIDS are clearly visible in the communities, few NGO workers are familiar with it. They are often medical experts within the organization itself who have only limited knowledge about disability and HIV/AIDS. Their knowledge is confined largely to the medical aspects. In other cases, social workers have a good knowledge of the social factors, but lack the knowledge to address disability and/or AIDS from a medical perspective.

In order to evaluate the social impact of disability and/or HIV/AIDS, it is also necessary to have a global view on the general impact of disability and/or HIV/AIDS on the personal, social and economic well-being of people with disabilities and/or HIV/AIDS. Therefore, we must understand how disability and/or HIV/AIDS influence the development opportunities of a person and of the household he/she belongs to. In developing countries, this insight is often lacking to the leaders of organizations as well as to people active on the field.

For these reasons it is advised that all NGO workers receive a basic training on :

- Factors increasing vulnerability to disability and/or HIV/AIDS
- The intensifying role of poverty in the appearance as well as in the consequences of disability and/or HIV/AIDS.

- The link between disability and/or HIV/AIDS on the one hand, and the gender factor on the other.

Besides these general basic trainings, we must study the concrete meaning of mainstreaming in each field of activity of the NGO, as well as the steps to follow in order to be able to work at it. In this phase, a different training should be given to the different departments of the organization, focusing on their field of activity. Mainstreaming of disability and/or HIV/AIDS does not have the same consequences on education projects and on income generating projects. Similarly, mainstreaming at the project level differs from mainstreaming at the policy level of the organization itself.

A view on the local situation

If we want to mainstream disability and HIV/AIDS in a concrete project, it is absolutely necessary to have a global view on the local situation. In order to have a good idea of the situation, we can adopt different strategies. It is important to know who are the key persons in the local community, not only in general, but also specifically in the field of disability and/or HIV/AIDS. In a community, everybody does not have the same knowledge of these subjects, and is not open to think about mainstreaming.

People with disabilities and/or HIV/AIDS themselves, or their relatives, may be good contact persons and must, in every case, be involved in this exploration. It is possible that, because of the taboo, these people are difficult to reach. An efficient, but time consuming method would be to try to establish personal contact with families by going from door to door in order to informally collect information on the following aspects:

- Behaviours towards men, women, adolescents and children with disabilities and/or HIV/AIDS
- The proportion of households with individuals with disability and/or HIV/AIDS
- The effects of disability and/or HIV/AIDS in the different kinds of households, on individual members of the family and on food provision
- The impact of disability and/or HIV/AIDS on the household and the community levels.
- The changes in behaviour of the larger community towards men, women and children with disabilities and/or HIV/AIDS

We must also have an idea about the experiences of men, women, and children with disabilities and/or HIV/AIDS:

- How do they experience the evolution of their disabilities and/or disease?
- According to them, what is the impact of their disability and/or disease on themselves and on the different members of their household?
- What do they consider as being the cause of their disability and/or disease?
- What are their conceptions of how to prevent disability and/or HIV/AIDS?

We do not get answers to such questions in only one home visit. Therefore, it is advised to set up discussion groups through participative methods. For the formation of the different discussion groups, it is possible to use already existing informal groups or organizations of persons with disabilities or HIV/AIDS. However, because of the stigma and of the practical difficulties people with disabilities and/or HIV/AIDS have to cope with in order to get organized, such groups generally do not exist and must be created.

Because of the sensitivity of themes like disability and HIV/AIDS, we must pay attention to the following aspects:

- Are all disabilities present in the communities represented in the discussion group? Are people at different stages of HIV/AIDS represented?
- Is there a balance in the number of men and women, the division by age groups, and the social positions in the community?
- Who are the main figures in the group and how can we guarantee that the opinion of the others will also be considered?
- It would be good if the facilitator asked the participants, what they'd liked to see happening at the beginning of the discussion. At the end it is important to check whether everyone is satisfied. A good way to do this is by asking the following question: "What have I failed to bring up that is important to you about this issue?"

It may be interesting to complete the group discussions by a few individual interviews in order to consider personal aspects that people do not want to talk about with the group. If we want to work on disability as well as on HIV/AIDS, it is better to work with two distinct groups, because there are many differences between disability and HIV/AIDS. Moreover, people are generally more open to discussion in groups where everybody lives with more or less the same situation.

It is also advisable to launch a separate discussion group with key figures in the community, as well as with other interested people who are not directly involved in these themes of disability and/or HIV/AIDS. This would involve people who are not themselves, nor through their families, directly affected by disabilities and/or AIDS. It is also possible to discuss the following subjects with them:

- How do they behave with people with disabilities and/or HIV/AIDS within their communities?
- What do they know about the prevention of disability and/or HIV/AIDS, and what do they do concretely about it?
- Which do they themselves see as the cause of the different disabilities and/or HIV/AIDS?
- According to them, what is the impact of disability and/or HIV/AIDS on the community?

Here also, it is important to have a balance between men and women, between different ages and between individuals with different social positions. Once we have a global view on the visions and attitudes existing around disability and/or HIV/AIDS among people directly concerned, as well as in the community at large, we can then bring the two groups together. In this joint discussion group, the following questions could be raised:

- Do the activities and projects set up by the community take disability and HIV/AIDS into account?
- If yes, how? What does work? What doesn't work? How can these things be improved?

If no, set up a plan of the steps to be taken towards disability and/or HIV/AIDS that is supported by everybody, and designate who will take responsibility for what.

In order for a project to have a real impact on the inclusion of people with disabilities and/or people living with HIV/AIDS, the project should address the inclusion of disabled people and/or people living with HIV/AIDS can't get out of this cycle. CDD and Handicap International mainstreamed disability within within the community at large. Only when the general public is targeted and included can a difference be made on the community level.

This aspect has been tested in Bangladesh, where Handicap international, with its partner CDD (Centre for Disability in Development) have implemented a project to include disabled people in the development projects, as well as in the community. The concept of Community Approaches to Handicap in Development (CAHD) stems from the idea that people with disabilities are trapped in a vicious circle that links poverty and disability, and the projects of development NGOs. In the context of Bangladesh, where over 20,000 NGOs are working in the communities in various areas such as education, income acquisition and health care, it seemed appropriate to persuade these development NGOs to mainstream disability not only in their projects, but also in their project areas. The idea behind this was that mainstreaming disability within the development projects was a necessary component, but was not sufficient to promote the inclusion of disabled people. Therefore, the CAHD included another component, namely: advocacy to ensure that not only committed NGOs, but also other key actors (school teachers, health workers, political and religious leaders mainstream disability.

The CAHD activities started in 1997, when CDD started training social workers, specialists in social communication as well as managers of community based NGOs. Once trained, the NGO's staff would go back to their field, and start mainstreaming disability, while being supported by CDD in the background. In 2004, over 200 organisations had been trained and were mainstreaming disability in their work, as well as encouraging the local communities to include disabled people. This approach has proved to be successful, according to the monitoring reports. Children with disabilities are being accepted in schools, adults with disabilities are starting to have access to income generating activities. Disability is starting to be better understood in the communities where the project has been initiated.

One of the lessons learned from the projects in the field is that mainstreaming in one project only is not enough. It needs to be linked to efforts to encourage the community to include disabled people in society in order to actually see people with disabilities being included. Monitoring and evaluating the impact of the approach in the field is a key to provide evidence to encourage further similar projects to be implemented in other countries.

Project with indirect attention towards disability and/or HIV/AIDS

Once we have received, via the discussion groups, an initial understanding of the changes to be made and of the community members who should play a role, we must study existing activity and projects in the community, as the way in which general elements of a plan can be implemented. It can be done within the common discussion group but, for large scale and complex activities, it is better to create a project group that makes concrete propositions and transfers them to the discussion group.

The content of these concrete propositions depends on the nature of the project or the activity and of the evaluation of the local situation, as we already told it in point B. However, we can give some general guidelines:

1. Describe the project with the following questions in mind:
 - How do disability and/or HIV/AIDS influence the living conditions of people who are confronted with it?
 - How does that influence their chances to avoid poverty?
 - How does an NGO's work contribute to the prevention of disability and/or HIV/AIDS?
 - How does an NGO's work help people directly concerned and, more generally, the community, to behave differently towards those with disability and/or HIV/AIDS?
2. Reinforce the security net on which households can call by:
 - Targeting a general increase in the revenues of the household
 - Stimulating savings and the growth of the finances of the families
 - Avoiding the need for people to sell their means of production, (for example, machines or cattle), in order to buy the food they need.
3. Build or reinforce the security nets at the community level by :
 - Supporting families in educating and caring for their children
 - Bringing food to people or supporting them in their capacity to get food on their own
 - Putting other needed resources at their disposal such as clothes and soap.

Concrete examples of measures or points of attention:

- In the framework of an agricultural project: to adapt the tools and techniques to old people with disabilities or diseases, for example, by using donkeys instead of people to plough.
- In the framework of micro credit projects: to adapt lending conditions so that people with a disease or a disability are not excluded in advance. The caretakers should not be excluded from micro credit because of the care they provide. We must show tolerance towards people with disabilities when they are absent at meetings, as long as they bring their contribution to the micro-credit system set up by the community. Apart from that, meeting other people is also important for people with disabilities and/or

- HIV/AIDS. Putting objective criteria in place to approve credit can help to include all the people who are able to conduct a successful income generating activity and reimburse the loan. Criteria should include: experience in managing such a business before and a marketing study showing that the business can be profitable. But the criteria should not be discriminatory on the basis of one's disease or physical condition.
- In the field of healthcare, we must draw special attention towards prevention. Sufficient sanitation services and basic hygiene are essential. Sanitation services have to be adapted to the needs of people with disabilities. They should be wheelchair accessible, and not so far away that individuals who are in poor health or cannot walk far, must decide not to attend because the walk is too far or the hillside too steep. It is essential however for health care professionals to be aware that many of the health issues that individuals with a disability have to face are the same as for the rest of the population. In the context of campaigns about basic hygiene or the prevention of HIV/AIDS, one must stay attentive to the need for people with different disabilities to also be reached by this kind of information. To be more able to produce promotional materials which are accessible to people with a visual or hearing impairment as well as a learning impairment, it is good to contact local organizations that are representing those people. Beside, local disabled people organizations (DPOs) are the right channels to spread the message among people with disabilities. Many persons with disabilities, also those with a physical impairment are not reached by traditional ways of communication. But training and information on those medical treatments and therapies which make the lives of people with certain conditions more pleasant are also an important component of an inclusive development project. Health services should be accessible for all, including disabled people. People affected by HIV/AIDS should be confident enough to visit the appropriate services to investigate the evolution of their illness.

In projects on education and training, it is possible to systematically foresee the prevention of aspects of disability and HIV/AIDS. We must also see to it that children, youngsters and adults with disabilities and/or HIV/AIDS have enough training opportunities, in order to reinforce their social position. Efforts should be made to include disabled children in schools.

In all these fields, we must not only pay attention to the most vulnerable and most affected persons, but also to the gender factor, the age factor and to other diversity factors that change the vulnerability towards disability

Fitting in the project cycle and procedures

The way in which we can anchor the measures that contribute to the mainstreaming of disability and/or HIV/AIDS, within the project cycle and within the procedures of the organization depends on the type of activity and on the local context.

It is however possible to give some advice:

- Pay attention to the mainstreaming of disability and/or HIV/AIDS in the job descriptions for the staff, in the evaluation mechanisms and in the vision and mission statements of the organization.
- Establish standard procedures on the non-discriminatory treatment of people with disabilities and/or HIV/AIDS.
- Determine what measures will be taken should collaborators, at different levels have discriminatory attitudes and practices
- Provide concrete action points for the mainstreaming of disability and/or HIV/AIDS in each phase of the project cycle

Because mainstreaming is a long process, the follow-up and adjustments needed to the existing measures and procedures must be feasible. Sanctioning measures to be taken should there be breaches of agreements to assure inclusion is useful, but this should not create a negative atmosphere, in which mainstreaming would be considered a straitjacket imposed from above. As we've already emphasized, a mainstreaming process on the level of activities, particularly in the field of disability and/or HIV/AIDS, cannot succeed without an active participation of all the people concerned. In the first place, these are the persons with disabilities and/or HIV/AIDS themselves, their family members and the caretakers, people committed individually, the local leaders in the community and, finally, members of the general community. When it comes to HIV/AIDS, this should also be done while respecting confidentiality.

Of course, it is utopian to believe that it is possible to convince all the members of the community to contribute to mainstreaming of disability and/or HIV/AIDS. But it cannot be an argument used in order not to begin or not to persevere after the first little steps. As we already mentioned in the preceding chapters, the essence of mainstreaming often lies in small, incremental adaptations and not in great structural changes.

Another issue that can make an important contribution to mainstreaming of disability and/or HIV/AIDS is the structure and the culture of the NGO. This form of mainstreaming is not totally independent from mainstreaming on the activities level, but requires other points of attention and methods that build the link with diversity in the management of the organization in general.

Mainstreaming of disability and/or HIV/AIDS in the organizations policy

Composition of a preparatory working group

A working group is set up. The tasks of this group can be the following:

- Setting up a code for the promotion of diversity.
- Process management: to develop, stimulate, follow up, evaluate and adjust.

The working group can take different forms:

- Temporary working group (with attention towards different function levels or departments within the organization).

- Setting up a code for the promotion of diversity.
- Process management : to develop, stimulate, follow up, evaluate and adjust
- Permanent working group for staff, management, and other diversity groups
- Think-tank within the general assembly or team meetings.

It is important to mark out a number of cases and to make arrangements for:

- The mission of the working group.
- The skills and decision making role of the working group.
- Time investment and terms of the working group, attention to the financial level of commitment and possible exemptions of other tasks.
- Possibilities of education and training in connection with the theme.

Collection of internal and external information

Once a working group has been set up, its first mission should be to collect information. It is important therefore, to collect information first on a large scale, e.g.:

- Mapping the legislation
- Looking for examples of other provisions
- Collecting some examples of previous experiences with disability and/or HIV/AIDS, or other forms of diversity
- Following education and training
- Scrutinizing current labour legislation and/or internal regulations
- Interviewing specialists: both legal experts as well as experienced specialist
- Interviewing vulnerable groups
- Collecting scientific research and figures
- Surveying within one's own organization
- Large brainstorming sessions etc.

It is important for every participant of the working group to receive the assignment to collect information, and that a number of arrangements are made about who searches where. It is evident that there will be some overlap, but this is not a problem. On the contrary information that repeats findings from other sources is often important information.

Prospecting arguments in favour of diversity within the staff

An important task of the working group is to show all levels and departments the advantages of a general diversity policy within the staff. These are applicable to for-profit as well as non-profit organizations. This applies to all diversity factors, including disability and HIV/AIDS.

Talents and skills

1. New talents for the staff of the organization:

Diversity is an important characteristic of every society since everyone knows someone with a disability and/or HIV/AIDS. This could be a family member, a

neighbour, a schoolmate, a colleague at work, a friend etc. The thing is that people often forget the experiences they already have with diversity because homogeneity is the norm and not diversity. But there is also a more positive reason why diversity has always been overlooked. If you know people very well, they become just like everyone else, and they are no longer seen as a person with a disability or HIV/AIDS. If this is the case, people just need to be reminded of this. Therefore, a society with more systematic attention towards diversity offers possibilities to discover and to explore new talents.

2. Increasing one's skills and creativity

Diversity management with attention towards disability and HIV/AIDS can lead to diversity in knowledge, ideas, perspectives and creativity. It is a plus when developing working processes, the products and solutions. It also improves relations with clients and with the general public.

Internal processes

1. Better collaboration between the staff members

Diversity management leads to a better understanding of the differences and consequently, to better communication, more collaboration and an increased effectiveness.

2. Involvement of the staff in the organization

The employer plays an important role in keeping a competent and concerned staff. Such involvement can be increased if the working atmosphere favours the existence of different ideas, habits and ways of live.

3. Improvement of the working atmosphere

The development of mutual links between the employees is useful to overcome prejudices and to discover the added value of differences in cultural experiences, backgrounds, faiths, habits, and physical and intellectual variations.

Marketing and innovation

1. Improvement of the organization development:

Diversity encourages learning processes in the organization. This offers opportunities for new ideas.

2. A broader view on disability and HIV/AIDS

By expanding the understanding

3. Targeted information provision for management and employees

It can be useful to bring together the employees of the department concerned when somebody with a disability and/or HIV is recruited, in order to discuss what support and adaptations are necessary to the recruit in order to create the optimal work environment. This process can also be applied when somebody already employed acquires a disability and/or HIV. The most important goal is that everybody must feel at ease, people with disabilities and/or HIV, as well as their colleagues. In order to break the ice, discussion about these issues can be initiated by concrete anecdotes on disability or disease told in an informal atmosphere. During such discussions, it is important that the privacy of every person involved is respected. Openness does not mean that everything is told to everybody. In some cases, the provision of formal information about disability can be advised, e.g. information on how to adapt training packages for people with a visual or hearing impairment. Employees with disabilities can often give this basic information themselves but sometimes it is difficult for them to speak of their own situation and disability. It can be useful to perform training on a disability, with which the organization has never been confronted. Such trainings raise the awareness of possible blunders and pitfalls.

Mentors for (new) employees with a disability and/or HIV

- A mentor could counsel new employees and when a mentor is used they should meet regularly with the employee. Aiming at a relationship based on trust (with all employees in the immediate environment), the problems should be taken seriously at all times. Such a mentor has to be trained for this task. Preferably, the same person should be trained to deal with the different factors of diversity. Only under this condition will this person be able to perceive the differences and similarities of each individual's situation. Beside examining cases in which persons with HIV are treated similarly or differently compared with persons with a disability, the impact of a combination of different diversity factors should be assessed as well. The condition of women with a disability differs from that of women or men with HIV. The diversity mentor should also be dealing with complaints, both on behalf of persons with a disability and on behalf of the other employees. Not every person with a disability and/or HIV feels the need for such a mentor. This should be looked at on an individual basis. Persons with a disability and/or HIV could also act themselves as mentor for others.

Career planning for people with disabilities and/or HIV

From the beginning, the employees with disabilities and/or HIV have to be embedded in the existing training policy of the organization. After the recruitment and as soon as the employee has settled in, a plan should be set up for further development and training. This work reduces the risk of problems with the employee and serves as a motivating factor. It also complies with the European principles of permanent learning, which were formulated in Lisbon in 2000. It is advisable to send announcements to people with disabilities via their special organizations, when new jobs are posted, specifically noting that persons with disabilities are encouraged to apply, should they have the necessary qualifications.

A number of concrete adaptations for employees with disabilities and/or HIV

It is important to underscore the fact that most of these recommendations are beneficial to every employee. Below we cite a few, but this list is not exhaustive:

- Training in specific tasks linked with the function.

This is very important for NGOs which, in the developed as well as in the developing country, have to reach different social groups with, among others, people with disabilities and/or HIV/AIDS, and which have to deal with them in a participative way.

- Increasing the potential for a better target group management:

The possibilities for manufacturing products, providing services and offering solutions for diverse target groups, among whom are people with disabilities and HIV/AIDS, are increasing. Within this process, each staff member should be invited to bring in new ideas and approaches.

The public image

Improvement of the public image of the organization:

An organization that is well known or its successful diversity management is able to create a better public image.

International perspectives

1. Wider vision on the field surrounding disability and HIV/AIDS:

Employees with disabilities and/or HIV have easier access to persons with disabilities and/or HIV/AIDS, their environment and their organizations. When they belong to the staff, the whole organization is more able to provide products and services that fulfil the needs and wishes of people with disabilities and/or HIV/AIDS in countries where the NGO is active.

2. Improvement of the international communication:

Organizations can take advantage of diversity management when they have to cope with target groups that are difficult to reach in other cultures in a world that's becoming increasingly globalized.

3. Development of global capacity:

An organization that is known for its "diversity culture" with attention towards disability and HIV/AIDS is in a better position to attract specialists on disability and HIV/AIDS from throughout the world, and to integrate them into the staff in order to collaborate.

The process of organizational mainstreaming

The implementation of diversity in the management does not have to follow any fixed steps. Its application can respond to the specific requirements of each organization.

At the same time, a minimum number of components have to be present. In this paragraph, we'll describe a blueprint for the implementation of diversity in the management within non-profit organizations and, consequently, also NGOs. We have concentrated on the specific steps of the inclusion of disability and HIV/AIDS within a diversity policy.

1. Involvement of the management

It is very important for the top level of the organization to radiate a positive approach towards the diversity policy. In addition, it should take the initiative to integrate attitudes, approaches and individuals with disability and HIV/AIDS into the senior levels of the organization. In this way, the higher levels of the organization determine the framework within which all the managers in the organization should work. Besides, it provides a positive message for the employees.

2. Analysis of the current situation and definition of the objective

The application of diversity with management raises consequences for everybody. A diversity scan can clearly show which adaptations within the culture of a specific organization are needed in order to integrate disability and HIV/AIDS.

The essential points of such analysis are the following:

- Do people with disabilities and/or HIV/AIDS work in the organization? Don't only mention those with visible impairments but also those whose disabilities are hidden, or less marked.
- Do people who become disabled or HIV+ keep their jobs and is their private life respected?
- Do people with disabilities experience inequalities that are directly linked to their disability or condition?
- Do these inequalities affect the working process?
- What can we do to solve existing problems?

The necessary steps and pursued goals have to be formulated in a measurable and quantifiable way. After having analysed the place of disability and HIV/AIDS within the organization and the changes that are produced, it is possible to choose several strategies to cope with these differences in order to strengthen the overall potential of the organization.

3. Attention towards disability and/or HIV/AIDS, without singling them out

When persons with disabilities and/or HIV receive extra attention, this can lead to frictions with other employees. This must absolutely be avoided because it only causes additional stigmas. For these reasons, it is also important to keep contact with all the employees and to pay attention to the experiences and feelings of all.

4. Introduction of forms of collaboration in the workplace with attention towards the diversity culture pursued within the business

It is advisable to set up a working party composed of representatives of several levels of employees within the organization under the supervision of one person who

is officially placed in charge. Recommendation from employees who are knowledgeable about and experienced with disability and/or HIV/AIDS among the members of the working party is a priority.

Examples for this are:

- How do I make my organization accessible for people with disabilities?
- How do I deal with functional limitations among people with disabilities and/or HIV/AIDS?
- How do I learn, in my practice but also in my attitudes, to deal with feelings of opposition among people with disabilities and/or HIV themselves and their colleagues?
- Training courses in “Being assertive” and ‘Standing up for yourself’ for each employee who wants it. See to it that all important information is accessible and that everyone can consult it. What this means for persons with disabilities will depend on the disability. For blind people it means that electronic information is available in Braille, for wheelchair users, it means that important information is not stored out of reach high up in cupboards.
- Meetings and/or informal discussions about the situation of people with disabilities and/or HIV within the organization, their needs and rights, and possible measures to will add to wider discussions of diversity.

Measures for the promotion of skills, for example: training on the workplace for people without formal training will benefit all

- Control and improvement of the access to training for everybody.
- To allow sick leave for medical controls that are connected to the disability or long-lasting diseases.
- The possibility of taking longer holidays or leaves without pay when performances such as travels abroad, require longer recovering periods because of disability or other limitations, such as old age.

9. Evaluation of the implementation process

In order to correctly judge the measures taken on a regular basis, an annual structured evaluation is needed. This may well lead to a renewed formulation of goals and steps.

Mainstreaming as a positive challenge

Targeted work on disability and/or HIV/AIDS is valuable and has to keep on existing in addition to mainstreaming.

- Impose mainstreaming once again as an additional requirement, which an organization has to fulfil. After all, mainstreaming cannot be dictated from outside, but has to grow up within your organization. It is a gradual process in which we must first learn from our own positive experiences and mistakes.

- Bring disability and/or HIV/AIDS forward as the only theme to which mainstreaming can be applied, to the detriment of other themes. We would however, like to indicate that mainstreaming is suitable for the various group of diversity issues that we find in all organizations. This brochure dealt with the mainstreaming of disability and AIDS, but we can also mainstream other things, e.g. gender or age. It is important not to see these different 'branches' as competitors, but rather as fields that can complement each other in the management of a diversity that is as wide and inclusive as possible
- Diversity within an organisation is a first step towards promoting diversity within activities and programmes. In order to have a greater impact and to make a difference in the life of disabled people, actions can be taken within the whole community to promote the inclusion of people with disability.

REFERENCE:

1. Groce, N. E., & Trasi, R. (2004). Rape of individuals with disability: AIDS and the folk belief of virgin cleansing. *Lancet*, 363 (9442), 1663-1664. Health and Disability Working Group. (2004). *HIV/AIDS and people with disabilities*. Boston: School of Public Health, Boston University
2. Kelly, K., Ntlabati, R, Oyosi, S., Van der Riet, M., & Parker, W. (2002). *Making HIV/AIDS our problem: Young people and the development challenge in South Africa*. Grahamstown, South Africa: Centre for AIDS Development, Research and Evaluation
3. World Health Organization. (2002). *The world health report 2001: Mental health: New understanding, new hope*. Geneva: Author
4. Yousafzai, A. K., Dlamini, P. J., Groce, N., & Wirz, S. (2004). Knowledge, personal risk and experiences of HIV/AIDS among people with disabilities in Swaziland. *International Journal of Rehabilitation Research*, 27,247-251.
5. John H. Philander and Leslie Swartz needs, barriers, and concerns regarding HIV prevention among south Africans with visual impairments: a key informant study
6. Nganzi Patrick, George Matonhodze. Disability and HIV & AIDS; A participatory rapid assessment of the vulnerability, impact, and coping mechanisms of the disabled people on HIV/AIDS. Commissioned by; Zimbabwe Parents of Handicapped children (ZPHCA), Bulawayo Branch
7. Jewkes R, Levin J, Mbananga N, Bradshaw D. Rape of girls in South Africa. *Lancet* 2002
8. National federation of people with disabilities in Namibia HIV & AIDS programme
9. World Bank, Disability and HIV/AIDS at a glance, November, 2004
10. Nora Groce, Rape of individuals with disability: AIDS and the folk belief of virgin cleansing
11. Jewkes R, Martin L, Loveday P. The virgin cleansing myth: cases of child rape are not exotic. *Lancet* 2002
12. Nora Groce, HIV/AIDS and people with disabilities, *Lancet* 2003
13. Platform Disability and Development Cooperation, Mainstreaming of disability and HIV/AIDS, A double challenge
14. The World Bank/Yale University, HIV and AIDS Capturing Hidden Voices, Global Survey on HIV/AIDS and Disability, April 2004.

1. UNAIDS. Report on the global HIV/AIDS epidemic 2002. Joint UN Programme on HIV/AIDS, 2002.
2. Nosek, MA; Howland, CA; and Hughes, RB. "The investigation of abuse and women with disabilities: going beyond assumptions." *Violence Against Women* 2001; 7: 477–99.
3. UNICEF, Global survey of adolescents with disability: an overview of young people living with disabilities: their needs and their rights. New York: UNICEF Inter-Divisional Working Group on Young People, Programme Division, 1999.
4. AHRTAG and CBR, AIDS Action, The International Newsletter on AIDS prevention and care, 1997.
5. Gaskins S., Special population: HIV/AIDS among the deaf and hard of hearing. *J Assoc Nurses AIDS Care* 1999; 35: 75–78.
6. FHI, Comprehensive HIV/AIDS Prevention, Care and Support Programming, January 2003
7. FHI, Research Briefs on the Female Condom – No. 2, Effectiveness for Preventing Pregnancy and Sexually Transmitted Infections, 2001
8. FHI, Care for Orphans, Children Affected By HIV/AIDS and Other Vulnerable Children, a Strategic Frame Work, 2001.
9. J. Peinkofer, HIV Education for the Deaf, *Public Health Reports* 109/3 (1994): pp. 390-396.
10. Nora Groce and Reshma Trasi, Rape of individuals with disability: AIDS and the folk belief of virgin cleansing, 2004.
11. UNAIDS and WHO, 2007 AIDS epidemic update, 2007.
12. L. Li and J. Ford, "Illicit Drug Use by Women with Disabilities," *American Journal of Drug and Alcohol Abuse* 24/3 (1998): pp. 405-418.
13. Sara Burns and Sally Cupitt, managing outcomes: a guide for homeless organisations, 2003
14. Lisher, D; Richardson, M; Levine, P; and Patrick, D. "Access to primary health care among persons with disabilities in rural areas: a summary of the literature." *Rural J Health* 1996; 12: 45–53.
15. UNICEF. "Global survey of adolescents with disability: an overview of young people living with disabilities: their needs and their rights." New York: UNICEF Inter-Divisional Working Group on Young People, Programme Division, 1999.