

Mainstreaming HIV and AIDS in the work of CBRF concept paper

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New Delhi

Background:

MISEREOR, Germany, the Funding Partner of CBRF, promotes mainstreaming of HIV and AIDS through their partner agencies as a cross cutting issue throughout the world. **Misereor requested CBRF to consider mainstreaming HIV/AIDS in its work with NGO Partners.**

Ms. Ellen Schmitt representative of MISEREOR met the CBRF staff for two days in March 2011 and gave an input session on the subject and CBRF staff were convinced about the importance of the issue. Subsequently, during her visit to Bangalore in March 2012 she visited CBRF to check on progress made in this regard. She was briefed on work that had commenced in some of the partner projects. Possibilities of increasing Partner NGO involvement in mainstreaming HIV/AIDS were considered. It was suggested that a 'Concept note' on mainstreaming HIV and AIDS in CBRF's work be prepared by the Secretariat. It was also proposed that this note be discussed in the **Strategic Planning Meeting** to be held in Bangalore from May 7-9, 2012 and later at the **Board meeting** of CBRF to be held on 10 May 2012 in view of taking a final call on the subject.

At the Board Meeting on 10 May 2012, the decision was taken to Mainstream HIV and AIDS in the work of CBR Forum with persons with disability.

1. General Perspectives:

The growing relationship between HIV/AIDS and disability is an emerging issue and cause for concern as persons with disabilities are at risk of exposure to HIV. Additionally, there is a growing understanding that persons living with HIV or AIDS are also at risk of becoming disabled on a permanent or episodic basis as a result of their condition.

Like any other person, **persons with disabilities require information on HIV/AIDS and access to programmes, services, and resources.** The situation of persons with disabilities is further compounded by **societal barriers that hinder their full and effective participation in society, including access to education.** Despite the relationship between HIV/AIDS and disability, persons with disabilities have not received sufficient attention within national responses to HIV and AIDS. Furthermore, existing HIV prevention, treatment, care and support programmes generally fail to meet their specific needs. Persons with disabilities are often excluded from HIV education, prevention and support services because of assumptions that they are not sexually active or do not engage in other risk behaviours such as drug use.

Sexual and reproductive health service providers may lack knowledge about disability issues, or have misinformed or stigmatizing attitudes towards persons with disabilities. Services offered at clinics, hospitals and in other locations may be physically



inaccessible, lack sign language facilities or fail to provide information in alternative formats such as Braille, audio or plain language. In places where there is limited access to medication, persons with disabilities may be considered a low priority for treatment.

Low literacy levels make it all the more difficult for persons with disabilities to acquire the knowledge they need to protect themselves from being infected.

Women and girls with disabilities are especially vulnerable to sexual assault or abuse. They might also be married off to persons living with HIV as it is not easy to get grooms for them. **Persons with intellectual impairments and those in specialized institutions are also at risk.**

Persons with disabilities are seldom recognized as a group to be included in the national response to HIV/AIDS. Integrating their specific needs is a crucial component to mitigate the worsening condition of persons with disabilities. **The failure to understand and provide essential information to persons with disabilities concerning HIV/AIDS, results in their increasing marginalization.** Work on HIV/AIDS issues at all levels, local, national, regional and global levels, should consider the rights and needs of persons with disabilities through the design of legislation, funding structures, policies and programmes. HIV/AIDS professionals and advocates can help create a dialogue with and within the disability community to foster more open discussion of HIV/AIDS issues.

The Convention on the Rights of Persons with Disabilities provides a global policy framework to promote the equal rights to health for persons with disabilities, including sexual and reproductive health, on par with those without disabilities, and provides stimulus for other policies to include AIDS programming for persons with disabilities and programmes to fight against stigma, discrimination and other barriers faced by persons living with HIV/AIDS.

2. Indian Context:

In 2009 it has been estimated that 2.39 million people were living with HIV in India and the adult prevalence rate was pegged at 0.31 percent in the age group 15 to 49. Women of 15 years and older counted for 39 percent of the people living with the virus and 3.5 percent were children.¹ This means that there are more men HIV-positive than women. High-risk groups (transgenders, injecting drug users, men having sex with men, female sex workers, truckers, migrants) show higher HIV prevalence than the general population. There is no data available on people with disabilities who are living with HIV. However, there is no doubt that they are particularly vulnerable to HIV infection and to the effects of HIV and AIDS.

¹ NACO: Annual Report 2010-11, p. 4.



On one hand, the decline in the overall HIV prevalence in India in the last years is encouraging. On the other hand, the rise in HIV prevalence in some parts of the country (Chhattisgarh, Gujarat, Jharkhand, Odisha, Assam, etc.) is an alarming sign. National figures are not enough; the context of the local HIV situation has to be considered, too.²

3. NACO and SACS:

National AIDS Control Organization under the Ministry of Health and Family Welfare, Government of India provides leadership to the HIV/AIDS Control Programme in India. State AIDS Prevention and Control Societies (SACS) implement NACO programmes at state level.

4. Role of NGOs in addressing the issue of HIV and AIDS:

NGOs and civil society organizations have made significant contribution in reaching out HIV prevention and care services to the highly vulnerable population groups. There are numerous NGOs/CBOs working on HIV/AIDS at the local, state and national levels. The National AIDS Control Programme recognises the importance of their participation, particularly in:

- preventive or targeted interventions for high risk groups,
- care and support of people living with HIV/AIDS and
- general awareness campaigns.

5. Meaning of Mainstreaming HIV/AIDS in CBR.

“Mainstreaming AIDS is a process that enables development actors to address the causes and effects of AIDS in an effective and sustained manner, through both their usual work and within their workplace.”³

HIV/AIDS mainstreaming means that an organization should address the root causes of HIV infection and the effects of HIV and AIDS in areas that fall into its competence and mandate.⁴

² NACO: HIV Sentinel Surveillance 2010-11. A Technical Brief, p. 17

³ UNAIDS/UNDP/World Bank. 2005. Mainstreaming AIDS in development: Instruments and processes at the national level. A review of experiences. UNAIDS, Geneva.

⁴ Misereor. 2011. Responding to HIV and AIDS. A practitioner’s Guide to Mainstreaming in Development Projects. Misereor, Aachen.



Root causes and effects: What makes people with disabilities vulnerable to HIV infection and what are the effects of HIV and AIDS on people with disabilities?

HIV and AIDS among Persons with Disabilities	
Root Causes	Effects
<p>Physical causes:</p> <ul style="list-style-type: none"> • Disability and the lack of vision, speech, mobility, mental health etc. • Severity of disability that may hinder one from absorbing the information • Increased dependency on others (issues cannot be discussed freely with a resource person if accompanied by someone of the family - also possibility of abuse by them) • Over protection or disowned and abandoned by the family. • Lack of ability for self-protection and self exploration. • Vulnerability to physical, sexual and mental abuse at home. <p>Social causes:</p> <ul style="list-style-type: none"> • Institutionalization (PWDs stay in hostels and may experience abuse). Even within homes, in a controlled atmosphere. • Lack of participation in decision making. • Less opportunities for education particularly sexuality education. • Discussion on sexuality considered as taboo for PWDs, more for women and girls. • Denial of marriage. • Vulnerability to sexual abuse, Sexual harassment, rape of WWDs and forceful sex. • Peer pressure for experimentation. <p>Economic causes:</p> <ul style="list-style-type: none"> • Lack of livelihood opportunities. • Economic dependency. • Absence of earning capacity. • Poverty and no control over resources. • Exploitation at workplace and sexual abuse, Sexual harassment, forceful sex etc. • Sex for survival, employment, etc. <p>Political causes:</p> <ul style="list-style-type: none"> • No policies and programmes to specifically address the issue among PWDs. • Less capacity among service providers to deal with issues of PLHIV who are also PWDs. • Lack of access to proper services such as counseling, medication etc. • Contaminated blood transfusion. 	<p>Social Effects:</p> <ul style="list-style-type: none"> • Broken families (because of HIV infection). • Increase in the number of infected persons. • Social stigma and discrimination. • Social exclusion. <p>Effect on Livelihood:</p> <ul style="list-style-type: none"> • Lack of job opportunities for people living with HIV. • Economic dependency. • Reduced income and increased poverty. <p>Social pressure and lack of social protection:</p> <ul style="list-style-type: none"> • Denial of marriage (difficulty to find a partner if PWDs are infected or affected). • Absence of equal participation. • Discrimination in the family and community. • Lack of acceptance. <p>Systemic Effects:</p> <ul style="list-style-type: none"> • Excluded by service providers. • HIV Counselors not prepared to counsel PWDs who may need specific counseling. <p>Effects on the Individual:</p> <ul style="list-style-type: none"> • Increased expenses for medication. • Marginalization. • Individual dignity at stake. • Violation of human rights. • Children with disabilities excluded in the schools – situation is worse if CWDs are HIV positive. • Triple/ Four times vulnerable – disability, women, HIV infection, tribal background. <p>Psychological effects:</p> <ul style="list-style-type: none"> • Loose interest in life. • Suicidal tendencies. • Death. • Fear of meeting people.



6. Need to have HIV/AIDS as a crossing cutting issue in the work of CBRF:

HIV can lead to disability (e.g. immobilization) and disability can lead to HIV (due to risk factors). Efforts should be limited to CBR target groups (PWDs and family members).

The above mentioned causes such as **lack of information, sexually abusive behavior, poverty, and other factors of vulnerability** are some of the causes for spread of HIV amongst the PwDs. In case PwDs are found to be HIV positive their quality of life will deteriorate. Hence there is need to address HIV/AIDS in the CBR programmes for PwDs as a cross cutting issue.

Some suggestions to take this forward:

1. **Awareness** can be the first step, but this requires trust, knowledge, positive attitude and ability to find solutions and to access the appropriate services.
2. All staff should be **trained on vulnerabilities of PwDs to HIV** particularly women and girls. Women with disabilities do not have their personal space to voice their concerns/personal feelings and such issues need to be looked into.
3. Partners should **recruit male and female workers** in equal numbers as staff who are sensitized and are sensitive towards persons infected and affected by HIV such as the need to maintain confidentiality at all times.
4. Partners and staff should be **sensitive about the language used** when addressing issues related to HIV and AIDS and sexuality. The language and expressions should be appropriate to the context (e.g. if needed separate groups of women and men, use of local language, etc.), age group and the ability of people to understand (e.g. difference in level of understanding between mentally disturbed and physically disabled people).
5. **Trained and sensitized staff should always be present when sexuality issues are discussed** in the DPOs or in other meetings and interactions.
6. **Human Resource Development/ Training:** Review existing curriculum and ensure that the session on HIV and AIDS is adequately covered in the training curriculum of the 3 authorized Training Centres – ADD India, Bethany Society and Sanchar AROD.



7. **Health Promotion:** With the help of the above resources – when appropriate (when the DPO group / community is ready for it) include sessions on HIV and AIDS during the health promotion programmes for DPOs and Community.
8. **Prioritize:** Begin the mainstreaming of HIV and AIDS with the partners who are already engaged in HIV and AIDS programmes – these partners have both, programmes for PWDs and programmes on HIV/AIDS. This is the easiest way for CBRF to gain experience and expertise in HIV/AIDS mainstreaming and will assist CBRF for mainstreaming HIV/AIDS later with partners not directly involved in HIV/AIDS.
9. **Advocacy:** After the DPOs are sensitized about the issues around HIV and AIDS – include the issues affecting persons with HIV and AIDS in the Advocacy Plans of the DPOs.
10. **Networking:** CBRF networks with resource agencies such as CHAKA (Catholic health Association of Karnataka), INSA, Action Aid etc. – to identify and catalogue resources available in different regional languages and in accessible forms (such as audio tapes, braille, videos with sign language, etc.) and Resource Persons in different states of India – who could support the partner NGOs of CBRF.
11. **Future Plan for Expansion:** Arrive at an alternate strategy in mainstreaming HIV and AIDS in the programs of those partner NGOs who have not worked in the areas of HIV and AIDS until now. E.g. older partners may have sessions on HIV/AIDS during partner meetings.
12. **Systemic change:** CBRF to network with NACO and SACS in view of bringing about systemic change and promoting inclusion of PWDs and their needs in their programs. CBRF in association with its partners to organise a National Workshop on PWDs and HIV and AIDS as part of advocacy with the State.

References:

1. NACO: Annual Report 2010-11,
2. NACO: HIV Sentinel Surveillance 2010-11. A Technical Brief.
3. UNAIDS/UNDP/World Bank. 2005. Mainstreaming AIDS in development: Instruments and processes at the national level. A review of experiences. UNAIDS, Geneva.
4. Misereor. 2011. Responding to HIV and AIDS A practitioner's Guide to Mainstreaming in Development Projects. Misereor, Aachen.
5. Report of the workshop on mainstreaming HIV and AIDS in CBR – March 2011.
6. A report on review of status of HIV/AIDS mainstreaming in the work of CBRF by Ms Ellen Schmitt of MISEREOR March 2012.
7. United Nations Enable – an official website of the Secretariat for the Convention on the Rights of Persons with Disabilities (SCRPD).

