

# India's AIDS response: the missing voices of persons with disabilities

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#### Abstract

India has the third largest number of people living with HIV in the world. The UNAIDS Gap report has identified twelve risk groups that are especially vulnerable and have been left behind from the national AIDS response. Of these twelve, one is persons with disabilities. Disability is both a public health issue and a human rights issue; persons with disabilities are the world's largest minority. Low awareness, sexual abuse, and lack of access to health services are the major reasons for people with disabilities being vulnerable. While the gap report is a landmark report, in that it compartmentalizes the risk groups, disability cannot be looked at in isolation. Since any of the other risk groups may include persons with disabilities, the issue is a complex one meriting greater attention. The National AIDS Control Organization has completely ignored this group of persons. To efficiently close the gap, an integrated and disability-inclusive HIV response is needed so that people with different types of disabilities, their caretakers, healthcare professionals and society are empowered to fight the collective battle against HIV/AIDS.

Keywords: Blind; Deaf; Persons with disabilities; Health services accessibility; HIV/AIDS Programming; HIV infections; Sex factors; Vulnerable population

### Introduction

than a billion makes persons with disabilities opportunistic the world's largest minority. People living numbers, though limited,

with HIV may develop impairments and The World Report on Disability states that further add to disability.[2] It is estimated one in seven people globally experience some that between 10% and 20% of people living form of disability.[1] This number of more with HIV can lose vision as a result of infection.[3] Actual point to HIV

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prevalence among disabled persons to be equal to their non-disabled counterparts, as in the case of the Deaf (see footnote a) community.[4] However, the literature on disability and HIV/AIDS in the decade 2000-2010 averages a mere 6 articles per year in peer-reviewed journals.[5] Persons with disabilities experience negative attitudes that can result in violence, sexual abuse, stigma and discrimination.[6] Ignoring them in HIV response programs puts them in an even more vulnerable position. Urgent intervention is warranted.

The Indian scenario: frightening figures

The latest UNAIDS Gap report estimates that India has the third largest number of people living with HIV in the world – 2.1 million at the end of 2013 – accounting for about 4 out of 10 people living with HIV in the region.[7] This was after Government of India scaled up access to HIV treatment, putting up more than 700,000 people on anti-retroviral therapy – the second largest number of people on treatment in any single country. Despite this, the proportion of people who do not have access to treatment in India is 64%

[55–72%].[7] Of all AIDS-related deaths in the Asian region, 51% occur in our country.[7]

Why persons with disabilities are at risk for HIV exposure

Persons with disabilities are the world's largest minority.[1] Though the UNAIDS Gap report identifies them as one of twelve social groups that are vulnerable and at risk, and in danger of being left behind (Fig 1[7]), people with disabilities might also be found in any of the other groups as well.

A 2007 research study in India interviewed 521 people with disabilities from 14 states.[8] Aptly titled, 'Too few to worry about? Or too many to ignore' the research highlighted for the first time voices of persons with disabilities who themselves identified risk factors for HIV exposure as follows:

#### 1. HIV risk behaviors

Persons with disabilities do the same things as everyone else. It is a false assumption that they are asexual, unlikely to use drugs or alcohol, and at less risk of violence and rape than non-disabled peers.[8] They are equally prone to high risk behaviors like multiple

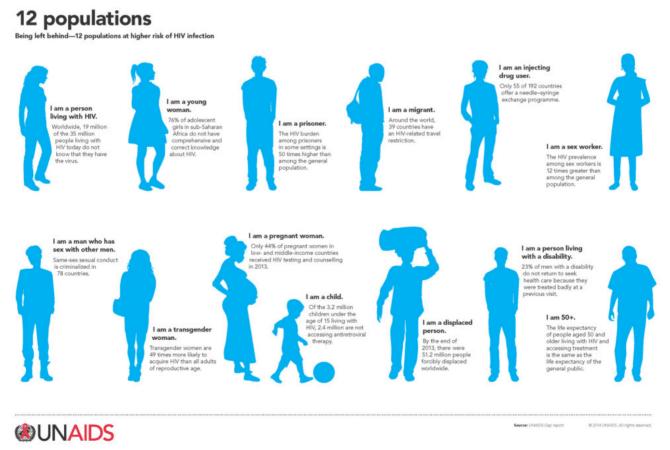


Figure 1. Vulnerable and risk groups according to the UNAIDS Gap report [Credit: UNAIDS/ONUSIDA 2014]

partners, visiting sex workers or injecting drugs. Α Chennai non-governmental organisation observed that many blind men engage in premarital sex since they settle later in life and marry late.[8] Instances of homosexual behavior were reported among people residential living in schools.[8],[9] Many people with leprosy live in their own communities and because of stigma, their sexual partners are often limited to other people with leprosy. In such a closed environment, infections quickly spread and prevalence can become higher.

## 2. Low awareness of HIV among persons with disabilities

The 2007 survey had a strong rural focus but the fact that one-fifth of people interviewed had never heard of HIV is a cause for great concern.[8] Deaf people were found to have very low levels of body literacy, so much so that a few young Deaf women had no idea that having sex could lead to pregnancy, which they instead thought was caused by eating certain foods or tying a mangalsutra (a piece of jewelry worn by women that symbolizes Hindu marriage).[8] The high prevalence state of Manipur has people with disabilities among both the categories of injectible drug users and men having sex with other men. However, a research studying awareness of HIV in North East that none of the participants revealed mentioned male-male sex as risk factor for HIV transmission.[9]

#### 3. Social skill deficit[8]

with mental or developmental disabilities generally lack the ability to develop the social skills to recognize predatory behavior and avoid vulnerable situations. Similarly, wheelchair users are isolated in homes and restricted communicating with society. Mental illness is often associated with destitution so street rapes are common; the fact that such persons are unmindful of their dress/behavior and temporary amnesia makes them particularly vulnerable.

#### 4. Sexual Abuse

Having a disability doubles an individual's likelihood of being assaulted.[10] Women with disabilities tend to be more vulnerable to sexual harassment, and exploitation in the workplace.[11] The rate of abuse of children with disabilities is more than that of non-disabled in many countries.[12] Sexual violence against disabled girls and women occurs at alarming rates within families, in institutions, and throughout society. Persons with disabilities are dependent upon a

number of people for daily assistance. For this reason, their family is understood to include not only parents and spouse but also friends, neighbours and relatives. The large number of people involved in their care, and the intimate physical and emotional contact they provide greatly increases the risk of abuse to women with disabilities.[13] Often the abuse is by a relative or caregiver on whom the girl is dependent.[12]

In a study conducted in 2005 on women with disabilities in 12 districts of Odisha, 13% with physical disability and 25% of those with mental disability reported having been raped. In these areas, 20% women with physical disability and 22% with mental disability were forced into sex or raped by family members.[13] Inability to communicate and therefore to protest and complain makes Deaf women, people with intellectual impairments, learning disabilities developmental delay particularly vulnerable sexual abuse and exploitation. Also, women with mental illness are less likely to be believed. The Odisha survey also revealed that only 19% use toilets which expose them to a threatened environment for sexual abuse.[13]

A look at the past 6 months reveals the extent of sexual abuse among all types of persons with disabilities in India. A girl with a psychosocial disability was raped on several occasions and impregnated by a family member;[14] another was brutally beaten and gang raped inside an orchard.[15] A woman with visual loss in Pilibhit was gagged and raped by her husband's friend whom she identified by his voice.[16] A 20-year-old girl with visual impairment was raped by her two neighbours.[17] A Deaf woman was raped on the way to a shelter home after a court hearing in August;[18] another was raped inside the building in June.[19]Parents who see no hope of jobs or marriage for their disabled children may place those children in exploitative situations with the intent of shedding a "burden" or seeking income. A Mumbai study revealed that episodes of sexual violence often went unreported, either because parents disregarded them or because they held their daughters responsible.[20] Sexual harassment by strangers occurred in public spaces, trains, buses and hospitals. Such events are not restricted to Mumbai alone; an incident was recently reported in the waiting area of a Delhi hospital.[21]

5. Notion of 'safe' option since persons with disabilities are assumed to be asexual The extent of disability is directly

proportional to the assumption of asexuality;[22] this increases the risk of sex trafficking for women and children with disabilities. The Global survey conducted by the World Bank and Yale University showed that women with disabilities were assumed to be virgins and thus targeted for forced sex, including by HIV-positive individuals who believed that having sex with a virgin would cure them.[23]

6. Lack of access to health care services Globally, persons with disabilities are among the most under-served people in terms of access to health care services.[24] Most of the medical institutions in India are not accessible. Not only is there a lack of physical access, but also lack of information, and attitudinal barriers. A petition through the Court of Chief Commissioner for Persons with Disabilities forced the Medical Council of India (MCI) to pass a directive to all medical institutions in India to be disabled friendly.[25] Only about 14% of the Institutions responded, showing their lack of social accountability [MCI. Information sought under the provisions of RTI Act, 2005. No.MCI-34(1)/2014-(RTI)Med/120220 dated 17 July 2014]; however, neither did the MCI incorporate the mandatory 'access audits' during MCI inspections, nor did it take action against colleges not submitting a compliance report.[26] The MCI has not passed any direction on making websites accessible, on including sign language interpreters, or on making Physical Medicine and Rehabilitation departments mandatory.[27] Verv service care providers are untrained on how to accommodate persons with disabilities through Braille, sign language interpreters, and by providing physical access.

Another right to information query revealed that none of the Anti Retroviral Treatment (ART) centres in Delhi has sign language facilities or information available in alternate formats [NACO. Information sought under the of RTI 2005. provisions Act, 11020/73/2010-NACO (ART) dated 15 Dec 2014]. Disability education is still not part of the medical curriculum. Social discrimination people with leprosy participation in public information campaigns. There is also lack of approval from families to participate in such programs because of low awareness.[9]

The missing voices in India
The National AIDS Control Organization
(NACO) is the nodal agency in India to
formulate policy and implement HIV/AIDS

prevention programs. The fourth phase of the National AIDS Control Programme (NACP-IV) 2012–2017 was launched with the key intensify strategy to and consolidate prevention services with a focus on high risk groups and vulnerable populations. Sadly, NACP-IV does not have any working group on disability. The NACO annual report of 2013-14 does not feature a single word with 'disability' or 'persons with disabilities'.[28] Disability is also not mentioned in the HIV/AIDS (Prevention & Control) Bill 2014 as introduced in the Rajya Sabha earlier this vear. To scale up the response, AIDS Control Department of memorandum of understanding with eight Departments/Ministries; however, the Ministry Social justice and Empowerment/ Department of Disability Affairs was left out.[28]

If we look at the capital of India, none of the nine ART centres have an accessible website for persons with disabilities. Despite ratification of United Nations Convention on the Rights of Persons with Disabilities [UN CRPD] [29] and guidelines from Web Content Accessibility Guidelines (WCAG 2.0AA), even the website of NACO (www.naco.gov.in) continues to remain inaccessible to persons with disabilities in general, and people with visual impairment, print impairment or hearing impairment, in particular. The exclusion goes beyond India as the very useful HIV and AIDS Data Hub for Asia-Pacific does not include data on persons with disabilities as a vulnerable population.[30]

In the first report of its kind, the UNAIDS Gap report identifies 12 populations at higher risk of HIV and emphasizes covering these to close the gap.[7] Table I shows the key population (which includes persons with disabilities) in comparison with key risk groups under NACO (which excludes persons with disabilities). Neither HIV nor disability organisations currently address the risks, needs, and preferences of persons with disabilities.[9]

Conclusion: How to close the gap

1. Include persons with disabilities in HIV response: "Nothing about us, without us" – the global disability rights mantra applies here too. Persons with disabilities living with HIV, and doctors with disabilities, must be included in the National HIV response. They should be involved in the planning, implementation and evaluation of HIV programmes.[31]

Table I - Comparison of Key risk groups in the UNAIDS Gap report[7] and those denoted by NACO[28]

PEOPLE IDENTIFIED AS	KEY RISK GROUPS COVERED UNDER 'TARGETED	
LEFT BEHIND, IN UN GAP	INTERVENTIONS' OF NACO	
REPORT 2014	Core High Risk Groups	Bridge Populations
1) People living with HIV		
2) Sex workers	1) Female Sex Workers	
3) Gay men and other men	2) Men who have Sex with	
	Men	
4) Transgender people	3) Transgenders/Hijras	
5) People who inject drugs	4 )Injecting Drug Users	
or reopic who inject drugs	H / mjeeting Drug Osers	
6) Migrants		1) High-Risk Migrants
7) People with disabilities		
8) Adolescent girls and young		
women		
9) Displaced persons		2) Long Distance Truckers
10) Children and pregnant		
women living with HIV		
11) Prisoners		
12) People aged 50 years and		
older		

- 2. Ending violence and sexual abuse: India has ratified the UNCRPD and the government must develop appropriate programs to prevent violence and sexual abuse of persons with disabilities. Settings, like specialized institutions, schools or hospitals, which place persons with disabilities at greatest risk, should be targeted first. Campaigns around violence, and laws protecting women/children from it, should be geared towards ending this menace.
- 3. Access to sexual and reproductive health (SRH) services: All the information should be available in 'accessible' ways to include mobility impaired, blind, Deaf, and psychosocially disabled. Human rights guarantee full sexual and reproductive rights; the Persons with Disabilities Act, 1995 and Article 25 of the UNCRPD also reinforce the
- commitment. The Indian Council of Medical Research provides funding for research on strengthening linkages between SRH and HIV/AIDS [34] Adding disabilities into the linkage might gather evidence that is more valid.
- 4. Data collection: Efforts should be made to estimate the prevalence of HIV among persons with disabilities. A realistic estimate will permit targeted and continuous supply of resources. When including disability questions in the existing surveys, care should be taken to use impairment-specific and disaggregated indicators. Additional data should collected on determinants so as to link disability with Sustainable Development Goals.[33]
- 5. Bridge the gap between disability and HIV sector: The Chief Commissioner for Persons

with Disabilities should be part of the National AIDS committee. Similarly, there should be engagement between State AIDS Prevention and Control Societies and State Commissioners for Persons with Disabilities. must be part of disability rights strategies. The international observances on December (World **AIDS** Day), 3rd December (International Day of Persons with Disabilities) and 10th December (Human Rights Day) should act as a bridge to create awareness in collaboration and in unison.

Medical humanities in the medical curriculum: Both disability and HIV/AIDS are extremely sensitive topics which need to be dealt with with more compassion. Health care break professionals often rather than communicate the bad news of HIV positive

Sadly, Indian doctors have status. exposure to medical humanities and disability studies are not part of the medical curriculum. The World Report on Disability itself states that globally physicians lack persons training handling on disabilities,[1] and India is no exception. Highlighting the lacuna, the current case in National Human Rights Commission against the Medical Council of India on disability curriculum inclusive becomes important in this regard.[36] Cultural taboos still limit the free discussion of sexual issues in our society; sexuality education should be more inclusive and open.

The elimination of HIV transmission will not be achieved till the missing voices of persons with disability are heard.

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Footnote a: Advocates of deafness as a culture distinguish culture by using the capital "D" whereas the lower case "d" signifies deafness as pathology. Major organizations representing Deaf people (National Association of the Deaf and the World Federation of the Deaf) find this as an acceptable and proper term to use when discussing Deaf people. The author being himself a person with disability has used 'D' to respect Deaf culture.