



**DISCUSSION  
BRIEF**

# From Awareness to Knowledge: Scaling Up Interactive Channels of Communication for HIV Prevention and Stigma Reduction in Uttar Pradesh

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Stigma is a common human reaction to disease.<sup>1</sup> It is heightened in the context of diseases about which people have little or incomplete knowledge and leads to discrimination. In the case of HIV and AIDS, the association with sex and sexuality further complicates the situation, especially in a society, such as India, where sex is a taboo topic. The fear of stigma deters men and women from seeking testing, treatment, and care services. This negatively affects HIV prevention efforts, in addition to causing human misery.

A primary and essential step toward preventing the spread of HIV and reducing stigma and discrimination is to promote comprehensive knowledge about HIV and AIDS. The 2005/06 National Family Health Survey, Phase 3 (NFHS-3), defines the key components of comprehensive knowledge as: 1) knowing that both condom use and limiting sex partners to one uninfected faithful partner are HIV prevention methods; 2) being aware that HIV status cannot be determined based on a person's appearance; and 3) rejecting the two most common misconceptions about HIV transmission in India—that HIV can be transmitted through mosquito bites and by sharing food.

The 2005/06 NFHS-3 report states that “low comprehensive awareness among women and men requires a strategic change in awareness programs.”<sup>2</sup> Although comprehensive knowledge may not be enough to reduce stigma and discrimination, it is a crucial basic ingredient of any such efforts.

This discussion brief outlines the importance of comprehensive knowledge for reducing stigma; examines the communication approaches and channels that can contribute to improved knowledge

and reduced stigma; analyzes the experiences in the state of Uttar Pradesh (UP); and explores possible solutions and inherent challenges to improving HIV knowledge, with the objective of generating dialogue and identifying suitable solutions.

## The Situation in Uttar Pradesh

According to the NFHS-3 data, only 16 percent of women (n=12,183) and 30 percent of men (n=10,902) in UP have comprehensive knowledge of HIV prevention and transmission.<sup>3</sup> In comparison, 45 percent of women and 78 percent of men have “heard of HIV/AIDS” in the state.<sup>4</sup>

Awareness is necessary, but not a sufficient condition for behavior change related to prevention, stigma, and discrimination. Nevertheless, mass media have played an important role in making people aware of HIV/AIDS, with TV rated as the most popular media for awareness generation. Of the 95 percent of men (n=11,458) and 72 percent of women (n= 12,183) in UP who have exposure to mass media, 80 percent of men and 59 percent of women have heard of HIV/AIDS. Further analysis shows that of the women who were exposed to mass media and had heard of HIV/AIDS, 50 percent had heard it from radio and 81 percent from TV—thus, largely through non-interactive communication channels.

Behavior change is, however, a complex process, “[it] needs a trigger, motivation, benefit, a skill to be learned, identifies personal and social/cultural barriers and facilitates to overcome them, the ability to act and can happen in a supportive and enabling

environment.”<sup>5</sup> This is especially true in communication for health and more so with behaviors related to HIV. Therefore, knowledge about HIV and AIDS communicated through mass media channels must be reinforced and expanded upon through interpersonal dialogue to help translate into behavior change, whether for HIV prevention or stigma reduction.

### Current State Response under NACP III

The National AIDS Control Program (NACP) III approach for reaching high-risk groups (HRGs) and raising awareness at the community level includes undertaking communication programs to encourage social normative changes aimed at reducing stigma and discrimination. Additionally, the National AIDS Control Organization (NACO) proposes to mobilize a cadre of 8,200 link workers and 187,000 volunteers to reach women and young people in 187,000 villages (and tribal areas) of 187 districts across the country with behavior change communication (BCC), condom provision, and improved linkages to health services. NACO also aims to reach a rural population of 280 million people with HIV information through mass media.<sup>6</sup>

In UP, the Link Workers Scheme is being implemented in seven districts<sup>7</sup> covering the 100 villages most affected by HIV, out of the more than 97,000 villages in the state. Each selected district will have 20 male and 20 female link workers. These 280 link workers are expected to reach out to the vulnerable populations in rural areas.

Interpersonal communication (IPC) and BCC are included in targeted interventions (TIs) for HRGs, which is a positive step in meeting their needs. However, the general population is being covered largely through mass media campaigns and hoardings, which are largely not interactive in nature. By the end of 2008, the UP State AIDS Control Society (UPSACS) had rolled out 91 TIs, the highest in the country for any one state.<sup>8</sup> Together these TIs are designed to reach about 23,600 sex workers, 12,000 men who have sex with men (MSM), and 11,700 injecting drug users (IDUs) across the state. Information, education, and communication (IEC) activities are planned for the rest of the state to raise awareness as well as promote demand for services. Thirty districts identified as most vulnerable have been prioritized in the IEC action plan. Media campaigns include closed circuit TV at railway stations, spots and talk

shows on All India radio (AIR)/private channels, slide shows in cinema halls, 7–8 hoardings per district, and observation of special events/national awareness days. UPSACS programs aim to reach rural and semi-urban populations through IEC vans in 10,000 villages (in the five category A districts<sup>9</sup> and 10 other priority districts). On average, 950 villages and 50 slums are expected to be covered in each category A district; and 450 villages and 50 slums will be covered in each of the other priority districts. Red Ribbon Clubs and school-based education programs are also proposed.

Mainstreaming and convergence are being supported by different government programs to achieve optimal results from existing systems. For example, NACO and the state AIDS control societies are partnering with the Ministry/Department of Social Justice, Women and Child, and other health sector programs—such as Reproductive and Child Health (RCH) program, National Rural Health Mission (NRHM), and Revised National Tuberculosis Control Program (RNTCP)—to maximize outreach. These initiatives are largely at a nascent stage in UP.

The IEC strategy of NACP III is informed by learnings from NACP I and II (see the box below).

*According to the national IEC/BCC strategic framework document of NACO (2004),<sup>10</sup> reviews and studies of IEC activities under NACP I and II reveal challenges related to the impact of IEC. These include, among others, the following:*

- *Mass media campaigns on HIV/AIDS were not adequately complemented by interpersonal communication and community involvement.*
- *The advocacy activities and other events like World AIDS Day have largely remained reactive and isolated activities.*
- *There is a need to sharpen strategy and respond to the strategic and specific needs of the audiences.*
- *Activities were concentrated in the same geographic areas, with little expansion and replication of model interventions into other states and departments.*

*The report also notes that the “messaging appears to be tiring out and failing to grab the needed [attention] pointing to the need to not only reinvigorate the basic message of how HIV/AIDS spreads and how it doesn’t but also go beyond the basic message for more effective primary and sustainable behavior change.”*

# Key Issues

**1. Stigma and discrimination have the potential to significantly affect the roll out of NACP III.** A key thrust area of NACP III is scaling up TIs among the HRGs. However, a NACO summary document<sup>11</sup> states that “attitudes towards high-risk behaviors are barriers to achieving the target saturation of High Risk Groups (HRGs).” This concern is also true for Uttar Pradesh. HIV testing and disclosure are hindered by stigma. Prevention efforts are also hampered because using methods such as condoms or discussing safe sex are themselves considered indications of HIV infection or immoral behaviors and are thus stigmatized.<sup>12</sup> Additionally, the stigma that associates HIV with certain HRGs has a dual effect: one, it gives a false sense of security to those who do not consider themselves to be in those groups and, two, it deters people from seeking services lest they be seen as a member of an HRG. For example, a married woman might not seek testing because she fears being associated with sex work.

**2. Peripheral knowledge may actually increase stigma and discrimination.** Awareness of HIV/AIDS may, in the absence of full and accurate knowledge, exacerbate stigma and discrimination. A UNAIDS report notes that “negative responses and attitudes towards PLHIV [people living with HIV] are strongly linked to general levels of knowledge about AIDS and HIV and, in particular, to the causes of AIDS and routes of HIV transmission.”<sup>13</sup> Prevention messages usually outline the routes of transmission. However, three of the four main routes of HIV transmission—heterosexual, unprotected multi-partner sex; injecting drug use and needle sharing; and MSM behavior—are either socially stigmatized and/or legally criminalized. As stigma usually reinforces pre-existing negative assumptions, beliefs, and prejudices, such information has the possibility of increasing levels of stigma and discrimination against PLHIV and HRGs as they are seen as practicing behavior that is deviant and/or criminalized. HIV prevention information must, therefore, be supplemented with education on rights-based approaches and the broader societal factors such as poverty, gender inequality, and marginalization, which increase vulnerability among certain groups. As such information is often complex, it would require interactive modes of communication in addition to general awareness raising.

**3. Stigma occurs largely within the general population settings, but much of the program focus of communication activities is on HRGs.** While TIs are crucial for limiting the spread of the epidemic, it is equally important to educate the general population so as to ensure a supportive and non-stigmatizing environment for HIV prevention, testing, treatment, and care. Cases where PLHIV or their families have been burned or children of PLHIV expelled from schools are typically instigated by community members who have inaccurate knowledge about HIV and are ignorant about the rights of PLHIV.<sup>14</sup> Similar to the witch hunt of the Middle Ages, they portray PLHIV as demons, accusing them of “wrong doing” and insisting that they be punished for contracting HIV.

Given that stigma is one of the biggest impediments to HIV prevention and is practiced in general population settings—be it within hospitals, workplaces, schools, or inside homes—developing comprehensive knowledge within the general population is essential for a successful HIV program.

UPSACS implements large-scale IEC programs and campaigns using mid- and mass media for the general population whereas IPC is limited to the populations covered by TIs, primarily the HRGs. Thus, groups that stigmatize and discriminate against PLHIV and HRGs are not provided comprehensive information that could help change their perceptions and attitudes.

**4. Despite limited and unequal reach, mass media-based programs have helped raise HIV awareness in the state. However, their impact on reducing stigma is limited and should be supplemented by other forms of communication.** TV and radio continue to be the main source of information for the general public. However, HIV communication through mass media has several limitations. First, there are some sections of the community who have little or no exposure to mass media. According to NFHS-3 estimates, 28 percent of women in UP have not been exposed to media. Second, the increase in levels of HIV awareness over the years is not uniform across all populations, especially the vulnerable groups. The illiterate, poor, and members of the scheduled tribes have comparatively lower levels of knowledge or awareness about HIV and AIDS. The percent of people who had heard about AIDS rose dramatically from 20 percent in 1998/99 (NFHS-2) to 70 percent in 2005/06 (NFHS-3). However, certain segments continue to be

disadvantaged. For example, the percentage of women belonging to scheduled tribes who had heard about AIDS increased very marginally (from 17.2% to 17.5%) during the same time period. In comparison, the proportion of women belonging to other (upper) castes who had heard about AIDS increased from 48 percent to 66 percent. Table 1 presents further details on HIV/AIDS awareness and comprehensive knowledge for various subpopulations based on the 2005/06 NFHS-3.

<b>Table 1. HIV/AIDS Awareness and Comprehensive Knowledge in UP, 2005/06</b>				
Background	% who have heard of AIDS		% with comprehensive knowledge about AIDS	
	Women	Men	Women	Men
<b>AGE</b>				
15-24	52.7	85.2	19.2	34.1
25-29	45	82.9	17.5	33.0
30-39	38.6	72.7	13.3	25.5
40-49	35.5	65.6	9.5	22.3
<b>RESIDENCE</b>				
Urban	72.2	90.2	36.6	44.9
Rural	35.8	72.7	8.7	22.8
<b>EDUCATION</b>				
No education	21.6	45.1	3.8	8.1
10 or more years	92.3	98.0	50.2	52.6
<b>REGULAR MEDIA EXPOSURE</b>				
Yes	67.9	86.6	27.8	35.9
No	20.4	50.5	2.9	9.1
<b>MARITAL STATUS</b>				
Never married	63.4	84.5	25.7	36.1
Currently married	40.2	74.9	13.2	26.2
Widow/divorced/separated	35.3	55.4	10.9	12.8
<b>CASTE</b>				
Scheduled caste	33.6	72.2	10.6	24.2
Scheduled tribe	17.5	37.0	1.3	7.8
Others	65.9	87.9	27.6	42.2
<b>WEALTH INDEX</b>				
Lowest	15.4	52.3	2.3	9.9
Highest	87.3	97.0	48.2	58.6

Source: NFHS-3

Finally, mass media have largely served to make people aware of HIV/AIDS, but stigma reduction requires more than basic awareness. This is evident from the fact that, although a larger segment of the society is aware of HIV/AIDS now than 10 years ago, incidents of stigma and discrimination continue.

## A Case for Convergence

Given the complex nature of HIV and AIDS, interactive, interpersonal platforms are most

effective in providing accurate information, clarifying misconceptions, and alleviating fears.

A study among rural women in Tamil Nadu and Maharashtra<sup>15</sup> shows that women who had been visited by family planning workers at least once in the past 12 months had greater odds of HIV/AIDS knowledge, compared to women who had not been visited by family planning workers. Visits by family planning workers were also shown to bring about a significant increase in the knowledge among women on ways to prevent HIV transmission.<sup>16</sup>

*Integrating substantive HIV-related information into the ongoing outreach activities of the service providers (e.g., anganwadi workers [AWWs], health workers, link workers, accredited social health activists [ASHAs], etc.) is a strategic and cost-effective way to build community capacity on HIV to reduce stigma and discrimination.* This approach is advised because health workers can connect with communities and individuals not reached by media; they already deal with intimate health-related aspects of the communities; they can tailor messages for different audiences; they can answer questions and clear up misconceptions and deep-rooted myths; they are a known and trusted source of information (giving them more influence than anonymous media messages); and they can reinforce knowledge and behavior through repeated visits.

There is growing emphasis on convergence within the health sector in the country. The long-term plan of NACP III is to move HIV programs from a vertical structure into the mainstream of the health sector, and alignment with NRHM is already underway. NACO guidelines state that all District AIDS Prevention and Control Units (DAPCUs) will be located within the NRHM structure at the district level. It is also clear from the budgetary allocations that the government intends to strengthen its overall health sector response rather than focus on vertical programs. The total allocation for the health sector in this financial year (2008/09) is Rs 16,534 crores. This is an increase of 15 percent over last year. Out of this, the NRHM has been allocated Rs 12,050 crores, a substantial increase from last year (see Table 2). In comparison, the allocation for the NACP has only marginally increased.<sup>17</sup>

Year	NRHM (Rs)	NACP (Rs)
2008/09	12,050 crores	993 crores
2007/08	9,947 crores	969 crores
2006/07	8,207 crores	N.A.

With the 2007 readjustment of the UNAIDS HIV estimates for India (from 5.7 million to 2.5-3.2 million people living with HIV), reduction in HIV resource allocation may be a matter of time. Aligning and subsequently integrating HIV education with ongoing health sector programs is a step toward a sustained, fully mainstreamed, and cost-effective program.

Engaging existing healthcare service providers/ outreach workers to build community capacity on HIV and AIDS would first involve a concurrence at the policy level between NACO/SACS and the concerned Ministries/ Departments (this is currently in process). Second, the existing training mechanisms for these service providers must be strengthened using user-friendly training and reference materials. As many of these issues—such as myths and misconceptions, trust between sexual partners, and other issues—also form part of RCH outreach activities, there are convergence opportunities with the RCH program that must be optimally utilized. Third, convergence would require field-based support to the service providers as the subject may be new and may require frequent clarifications. This support could be provided by UPSACS, the Technical Support Unit, DAPCUs, TI NGOs, and link workers. Investment toward integrating HIV into community-based interactions holds promise of a lasting impact on prevention.

## Inherent Challenges

***Under-utilization of existing community-level service providers for HIV activities.*** Among the key sources of interpersonal communication for HIV and AIDS (e.g., spouse, friends, school/teacher), health workers (and outreach workers) are the most reliable channels of correct information. However, the NFHS-3 data for UP reveal that the health worker is the least exploited medium of all possible interactive modes of communication (2.5%) (see Table 3).

Communication Channel	Percent
<b>NON-INTERACTIVE</b>	
TV	80.8
Radio	50.4
Newspaper/Magazine	24.7
Poster/hoarding	11.1
Cinema	1.5
<b>INTERACTIVE</b>	
Friend/Relative	22.5
Husband	5.4
School/Teacher	4.6
Health Worker	2.5

*Source: NFHS-3*

AWWs, lady health visitors, and auxiliary nurse midwives (ANMs), as well as the outreach workers and peer educators of TI NGOs, are the key people with whom rural and urban slum communities have interactions for various needs, such as health, sanitation, and nutrition. ANMs, in particular, are designated to educate communities on key health issues. If adequately trained, community-based workers could foster comprehensive knowledge on HIV and AIDS to different cohorts with minimal extra effort. As noted above, women who had been visited by family planning workers at least once in the past 12 months had greater odds of HIV/AIDS knowledge compared to women who had not been visited by family planning workers. Thus, a challenge is to scale up this promising approach.

***Low levels of transactions with service providers.*** In 2005/6, when NFHS-3 data were collected, more than one in five women in the rural areas was found to have been reached by a health worker in the past three months. Interestingly, twice as many rural women have met with a health worker than urban women (see Table 4). However, the number of people reached is still low. Many ANM positions, for example, are vacant; those selected are not adequately trained; and many ANMs do not undertake regular field visits.

**Table 4. Percent of Women Who Met with Healthcare Worker in Last Three Months, 2005/06**

Place of Residence	% women visited/ met health worker during last three months (N=12,184)
Rural	22.8 (2,063)
Urban	11.3 (355)
<b>Total</b>	<b>19.8 (2,418)</b>

Source: NFHS-3

To maximize the benefits of the existing system, coordinated efforts are needed to boost the health-seeking behavior of men and women, on the one hand, and improve quality and accessibility of healthcare services, on the other hand. Initiatives are needed to urgently fill vacancies, build capacity of healthcare workers, and foster a positive image of the health workers and healthcare centers.

**Community preference for private providers.**

Surveys<sup>18</sup> suggest that irrespective of age, residence (rural/urban), marital status, literacy, or Standard of Living Index, about 85 percent of women who seek health services go to private providers in case of illness, and a mere 15 percent go to government health facilities. The main reasons cited include poor quality of care (66%), no nearby facility (53%), and long waiting time (21%). Of the 34 percent of women who accessed any healthcare facility in the last three months, three out of four women accessed a private clinic. The challenge is that many private providers do not undertake outreach activities and are not likely to integrate HIV information into their work unless the benefits are evident to them.

**The risk of men being left out.** In the healthcare system in the state, the outreach workers cater largely to the needs of women. Integrating HIV and AIDS into the outreach activities of the Health and Women and Child department functionaries is likely to leave a large segment of the men out. Recognizing that men are key decisionmakers within most families and that their opinions have an effect on stigma and discrimination at the community level (e.g., family decisions about whether to send their children to a school that permits HIV-positive students and AIDS orphans or whether to isolate or throw out HIV-positive members of the family), strategies need to be evolved to cover both men and women through community-based outreach initiatives.

## Recommendations

Noting the boundaries of the challenges discussed above, the following actions are recommended within a long-term framework of at least three years to be able to translate into tangible results at the level of the end users:

1. Develop district-specific communication micro-plans, linked to the District Action Plans, based on the specific conditions within the districts to engage frontline workers in the fight against HIV-related stigma and discrimination. Given the community preference for private providers, this plan should include strategies for tapping into the resource base of the private providers and promoting Public-Private Partnerships and initiatives for convergence of resources. Similarly, for the media dark areas and those settings where access to mass media is hindered by power shortages, mid-media activities—such as street theater, *nautanki*, cultural programs on festive occasions (e.g., *ramleela*), and IEC vans—could be included in the district plans.
2. Since a large segment of young persons, especially girls, have limited access to education and the age of marriage is low in the state, communication plans must take into consideration the specific vulnerabilities of the youth and address them through youth-friendly communication channels. The University Talks AIDS and School Talks AIDS initiatives of UPSACS have met with positive response in the past and must be scaled up, along with Red Ribbon Clubs and other interactive forms of media that reach out to college/school and out of school youths as well as young married couples.
3. Corresponding to the plan of action, develop and roll out a capacity-building plan for key personnel, including ANMs, ASHAs, DAPCU staff, and others focused on implementing the micro-plan and tracking its progress.
4. Encourage mass media partners to develop more interactive platforms of communication, such as radio and TV talk shows, phone-ins, and expert-speak, among others. HIV-related messages could be embedded within the popular regional channels. Innovative approaches, such as community radio, could also be introduced in

difficult to reach terrains, especially in the Bundelkhand and Eastern regions of the state.

5. Engage the Panchayati Raj Institution members in planning and roll out of the district micro-plans, and advocate for the establishment of Rogi Kalyan Samitis<sup>19</sup> at the panchayat levels where these do not already exist. Once functional, these Samitis could support and monitor the implementation of the micro-plan.
6. Modify the SACS mass media plan to provide necessary support to the implementation of the district-based micro-plans. This would include educating the general public about the role of ASHAs, ANMs, and AWWs in HIV programs. Media could build greater confidence of the communities in the service providers through boosting their image. Recognizing that the success of an integrated approach depends heavily on the health-seeking behavior of communities, mass media and other programs should also use their platforms to encourage men and women to be proactive about their health and well-being. This also fits well with the fact that 2008 marked the 30th anniversary of the Alma-Ata Declaration, in which many governments made the promise of providing health for all.

The role of communication and knowledge in combating stigma against vulnerable groups and also breaking down barriers to general populations seeking HIV services is indisputable. From the analysis above, it is evident that the solutions are not simple. This brief aims to generate discussions around the immense potential for the use of interactive channels of communication in reducing stigma and improving the quality of HIV programs, so that innovative solutions can be found.

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## ENDNOTES

- <sup>1</sup> Brown, L., L. Trujillo, and K. MacIntyre. 2001. *Interventions to Reduce HIV/AIDS Stigma: What Have We Learned?* Washington, DC: Horizons, Population Council.
- <sup>2</sup> National Family Health Survey 2005/06 (NFHS-3). Available at <http://health.nic.in/NFHS-3%20HIV%20Knowledge,%20Stigma%20and%20Behavior.ppt#282,1,2005-06> [accessed May 5, 2009].
- <sup>3</sup> Uttar Pradesh, NFHS-3, 2005/06.
- <sup>4</sup> Ibid.
- <sup>5</sup> Ibid.
- <sup>6</sup> NACP III. 2007. *To Halt and Reverse the HIV Epidemic in India*. New Delhi: NACP III.
- <sup>7</sup> Allahabad, Banda, Deoria, Etawah, Lalitpur, Mau, and Moradabad.
- <sup>8</sup> 2008-09 Annual Action Plan of UPSACS.
- <sup>9</sup> NACO defines category A districts as any district with more than 1 percent HIV prevalence reported by any antenatal care site in the district in the last three years. Category A districts include Allahabad, Banda, Deoria, Etawah, and Mau.
- <sup>10</sup> NACO. 2004. *National IEC/BCC Strategic Framework for HIV/AIDS Program*. New Delhi: NACO. See pp. 2–4.
- <sup>11</sup> NACP III. 2007. *To Halt and Reverse the HIV Epidemic in India*. New Delhi: NACP III.
- <sup>12</sup> International Center for Research on Women (ICRW). 2003. *Disentangling HIV/AIDS in Ethiopia, Tanzania, and Zambia*. Washington, DC: ICRW.
- <sup>13</sup> UNAIDS. 2001. *India: HIV/AIDS-related Discrimination, Stigmatization, and Denial*. Geneva: UNAIDS. See p. 9.
- <sup>14</sup> Ranjita Biswas. 2008. “Discriminated to Death: Living with HIV.” *InfoChange News & Features*, May 2008. Available at [http://www.worldproutassembly.org/archives/2008/05/discriminated\\_t.html](http://www.worldproutassembly.org/archives/2008/05/discriminated_t.html) [accessed May 5, 2009].
- <sup>15</sup> Saseendran Pallikadavath, Abdoulie Sanneh, Jenny M. Mcwhirter, and R. William Stones. 2005. *Rural Women’s Knowledge of AIDS in the Higher Prevalence States of India: Reproductive Health and Sociocultural Correlates*. Oxford, UK: Oxford University Press.
- <sup>16</sup> Ibid.
- <sup>17</sup> Chandrakant Lahariya. 2008. “Budget India 2008: What is New for Health Sector?” *Focus 45* (May 17, 2008).
- <sup>18</sup> District Level Household Survey 2, 2002-2004.
- <sup>19</sup> *Rogi Kalyan Samitis* or Patient Welfare Committees are the registered societies constituted in the hospitals as an innovative mechanism to involve the peoples’ representatives in the management of the hospital with a view to improve its functioning.