Photo: Rajal Thaker, 2007, Courtesy of Photoshare

Health workers at the Mamata Clinic in Ahmedabad, India, stand in front of an advertisement for a help-line and website that provide information about HIV/AIDS. The Mamata Clinic is part of a programme to prevent parent-to-child transmission of HIV.

HIV: death sentence or chronic and manageable disease?

Changing attitudes of health providers and politicians towards women living with HIV in India

Suseela Anand

The Right to Health is universally acknowledged as a human right and Article 21 of the Constitution of India considers it as inherent to the Right to Life. State health-care providers are obliged by law to provide medical treatment to all persons without discrimination of HIV status in emergency and non-emergency situations. A recent assessment by the Positive Women Network (PWN+) on the availability and accessibility of HIV/AIDS care and treatment in India found that health care is greatly influenced by gender and that women and children living with HIV face huge hurdles in accessing treatment and care because of discrimination by government health-care providers. Through focus groups discussions, PWN+ found a discrepancy between the government stance and realities on the ground.

PWN+ is a network of women living with HIV in India. It combines advocacy work with services for beneficiaries. Services include peer counselling, capacity building of women living with HIV (WLHIV) and strengthening of WLHIV groups and networks. Stigma and discrimination has emerged as a major hurdle in ensuring universal access to care and treatment. Women living with HIV across the country have reported cases of discrimination by the health-care system. We have also noted that while some difference can be seen in the attitude of doctors and other senior health-care professionals, sensitization of health staff remains limited to specialized centres including those for Integrated Counselling and Testing (ICTC), STD care, prevention of vertical transmission and for antiretroviral treatment.

Women and families affected by HIV are afraid to access care and treatment for fear of being stigmatized and insulted. In many health centres, pre and post-test counselling is not conducted according to guidelines issued by NACO. Results of the focus group discussions revealed that the counsellors in prevention of vertical transmission services and VCT centres conduct group counselling rather than individual counselling. Also, they tend to give the test results but do not refer HIV-infected women for further treatment. Information on breastfeeding, safer sex practices and nevirapine treatment to prevent transmission from mother to child, is not given to pregnant HIV-infected women. WLHIV are denied access to hospitals and some doctors even refuse to perform caesareans during delivery.

Even though confidentiality of test results is a guaranteed right, it is common for the patient's HIV status to be publicly displayed in wards. This leads to further isolation of the individual and at times even violence in different forms.

In general, women living with HIV in India lack important information and access to services because:

- Information on services available for HIV-infected women and children is very poor because there are no trained counsellors. Many of those who could benefit from existing services are not accessing them.

> Even today many health professionals including counsellors and doctors continue to regard HIV as a death sentence and not a chronic manageable illness

- Current programmes do not have women-friendly services. Many of the STI Departments available for WLHIV do not have female doctors or female staffs who are trained to treat patients sensitively.
- There is no information on reproductive health and positive living for health-care providers, women and children living with HIV.

Lack of updated information on HIV and AIDS among the general public contributes greatly to creating an environment of stigma and discrimination. This causes barriers for people living with HIV to access care and treatment freely and openly. Even today many health professionals including counsellors and doctors continue to regard HIV as a death sentence and not a chronic manageable

illness. Health services require basic infrastructure like laboratories, basic amenities such as gloves, sterile needles and post-exposure prophylaxis. There is no correct information on HIV/AIDS and training on counselling of HIV-positive people. There are many cases where infected people are informed that HIV infection warrants death. It is sad that health-care providers still give such counsel.

Public hearings to sensitize governments

In 2003, PWN+ together with the Centre for Advocacy and Research and with support from UN organizations conducted a study based on the Convention on the Elimination of all forms of Discrimination Against Women (CEDAW).[1] As a result of the findings, PWN+ with support from the National Commission for Women-India organized public hearings at state level in the southern Indian states of Tamil Nadu, Karnataka and Kerala in 2004. The objective was to persuade state governments to address the issue of stigma and discrimination in the health sector. The advocacy generated effective responses, which led to a considerable reduction in the incidence of stigma and discrimination against WLHIV in these states. Subsequent to the hearings, women who accessed services from government interventions reported to have received better conduct and kindness.

> The experience has shown that government officials and health staff can be sensitized on the plight of women living with HIV and that stigma and discrimination in the health system can be tackled

Respective state governments relaxed minimum age requirements regarding Widow Pension to allow young widows of deceased HIV-infected men access the support. Also, important guidelines to reduce stigma and discrimination in health settings were issued, after which it became much easier for HIV-positive women to approach government offices. The experience has shown that government officials and health staff can be sensitized on the plight of women living with HIV and that stigma and discrimination in the health system can be tackled.

Urgent need for a national response

Unfortunately, there has been no real decline in the incidence of stigma and discrimination by health providers elsewhere in the country. As recently as 29 June 2007 a man had no alternative but to deliver his baby at the Government Hospital, in Meerut, Uttar Pradesh, because the doctors allegedly refused to conduct the delivery because of his wife's HIV-positive status. On 28 October 2007 a woman who had gone for pregnancy-related problems at the Jawaharlal Nehru Memorial Hospital in Nadia in West Bengal was moved to an isolated bed and a sticker marking her as an HIV positive was stuck on her forehead.

An increase in such incidents indicates an urgent need for a response from the government at national level. To sensitize government officials and others on their critical role, PWN+ was supported by the Canadian High Commission to conduct a National Public Hearing on Health in New Delhi on November 15, 2007. At the meeting, WLHIV from eight states shared the discrimination they faced in public health settings. This was followed by a panel discussion and an interactive session. Participants comprised of WLHIV from various states, representatives from the government, NACO, UN bodies, Human Rights agencies and the medical profession.

PWN+ will continue to advocate for greater involvement of the government in the struggle against AIDS stigma and discrimination. We believe that the government has a role to play in instructing and motivating health staff to fulfil the Right to Health of all people living with HIV and refrain from stigmatizing and discriminatory attitudes and practices. We also advocate for the development of new policies and recommendations that will bring about much-needed changes in the health sector, especially with regard to better and increased access to treatment by women and children living with HIV. Our National Public Hearing on Health was only a first step. We are currently conducting state level advocacy events to address the concerns of women living with HIV over the government health system. Live interactions between women and government officers of concerned departments are conducted in the presence of the media and other stakeholders. This is an effective advocacy model which gave good results at the national level. It also builds confidence of WLHIV to advocate for their issues. Also, we are sensitizing police constables to commissioners, government officers at various levels and Village Panchayat Leaders, by putting them in contact with our Positive Speakers. Our goals for the coming year or two are to build a network of WLHIV leaders, by strengthening their capacity on advocacy, and expand our sensitization programme to other states where it is needed. ■

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