



## District Meeting/Training on Legal Literacy for PLHIV

Report submitted and edited by Jaya Singh

Office of Love, Life Society  
House No. 853, Second floor,  
Janta flats, GTB enclave,  
Near Shree Ram Sweets,  
Delhi - 110093  
16th October, 2019

# Agenda

Time	Topic	Resource Person
11:00 am – 11:30 am	Welcome	Aishwarya Adhikari and Hari Shankar
11:30-01:00pm	Experience Sharing	Panelists from OPNP, Love, Life, Society and DNP+
01:00 pm - 1:15 pm	Discussion	
01:15 pm - 02:00 pm	Lunch	
02:00 pm - 02:45 pm	Know Your Rights: Medical Negligence and Reproductive Rights of PLHIV	Advocate Sneha Mukherjee, <i>HRLN</i>
02:45 pm - 03:30 pm	Legal recourse on harassment, mistreatment and discrimination of PLHIV	Advocate Rushila Rebello, <i>HRLN</i>
03:30 pm - 04:00 pm	Discussion and Closing Remarks	

# Introduction

HRLN in collaboration with Love, Life, Society, DNP+ and OPNP organized a one-day Know Your Rights meeting for young activists, lawyers and PLHIV (People Living with HIV) on 16th October, 2019 at Love, Life, Society: House No. 853, Second floor, Janta flats, GTB enclave, Near Shree Ram Sweets, Delhi - 110093.

HIV-related stigma and discrimination, as well as gender based inequalities, drive vulnerable communities away from HIV prevention, treatment and care. Gender inequalities often limit young women's access to health care and education, resulting in young women accounting for a disproportionate number (60%) of new infections among young people living with HIV. Gender based violence, including rape, and early marriage also prevent women and adolescent girls from being able to adequately protect themselves from HIV. Women living with HIV also face challenges to being able to make autonomous and informed family planning decisions; they do not receive adequate information on family planning.

HIV-related rights are well recognized under international human rights standards protecting the rights to life, health, privacy and non-discrimination. The right to health includes *“the prevention, treatment and control of epidemic...diseases”* as well as *“the creation of conditions which would assure to all medical service and medical attention in the event of sickness.”* The right to health has been interpreted to include *“the availability and accessibility of HIV prevention, treatment, care and support for children and adults.”* International human rights bodies have also explicitly recognized HIV status as a prohibited ground of discrimination. International standards also protect the right to privacy, which *“encompasses obligations to respect physical privacy, including the obligation to seek informed consent to HIV testing and privacy of information, including the need to respect confidentiality of all information relating to a person's HIV status.”* The right to physical integrity and the right to choose the number and spacing of one's children are also relevant as HIV positive women face heightened risks of being subjected to forced abortion or sterilization.

There exists a deep seated prejudice against HIV positive people in both public and personal spaces in India. Another compelling plight unrepresented in media and political discourse falls in the context of discrimination, mistreatment and harassment. Lack of legal awareness owing to governmental apathy in familiarizing people with their legal rights and entitlements make them vulnerable at the hands of medical practitioners, family members, employers and others.

People living with HIV/AIDS often face mistreatment by health care providers, *“they are reportedly turned away from hospitals, summarily discharged, denied access to medical services unless they consent to sterilization, and provided poor quality care that is both dehumanizing and damaging to their already fragile health status.”*<sup>1</sup>

This meeting was part of a series of trainings, facilitating awareness and practical knowledge of legal rights and entitlements. The meeting aims to bring together young activists, lawyers and PLHIV to aware them on the use of law to fortify against an antagonistic climate of discrimination and social abuse. As a part of consolidating a network of activists and lawyers grounded in the everyday reality of experience, this meeting aimed to build a formidable link between activists, lawyers and people living with HIV to secure better avenues of socio-legal intervention.

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<sup>1</sup> Ohchr.org. (2019). *Information Series on Sexual and Reproductive Health and Rights: HIV/AIDS*. [online] Available at: [https://www.ohchr.org/Documents/Issues/Women/WRGS/SexualHealth/INFO\\_HIV\\_WEB.pdf](https://www.ohchr.org/Documents/Issues/Women/WRGS/SexualHealth/INFO_HIV_WEB.pdf) [Accessed 12 Oct. 2019].

## Experiences of people living with HIV

One of the counsellors present at the meeting shared the story of a PLHIV person who had met with an accident and was admitted thrice at Safdarjung Hospital but was discharged soon after as the doctor had told him that the operation theatre would have to be cleaned entirely because he was HIV positive patient. The counsellor further discussed how people get fired from work based on their HIV status. Additionally, women with HIV are discriminated against solely because of being a woman, often kicked out to the streets.

Swati's (*name changed*) husband is HIV+. They found out about his HIV status 2 years back. He is also disabled, and his status was figured only during the surgery that he was going under for his leg. Their marriage already had several issues and they failed to understand the reason behind his HIV status. They also have a 6 years old son together. After the husband's family found out about his HIV status, they started discriminating and harassing him. Eventually, they stopped supporting them. Swati was also advised to not let their son near the father. This was furthered when somebody from their society overheard their conversation. This resulted in them facing harassment within the society as well.

During fieldwork, counsellors have encountered several cases where the doctor has refused to provide treatment to HIV positive patients. They make up excuses such as not having the testing kit or that their operation theatre is not prepared for operating. They even write 'HIV+' on the OPD cards, so as to make their HIV status public. A woman attending the meeting spoke of her husband who is HIV+ and is often discriminated against by the hospital staff as they are segregated from the rest of the crowd and are made to wait for long hours. Her husband eventually passed away but now, her in-laws have been threatening her to sell off the property as they do not want their son's property to go to his wife.

The counsellors also shared how certain people living with HIV have contacted them in the past but have refused to meet them because they worry that their HIV status would be disclosed. They are scared of being discriminated in the society. On the other hand, they have also come across people living with HIV who are supported by their direct as well as extended family. This derives an extremely paradoxical state of affairs of the people living with HIV. Some clients who have been seeking counselling are adults who are being pressured into getting married by their families who do not know of their HIV status.

Lakshman (*name changed*) was operated in 2010 for a surgery. In 2012, he fell sick and it was found that he had become HIV positive. His wife started to treat him differently as she would separate the utensils he would use from the rest in the kitchen. She eventually took off with their two daughters and the property papers. He served 3 years in prison for a case filed against him by his wife. In the prison, he was further harassed and treated differently to the point that he filed a complaint against the Delhi jail warden. The SDM also spoke to him rudely based on the fact that he knew of his HIV status. Lakshman's house was sealed and he presently stays on the roof of the house. He leaves at 9 in the morning and comes back after 9 to sleep.

A case of grave medical negligence was shared by one of the counsellors. She spoke about one of the clients who was referred to Safdarjung hospital. After the tests prescribed were performed, the doctor referred her to LNJP hospital who referred her to be tested from a private place outside. Neither the doctor nor the patient knew what the prescribed tests were for, but she was referred then to GB Pant hospital who then found that she had a knot in her stomach. The hospital then referred her to LRS hospital who in turn referred her to a private hospital in Vasant Kunj that demanded Rs.50,000 in advance for the operation. The client could not have paid such a big amount. DNP+ took her to Safdarjung Hospital and got her admitted. After 2 hours, she was discharged and taken to NITRD hospital. She eventually got discharged without any treatment and on 14th October, 2019, she passed away at the age of 40. Her husband is also HIV positive and also has TB. They had three kids, two of whom are married. With her body, the family chose to burn off all of her documents during the cremation. The government hospital

takes a long time to treat patients that are HIV positive, forcing the patients to approach private hospitals that they cannot ultimately afford.

Another case of harassment was shared by a counsellor about Dr. Baba Sahib Ambedkar Hospital where a nurse became infected and was fired from work consequently. The counsellor spoke about another client who had gotten fired from work after his HIV status was disclosed. He now rides a cycle rickshaw, while in his previous job he used to earn Rs. 20,000 per month. There are also cases of people being fooled by doctors claiming to cure HIV. One such case occurred in Sikkim where a man ended up paying 2-3 lakhs for treatment. The hospitals further engage in creating a hostile environment by testing patients over and over for TB in order to refer them to other hospitals. The discrimination faced by people living with HIV further creates an environment of exclusion where they feel that since the society and the healthcare system have treated them in an unfair manner, approaching the court would not make their situation any better.

Aditya (*name changed*) shared how he had to be treated for appendix two years back at GTB hospital but since he had disclosed that he was HIV positive, the hospital refused to operate on him. They instead told him that an emergency case had come and they chose to move him to the ward where he stayed for 2-3 days. The doctors at the hospital resorted to treat him with medicines, while he was stopped from consuming food. Similarly, a year and a half back, his wife needed to be operated but the hospital refused to perform ultrasound. She was untreated to the point that she had started bleeding from her mouth. He then resorted to go to a private hospital for which he had to borrow money and he is still paying debt on it. At the private hospital, they did not disclose that they were both HIV positive and so the operation happened normally. 9 months back, his wife was beaten up by his sister, mother and brother-in-law who then kicked them out on the street. After spending a night on the street, they found a relative to with but Aditya had lost his job overtime and not having a proper place to stay impacted his options for employment. His father also got him arrested where the police advised his father to

take his name off the ration card and property papers. Within the society he lived with his parents, his sister and brother-in-law told everybody of his HIV status.

One of the participants present at the meeting spoke about how he had been supported by his family, but his brother constantly harasses them for property. He fears that one day he will get home from work and finds his mother hurt or worse. A counsellor shared an account of a woman who found out after her marriage that her husband was HIV positive; he passed away soon after. She got married again to a man much older to her who already had children from his previous wife. When the woman got pregnant, she was kicked out by the husband while his children from the first marriage started harassing her and physically assaulting her.

Aniket (*name changed*) and his wife are both HIV positive. Their sister-in-law found out about their HIV status and started to warn her kids against going near to them. She disclosed the same to their neighbors. Until then, he used to sell burgers on a cart but he eventually lost his customers which made him shut shop. On one occasion, he was asked by a customer if his child was HIV positive too. His child is 4 years old now and he does not have HIV. While his wife was pregnant, the hospital staff made him clean all of her waste and things that were being supplied to her because they refused to touch her. They kept her in isolation at the hospital while the doctors and nurses treated her in a rude manner.

Harsh (*name changed*) was born with HIV. On getting admitted to a school, Harsh's parents informed his teacher about his HIV status for his safety. The teacher shared this with the principal and the parents received a call from the school administration claiming that the school had miscommunicated the decision regarding his admission. On further speaking with the teacher, his parents were told that they did not have a place for him at the school because they felt there existed a risk of other students getting HIV from him. The counsellors spoke to the school administration and the child was eventually given admission but he continues to be isolated at the school.



People living with HIV are gravely mistreated throughout the country. Hospitals refuse services by lying to them, saying that their blood pressure is too high and hence, they cannot operate. Family planning services are often denied to the people living with HIV. They are further discriminated at work and within educational institutions. Health Insurance companies such as LIC and more refuse to issue insurance to people living with HIV. The constitution of India has given the people the power to question the refusal of services, but the Indian society needs to be sensitised as a whole so as to ensure that the rights of people living with HIV are not further infringed.

# Rights of People living with HIV in India

The meeting was addressed by Advocate Sneha Mukherjee and Advocate Rushila Rebello who elaborated upon the rights of the people living with HIV in India.

Union of India has signed various treaties, agreements and declarations relating to HIV/AIDS and the protection of the rights of those who are HIV positive. The two conventions that aim at non-discrimination on the basis of creed, political affiliation, gender and race are the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. It also covers within its ambit the non-discrimination of the people infected with HIV.

The Universal Declaration of Human Rights also lays down that the principle of non-discrimination is fundamental to human rights law. It equally applies to people suffering from HIV/AIDS because they have to suffer a very high level of stigma and discrimination. It lays down certain work related provisions for a HIV/AIDS infected people which includes right to life, liberty and security of person, no person should be subjected to forced testing and/or treatment or otherwise cruel or degrading treatment, all people including HIV+ persons have the right to work and participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits and all persons including the people living with a positive 'HIV' diagnosis are equal before the law and are entitled without any discrimination to equal protection by the law. People diagnosed with HIV+ are also entitled the rights enshrined in Art. 25(1) of the Declaration which includes the right to an adequate standard of living, assistance, medical care and necessary social services, and the right to security in the event of unemployment, according to their needs and their treatment choices.

Legal provisions within the Indian constitution:

- Constitution of India, 1950 guarantees every person justice, liberty and equality.

- Article 14 guarantees the right of equality of treatment to the HIV/AIDS patients.
- Articles 15 and 16 protects them against discrimination.
- Article 21 of the Constitution protects their right to life and personal liberty and ensures their right to privacy.
- The Directive Principles of State Policy also cast a duty upon the States to ensure right to livelihood and prevent discrimination.
- Article 39 of the Constitution directs the States to ensure that all the citizens including the HIV/AIDS patients have an adequate means of livelihood.
- Article 42 casts a duty upon states to make provisions for securing just and humane conditions of work. States have been entrusted with the duty to improve public health vide Article 47 of the Constitution.

The government's major AIDS control initiative is the National AIDS Control Programme and the premiere AIDS agency is the National AIDS Control Organization or NACO. This organization aims to create a place in India where every person living with HIV is treated with dignity and have access to quality care. Every State has a State AIDS Control Society run by the State government. These State societies are a part of NACO.

Besides government bodies at the Centre and the State level, a large number of NGOs are involved in spreading information regarding the spread of HIV/AIDS, its prevention and possible cure. Many international NGOs and organizations run by the United Nations are also involved in spreading information about AIDS. Some of these international NGOs are: ActionAid, AVERT, AIDS Care Education and Training (ACET), Family Health International (FHI), the International Red Cross and the Panos AIDS Programme.

Certain legal provisions within Indian Medical Council Act, 1976 binds medical practitioners as per the Medical Council of India that has laid down certain duties that have to be observed by the doctors towards the HIV/AIDS patients. These are enumerated below:

- Duty to take care and to take informed consent from the patient.
- Disclosure of information and risks to the patient.

- Provide information of options available & benefits.
- Duty to warn.
- To admit patient in emergency without consent.
- The physician should not abandon his duty for fear of contracting the disease himself.

# Recommendations

Some of the key findings from the meeting reveal that more often than we would like to believe, discrimination is meted by close family members, neighbours and members of society that a PLHIV may interact with in daily life. While organizations mostly focus on working with people living with HIV, it is equally important to work with all members within a community and sensitize them about HIV. Regular sensitization has the potential of bringing behavioural changes within the community in order to change the discourse around HIV, thereby, directly lowering instances of harassment and discrimination against PLHIV.

The testimonials reveal that there has been an increase in the instances of discrimination and harassment by service providers, specifically doctors. One of the primary reasons for continued acts of discrimination is lack of sensitization amongst both service providers and persons living with HIV. Regular sensitization programmes and legal awareness programmes should be done with both groups. Specific meetings should be conducted for PLHIV so that discussions can take place with service providers such as doctors and legal professionals, to better understand their rights and seek legal recourse in cases of violations and/or harassment.

## Glimpses from the Meeting

