

# RGICS

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# RGICS LEGISLATIVE BRIEF

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**HIV & AIDS (PREVENTION AND CONTROL)  
BILL, 2014**

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### KEY MESSAGES

- The clause “as far as possible” in the Bill needs to be immediately removed. It dilutes the legal right of the PLHIV to receive guaranteed Anti-retroviral Treatment provided by the Government.
- A large number of PLHIV belong to the marginalised sections that are subject to criminal conduct beyond the purview of the HIV Bill. Therefore, to achieve complete non-discrimination, the Government has to reflect upon other legislations to decriminalise these marginalised sections to achieve the objectives of the Bill.
- Should incorporate the phrase “by an order of the court” instead of “by an order”, as recommended by the Parliamentary Standing Committee on Health and Family Welfare, for the exemption of disclosure of HIV status of the HIV person without prior informed consent in clause 8.
- To make the informed consent of the HIV person compulsory in case of medical research or epidemiological purposes.
- To provide penalty and punishment for the violation of clause 5 (informed consent) and clause 8 (disclosure of information).

### PART I. INTRODUCTION

Human Immunodeficiency Virus (HIV) is a virus, found at infectious levels in human body fluids, such as, blood, semen, vaginal and rectum fluids, and breast milk. It is not easily spread. It can only be transmitted when the body fluids of an HIV infected person come in direct contact with body fluids of another person, who then gets infected by HIV.<sup>i</sup> The general medium of virus transmission is through 'infected needles, syringes or other drug-taking equipment (blood transmission), or from mother-to-child during pregnancy, birth or breastfeeding'. HIV gradually attacks the immune system, body's natural defence system against illness. If the virus is left untreated, over the years, it leads to a syndrome called Acquired Immune Deficiency Syndrome (AIDS). This is the advanced or the last stage of the HIV infection, when the body is unable to defend itself against various diseases. AIDS can lead to death of the person. Presently, there is no permanent cure for HIV/AIDS. However, with early diagnosis and effective Anti-retroviral Treatment, people living with HIV (PLHIV) can live a normal and a healthy life.<sup>ii</sup>

In 2015, there were about 36.7 million PLHIV globally.<sup>iii</sup> South Africa and Nigeria were ranked first and second in respect to the total number of HIV patents in the world.<sup>iv</sup> India is ranked third globally, with roughly 2.1 million PLHIV. The States which account for the highest HIV prevalence in India are Nagaland, Mizoram, Manipur, Andhra Pradesh and Karnataka. The people who are most vulnerable by the HIV/AIDS are the sex workers, men who have sex with men (MSW), transgender people, people who inject drugs (PWID), migrant workers, and the truck drivers.<sup>v</sup> It is these sections of the society who are the most discriminated and are treated as the marginalised group. They face discrimination across various walks of life, such as, employment, educational institutions, health care services, residing or renting property. This leads to the violations of their rights. Hence, it becomes difficult for PLHIV and those who belong to these groups to access the medical services. One important factor leading to the above circumstances is that India does not have anti-discrimination legislation which could cover the discriminated people on the grounds of HIV.<sup>vi</sup>

Therefore, the need for a HIV/AIDS Bill in India was highlighted at the International Policy Makers Conference on HIV/AIDS held in New Delhi, back in 2002. The objective of the Bill was to safeguard the rights of the PLHIV against any form of discrimination, and to prevent and control the spread of the HIV/AIDS. The draft of the HIV and AIDS (Prevention and Control) Bill was prepared and submitted to National AIDS Control Organisation (NACO) in August 2006.<sup>vii</sup> However, the Bill was pending ever since and, after a turbulent journey, the Bill was finally introduced in the Rajya Sabha (Upper house of the Indian Parliament) in February 2014. But due to the dissolution of the Lok Sabha (Lower house of the Indian Parliament), the Bill was further referred to the Parliamentary Standing Committee on Health and Family Welfare for their recommendations.<sup>viii</sup> The Committee had provided their recommendations and submitted the report to the Rajya Sabha in April, 2015. Subsequently, in October 2016, the amendments to the Bill were approved in a Cabinet meeting chaired by Prime Minister Modi.<sup>ix</sup>

### PART II: PROVISIONS OF THE BILL

The Bill seeks to provide for “*the prevention and control of the spread of Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome and for the protection of human rights of persons affected by the said virus and syndrome and for matters connected therewith or incidental thereto*”.<sup>x</sup> Therefore, to protect the rights of the PLHIV, **the Bill has mandated for an embargo on discrimination against HIV positive person or people living with them.** Here, discrimination is defined as ‘denial, termination, discontinuation or unfair treatment’ in regards to “employment, educational establishments, health care services, residing or renting property, standing for public or private office, and provision of insurance (unless based on actuarial studies)”. In addition, **the pre-requirement of a HIV test for employment, healthcare or education has been forbidden.**<sup>xi</sup>

People infected or affected by HIV, are often stigmatised in the society and often within their own households. Therefore, the Bill provides that **PLHIV, who are below the age of 18 years, have the right to share and enjoy the facilities of the household.** Further, if a person who is aged between 12 to 18 years, and has sufficient maturity and understanding to manage the affairs of his HIV/AIDS affected family member, then he shall be competent to **act as a guardian for another sibling below the age of 18 years.** Here, the guardianship will apply in the matters of educational establishments, operating bank accounts, managing property, care and treatment, amongst others. The Bill also **prohibits any person from ‘publishing information or advocating feeling of hatred’** against the HIV positive persons and the people living with them. In case of the above violation, the person shall be sentenced with **imprisonment of not less than 3 months and up to 2 years, with a fine up to Rs. 1 lakh or both.**<sup>xii</sup>

In order to safeguard the rights of the people, **no HIV test, medical treatment or research can be conducted on a person without his prior informed consent.** However, in certain cases the informed consent of a person **shall not be required, such as, a court order, medical research, licensed blood banks and epidemiological purposes,** where the HIV test is anonymous and shall not be for the purpose of determining the HIV status of a person.<sup>xiii</sup> However, it is **not clear from the Bill as to why should the informed consent has been exempted for the purpose of medical research or epidemiological purposes.** This is in contrast to the procedure laid down by South Africa’s ‘National HIV Counselling and Testing Policy Guidelines’ whereby an informed consent is required in writing in the case of research and clinical trials. Moreover, any participation in such studies has to be voluntary and subject to informed consent of the participant.<sup>xiv</sup>

Further, the Bill provides that no person can be forced to disclose his HIV status except with his informed consent, or if required “*by an order that the disclosure of such information is necessary in the interest of justice for the determination of issues in the matter before it*”.<sup>xv</sup> In this regards, the **Bill fails to incorporate** the recommendation made by the Parliamentary Standing Committee – “*by an order of the court.*”<sup>xvi</sup>

To further strengthen the identity of the PLHIV, **every establishment who maintains the records of the HIV positive person is required to keep such data confidential.**<sup>xvii</sup> However, there are certain **ambiguities** in the Bill where the **information can be disclosed without a prior informed consent** of the person. Here, a healthcare provider, a physician or a counsellor of the HIV positive person can disclose the status to his/her

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partner, if he thinks it is necessary. Similarly, it can be disclosed during legal proceedings, for statistical information or to the officers of the central and state governments or the State AIDS Control Society for the purposes of monitoring, evaluation or supervision.<sup>xviii</sup>

Every organization engaged in **healthcare services** or any other such establishment where there is a significant risk of exposure to HIV shall adopt, educate and provide training on the **'Universal precautions' to all the persons working in such establishments**. In accordance to the guidelines for a safe working environment, every such establishment is required to **designate a Complaint officer**, who will deal with the complaints regarding the violations of the Bill.<sup>xix</sup>

Every **State Government** has been designated with the responsibility to **appoint one or more Ombudsman**. He shall **inquire into complaints regarding the violations** of the prescribed healthcare services of the Bill. If these norms are violated, the accused person shall be punished with **a fine of Rs. 10,000** and if the violation continues, an additional fine of Rs. 5,000 per day can also be imposed. Every six months, the Ombudsman has to report to the State government, on the number and nature of complaints received, action taken and orders passed in relation to such complaints.<sup>xx</sup> However, it can be noted that the Bill has **no provisions for any penalty or punishment** for the violations of the **clause 5** in regards to the informed consent of the HIV person and **clause 8** in regards to the disclosure of information.<sup>xxi</sup>

In any legal proceedings, **if an HIV infected person is an applicant, then the court shall take up and dispose off the case on a priority basis**. During the proceedings, the court can suppress the identity of such a person by substituting the name, and can refrain any person from publishing any such information, which may reveal the true identity. The proceedings may be conducted in camera. In case, a maintenance application has been filed, the court shall also take into account the medical expenses and any such HIV related costs incurred by the applicant. No Court other than the Judicial Magistrate First Class shall take cognizance of an offence under this Act.<sup>xxii</sup>

### PART III: WELFARE MEASURES PRESCRIBED FOR THE GOVERNMENT IN THE BILL

The Bill has assigned the Central and the State Governments, as the case may be, with some important responsibilities to **check the spread of HIV/AIDS**. This shall be done by facilitating better access to welfare schemes to the people infected or affected by the HIV/AIDS, and **without any prejudice to address the needs of the affected women and children**. They shall lay down the guidelines for the care, support, and treatment of the affected children. They shall also take steps to **protect the property of the children affected by HIV/AIDS**. The guardians or the parents of the affected children may approach the Child Welfare Committee for the safe keeping and depositing of the documents of the child's property. The government shall **formulate information, education and communication programmes for HIV/AIDS** which are age-appropriate, gender-sensitive, non-stigmatising and non-discriminatory. Government shall provide counsel and information and treatment regarding the outcome of the pregnancy to the HIV infected woman. **No HIV positive woman, who is pregnant, shall be subject to sterilisation or abortion without obtaining her informed consent**. For every person in the care and custody of the State shall have the right to HIV prevention, counselling, testing and treatment services.<sup>xxiii</sup>

In order to prevent the spread of HIV or AIDS, the Central Government or the State Government has been assigned the responsibility to, ***“take measures for providing, ‘as far as possible’, diagnostic facilities related to HIV/AIDS<sup>xxiv</sup>, Anti-retroviral Therapy and Opportunistic Infection Management to people living with HIV/AIDS”***.<sup>xxv</sup> The ART is offered free of cost to all PLHIV who are eligible clinically. All those PLHIV eligible as per technical guidelines are initiated on first line ART.<sup>xxvi</sup>

Out of the total 2.1 million PLHIV, about 1.3 million PLHIV are eligible to receive the ART. This is because ART is started for only those PLHIV whose CD4 count is less than 350. However, the World Health Organization (WHO) guideline provides that everyone with HIV should get anti-retroviral (ART) drugs, regardless of their clinical stage and a white-blood-cell tally that India uses to determine who will be treated. Therefore, out of the eligible PLHIV only 940,000 are on anti-retroviral therapy (ART). The situation is worse among children, with no more than 36% getting ART. There are about 455 ART centres nationwide.<sup>xxvii</sup>

However, **the clause “as far as possible” included in the Bill has created distress amongst HIV activists and PLHIV**. This is because though the Bill has made treatment a right of the patient, but this particular clause **has diluted the legal right of the PLHIV**, as they cannot demand for a legal remedy by appealing in the Court, in case they are denied the ART.<sup>xxviii</sup> Therefore, the PLHIV and the activists have demanded for the removal of the above clause from the Bill, and to provide ART as the legal right of every PLHIV.

### PART IV. HIV/AIDS SCENARIO IN INDIA:

#### Major factors identified with HIV/AIDS

Some of the major factors leading to HIV infection:<sup>xxix</sup>

- Men who have sex with Men (MSM) - 95%.
- HIV transmission from infected pregnant women to her foetus or infant before, during or after birth - 3%.
- Infected needles and syringes - 0.9%.
- Transfusion through infected blood - 0.1%.
- Non-specified factors - 1%.

As per data, between October 2014 and March 2016, as many as 2,234 people contracted HIV through blood transfusions in hospitals.<sup>xxx</sup>

#### Affected population in India

The HIV prevalence amongst the National adult population (aged 15–49 years) had been estimated at 0.26% (0.22%–0.32%) in 2015. In the above percentage, the HIV prevalence is about 0.30% among males and at 0.22% among females. Whereas, children aged less than 15 years account for 6.54%, while two fifth (40.5%) of the total HIV infections in India are among females. With an annual estimation, in 2015, India had around 86,000 new HIV infections. In comparison this has declined by around 66% (2000) and 32% (2007). In 2015, estimated 67,600 people died from AIDS-related diseases. In comparison, this has declined by around 54% since 2007. This declining trend is due to the expansion in the access to free Anti-retroviral Treatment to PLHIV since 2004.<sup>xxxi</sup>

However, we need to glance at the trends amongst large sections of society affected by HIV/AIDS. There are **about 868,000 female sex workers in India, and out of this 2.8% are living with HIV**. Though sex work is not strictly illegal in India but, associated activities such as running a brothel are illegal. Amongst the **male sex workers, a similar condition prevails and about 33% of them are HIV infected**. In 2009, Delhi High Court had de-criminalised consensual same sexual conduct. However, later in 2013, it was re-criminalised by the Supreme Court of India. There are **about 427,000 men who have sex with men (MSM) in India. Out of these 4.4% are living with HIV**. Though the exact number of transgender people in India are not known. In April 2014, the Supreme Court of India had recognised the transgender people as a distinct gender. According to the data collected by the NACO since 2012, indicates that there are about **8.8% of the transgender people were infected by HIV**.<sup>xxxii</sup>

**The HIV prevalence amongst the 177,000 people who inject drugs (PWID) is 7%**. This has remained unchanged since 2007. This is because many people get on to drugs in their teenage years. Eventually, with the use of shared needles and syringes puts them at higher risk of HIV transmission. Available data indicates that

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**prevalence amongst the female PWID is twice that of male PWID.** According to researchers across the world, migrant workers are also prone to a higher risk of HIV infection. In India, there are **about 7.2 million migrant workers and of these about 1% is HIV infected.** It is also noted that about 75% of the women who test positive for the HIV test have a husband who is a migrant worker. Similarly, 2 million truck drivers in India are also prone to HIV. Out of these, 2.6% are HIV positive. This is because about 36% of the clients of sex workers are truck drivers.<sup>xxxiii</sup>

### The Criminals - Marginalised Sections

Despite its efforts against discrimination, **the Bill fails to reflect upon the legal conflict with the case-laws, which discriminate against sex workers, homosexuals and transgenders.** For instance, the **Immoral Trafficking Prevention Act, 1956**, does not provide for the illegality of the sex workers, however, it is often used by the police to criminalise, punish and prosecute female sex workers. Similarly, the homosexual community is subject to criminal actions under **Section 377 of the Indian Penal Code.**<sup>xxxiv</sup> By not safeguarding the rights of these marginalised sections, the State continues to harass and persecute them. Hence, the HIV Bill is isolated, and it would definitely face difficulties with the effective implementation of its objective.



### PART V. CONCLUSION

The Bill has incorporated the principles of human rights and seeks to establish an egalitarian legal regime to support India's prevention, treatment, care and support efforts against the HIV infection. However, in isolation the Bill will not be able to achieve any significance success. The prime emphasis of the Bill has been on guaranteeing the non-discrimination of the PLHIV in the society around them and in the healthcare services being offered. Since, a **large number of PLHIV** belong to the marginalised sections who are subject to criminal conduct beyond the purview of the HIV Bill, **will continue to be discriminated against based on the other laws**. Therefore, to achieve complete non-discrimination, the **Government has to reflect** upon the other legislations, such as, the **Anti-Trafficking Bill** which does not convict all sex-workers; the **Transgender Persons Bill, 2016** which provides for a broad understanding of the transgender identity; the **decriminalisation of Section 377**.<sup>xxxv</sup> Once these legislations are approved, only then will these marginalised groups really have an effective framework that will ensure non-discrimination in its true sense.

Second, being the removal of the **'as far as possible'** phrase in regards to the ART in the Bill. Though the diagnosis and the treatment of HIV are provided free of cost by the Government. However, this clause **will snatch away the legal right of the PLHIV**. Hence, the Bill will be handicapped. Therefore, the Ministry of Health and Family Welfare should **completely do away with this phrase, and take a strong position on the access to the treatment** clause. This will empower the PLHIV and **will provide them access to legal remedies in case of discriminations**, which will not be possible otherwise. With this, India will be able to prevent, control and possibly end the HIV/AIDS epidemic by the year 2030, as a target set under the Sustainable Development Goals of the United Nation.

Third, the Bill has provisions to safeguard the privacy of the HIV person by providing clauses for informed consent and measures for the organizations from disclosing information or the HIV status of the person. However, the Bill includes a few exemptions whereby informed consent is not required or where the information can be disclosed for medical research, and for the purpose of statistical data collection. Moreover, no penalty or punishment has been laid down for the violation of these clauses. Therefore, the Ministry should make it compulsory for an informed consent for medical research and exemptions to disclose information to be allowed on the order from a competent court only. The penalty and punishment should be ascribed for the violations of these clauses.

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### PART VI. BACKGROUND/REFERENCE DOCUMENTS

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