

2020

# HIV/AIDS MODULE for Ombudsman

The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act, 2017 provides for appointment of Ombudsman at State level for redressing grievances related to discrimination against people living with and affected by HIV and AIDS



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## Acronyms

HIV	Human Immuno deficiency Virus
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AIDS	Acquired Immunodeficiency Syndrome
PLHIV	People Living with HIV
NACO	National AIDS Control Organization
UNDP	United Nations Development Programme
IEC	Information Education Communication
NACP	National AIDS Control Programme
NALSA	National Legal Services Authority
SALSA	State Legal Services Authority
DALSA	District Legal Services Authority
FSW	Female Sex Worker
MSM	Men who have sex with men
TG	Transgender
IDU	Injecting Drug User
STI	Sexually Transmitted Infection
RTI	Reproductive Tract infection
ICTC	Integrated Counselling and Testing Centres
FICTC	Facility Integrated Counselling and Testing Centres
CBT	Community Based Testing
HST	HIV Self Testing
PPTCT	Prevention of Parent-To-Child Transmission of HIV
ART	Anti-Retroviral Therapy
NGO	Non-Governmental Organisation
CBO	Community Based Organisation
OI	Opportunistic Infection
LWS	Link Worker Scheme
TI	Targeted Intervention
CD4	cluster of differentiation 4
TTI	Transfusion Transmitted Infections
NACB	National AIDS Control Board
DAPCU	District AIDS prevention & Control Unit
DACO	District AIDS Control Officer
NHM	National Health Mission
CD4	Cluster of Differentiation 4
HSS	HIV Sentinel Surveillance
IBBS	Integrated Biological & Behavioural Survey
NFHS	National Family Health Survey
CSC	Community Care Centre
DDG	Deputy Director General
BCC	Behaviour Change Communication
<u>FICTC</u>	<u>Facility Integrated Counselling and Testing Centres</u>

HCTS	HIV Counselling and Testing Services
EMTCT	Elimination of Mother to Child Transmission
CoE	Centers of Excellence
p-CoE	Pediatric Centers of Excellence
FI-ART	Facility Integrated ART Centers
LAC	Link ART Centers
HCP	Health Care Personnel
SRL	State Reference Laboratory
PrEP	Pre-Exposure Prophylaxis
SIMS	Systematic Information and Management System
SMS	Short Message Service
ICRW	International Center for Research on Women

## Introduction

India has third largest number of people living with HIV/AIDS (approx. 21.4 lakh). HIV is not driven only by a medical aspect but many socio-economic factors also affect the cause and consequence of HIV. We require a multi-faceted approach for dealing with HIV/AIDS.

HIV in India is more than three decades old and India's HIV Prevention Programme has been successful in halting and reversing the tide of the epidemic. The adult prevalence has come down from approx. 0.50% in 1999 to 0.22% in 2017. As per the recently released, India HIV Estimation 2017 report, National adult (15–49 years) HIV prevalence in India is estimated at 0.22% in 2017.

Laws are imperative to protect the rights of people against any misdeed by any person, institution and also the state itself. They also facilitate in regulation of the society. India's newly passed "*The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act, 2017*" is the first of its kind in south Asia. South Africa and Nigeria have also passed laws banning some forms of discrimination against People Living with HIV (PLHIV).

The HIV/AIDS Bill 2014 was passed by the Rajya Sabha on 21st March, 2017 and by the Lok Sabha on 11th April, 2017. The Bill received Presidential Assent on 20th April, 2017 and subsequently was notified on e-gazette on 21st April, 2017. The Act has come into force since 10<sup>th</sup> September, 2018.

The Act safeguards the rights of people affected and infected by HIV. The provisions of the Act address HIV-related discrimination strengthening the existing programme by bringing in legal accountability and a formal mechanism for inquiring into complaints and redressing grievances in the form of a Complaints Officer at Establishments and Ombudsman at State level. The Act also provides for informed consent and confidentiality in respect of testing and treatment of PLHIV.

This module has been developed for building capacity of Ombudsman to be appointed by States. This module has five chapters; first chapter provides an outline to basics of HIV and AIDS, the second provides an overview to AIDS Prevention Programme since its inception to gradual phases and various divisions at NACO along with their area of work. Chapter three explains important provisions of the HIV and AIDS Act, 2017 with special focus on roles and responsibilities of the Ombudsman drawing from the Act and State rules. Chapter IV covers stigma and discrimination at health, education and establishment settings and chapter V provides a basic understanding about guardianship and sex, sexuality, sexual orientation and gender.

## CHAPTER I-

### Basics of HIV and AIDS

Human Immunodeficiency Virus (HIV) is a virus that affects the immune system. Prolonged virus makes the body susceptible to many other infections and health eventually deteriorates. While Acquired Immunodeficiency Virus (AIDS) refers to a set of symptoms and illnesses that occur at the late stage of HIV infection. It is possible that one can have HIV but not AIDS. Treatment for HIV and AIDS is available which coupled with healthy lifestyle can prolong longevity. Earlier those infected with HIV would generally develop AIDS early

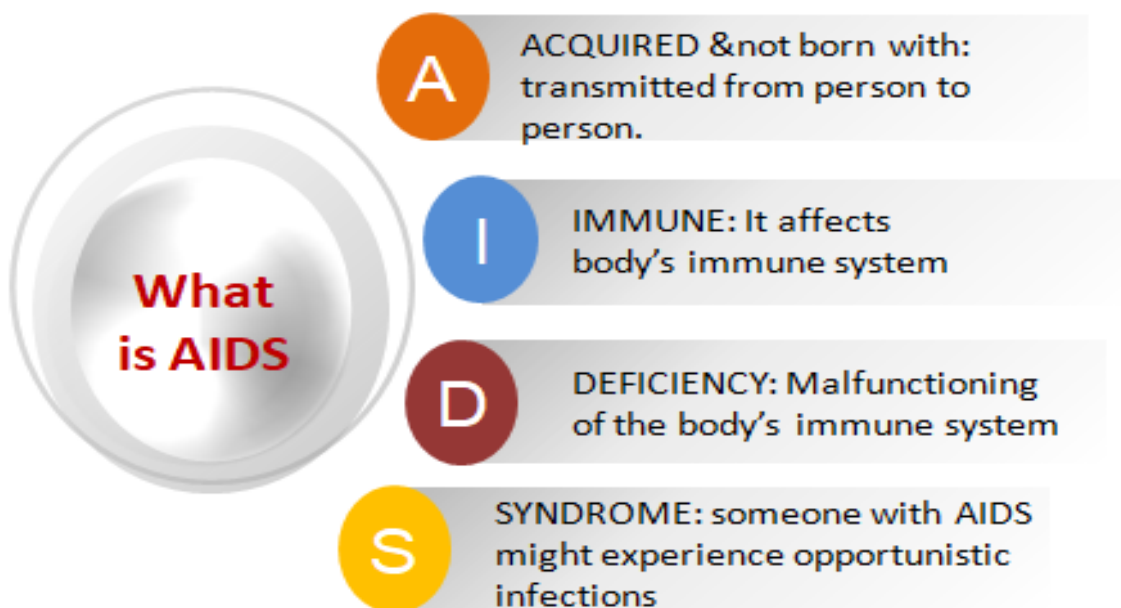
but currently due to advanced treatment and medication people can significantly delay getting AIDS.

### **What is HIV?**

HIV is a virus that attacks the immune system, which provides resistance against toxins and infections. It is the body's natural defence against diseases. The virus destroys T cells (also known as Helper T cells or CD4 cells) a type of white blood cell in the immune system. T-cells majorly regulate the responses of immune system by directing other cells to perform. They also regulate both innate and adaptive immune responses. HIV destroys CD4 cells which gradually breaks down a person's immune system. This leaves the person more vulnerable to other infections and viruses around and makes it harder for the body to fight diseases and infections.

### **What is AIDS?**

AIDS is not a virus in isolation, it is a set of symptoms caused by HIV itself. A person with AIDS has a very weak immune system and if untreated for long can be fatal. Although there is currently no cure for HIV with the right treatment and support, people with HIV can live long and healthy lives. For this it gets important to take correct treatment. Two things which assure correct treatment are, timely uptake of medication and proper adherence. Being diagnosed with HIV does not mean the person has AIDS. Healthcare professionals diagnose AIDS only when people with HIV infection begin to get severe opportunistic infections (OIs), or their CD4 cell counts fall below a certain level.



### Transmission of the virus

HIV can be transmitted through:

- Unprotected sex with an HIV infected person;
- HIV infected mother to her baby – during pregnancy, during birth or after delivery through breast milk.
- Transfusion of HIV infected blood or blood products;
- Sharing of needles contaminated with HIV infected blood;

Mode of transmission can be summed as blood, semen, vaginal and rectal fluids and breast milk. The virus doesn't spread in air, water or through casual contact. The virus cannot be transmitted through sweat, saliva or urine either.

Apart from the above modes of transmission, HIV doesn't spread by any other way. **HIV doesn't spread through** ordinary social contact or sharing physical spaces for example by shaking hands, travelling in the same bus, eating from same utensils, by hugging, contact with saliva, social kissing or mosquito bites.

## Precautions against the spread of virus

Transmission of HIV can be prevented by undertaking certain precautions:

- ✚ *Regular and consistent use of condom:* Regular use of condom at every sexual encounter provides protection from transmission of HIV virus as well as unwanted pregnancy and other sexually transmitted infections. They are much less protective if used inconsistently and/or incorrectly. Timely testing and treatment for sexually transmitted infections also reduces risk of contracting HIV.
- ✚ *Correct use of condoms:* Condoms are highly effective in preventing HIV transmission but the use has to be accurate and consistent. A new condom after due check of its expiry date should be used every time before every sexual encounter.
- ✚ *Non-usage of used syringe:* Sharing an already used syringe and needle puts a person at the risk of transmission of HIV virus. The reuse of a HIV infected blood - contaminated needle or syringe by another drug injector has some quantity of the HIV infected blood present in the hollow of the needle and the base of the syringe cylinder. Hence the reuse of such needles and syringes carry high risk of HIV transmission or any other blood borne virus when pushed into the blood stream of the next user. The person also becomes susceptible to other infections found in the blood like hepatitis C and hepatitis B etc.
- ✚ *Proper and just use of Post-Exposure Prophylaxis (PEP):* PEP is a regimen where antiretroviral medicines are taken after potential exposure to HIV to prevent from being infected by HIV. PEP should be used as early as possible and definitely within a stipulated time of 72 hours (3 days). On realization that one got needle stick injury from HIV positive person can take PEP after due consultation with the healthcare provider.
- ✚ *Know your status and that of the partner:* It gets imperative to know ones HIV status in order to assure speedy access to treatment and medication. Timely testing and treatment can assure a healthy life. With Gol's 'Test and Treat' Programme in place, a person tested positive for HIV is immediately put on Antiretroviral Therapy (ART) which suppresses the virus and stops the progression of HIV disease.

- ✚ Obtaining blood and components from a licensed blood bank: Registered Medical practitioners to procure and transfuse blood/ blood components which has been screened for HIV and other infections to any patient who needs it.
  - *Blood Bank's responsibility:* Blood Bank must select only healthy persons from low risk population to donate blood. All donated blood units must be screened for five Transfusion Transmitted Infections (TTI) ie HIV, HBV, HCV, Malaria and Syphilis in accordance to the provisions in the Drugs and Cosmetics Act and Rules thereof.
  - *Clinician's responsibility:* Blood or blood components must be prescribed only when actually indicated and transfused only when absolutely necessary. Guidelines for appropriate clinical use of blood/ components must be followed, with proper bedside practices and documentation. Blood and Blood Components should only be sourced from licensed blood banks/ approved blood storage centres.
  - *Recipient's responsibility:* Blood and Blood Components should only be sourced from licensed blood banks/ approved blood storage centres and transfused only with a proper medical prescription and supervision of a Registered Medical Practitioner.
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## CHAPTER-II

### HIV/AIDS Prevention and Control Programme

The **National AIDS Control Programme (NACP)**, launched in 1992, is being implemented as a comprehensive programme for prevention and control of HIV/AIDS in India. Over time, the focus has shifted from just raising awareness to behaviour change; from a national response to a more decentralized response, to increasing involvement of NGOs and networks of PLHIV and mainstreaming with other Ministries/Departments and industries.

#### **The evolution of National AIDS Control Programme:**

**NACP-I (1992-1999):** In 1992, the Government launched the first National AIDS Control Programme (NACP-I) and demonstrated its commitment to combat the disease. NACP-I was implemented with an objective of slowing down the spread of HIV infections so as to reduce morbidity, mortality and impact of AIDS in the country. National AIDS Control Board (NACB) was constituted and an autonomous **National AIDS Control Organization (NACO)** was set up to implement the project within the Ministry of Health and Family Welfare. The first

phase focused on awareness generation, setting up surveillance system for monitoring HIV epidemic, measures to ensure access to safe blood and preventive services for high risk group populations.

**NACP-II (1999-2006):** In November 1999, the second National AIDS Control Project (NACP II) was launched with two key objectives of NACP II:

- (i) to reduce the spread of HIV infection in India
- (ii) to increase India's capacity to respond to HIV/AIDS on a long-term basis.

This was the phase of set up of State AIDS Control Societies (SACS) and decentralisation of response. Anti retroviral treatment was also initiated during this phase in addition to Counselling and testing for HIV.

**NACP-III (2007-2012):** In response to the evolving epidemic, the third phase of the national programme (NACP-III) was launched in July 2007 with the goal of *Halting and Reversing the Epidemic* by the end of project period. NACP-III aimed at halting and reversing the HIV epidemic in India over its five-year period by scaling up prevention efforts among High Risk Groups (HRG) and General Population and integrating them with Care, Support & Treatment services.

In addition to above, District AIDS Prevention and Control Unit (DAPCUs) are also established in high priority districts that undertake cross-cutting management and coordinate with all the HIV facilities in the district.

**NACP-IV (2012-17):** after successful implementation of NACP-III, fourth phase was launched with the goal to accelerate reversal and integrate response. Other objectives were to reduce new infections by 50% (2007 Baseline of NACP III) and to provide comprehensive care and support to all persons living with HIV/AIDS and treatment services for all those who require it. The key strategies are as follows:

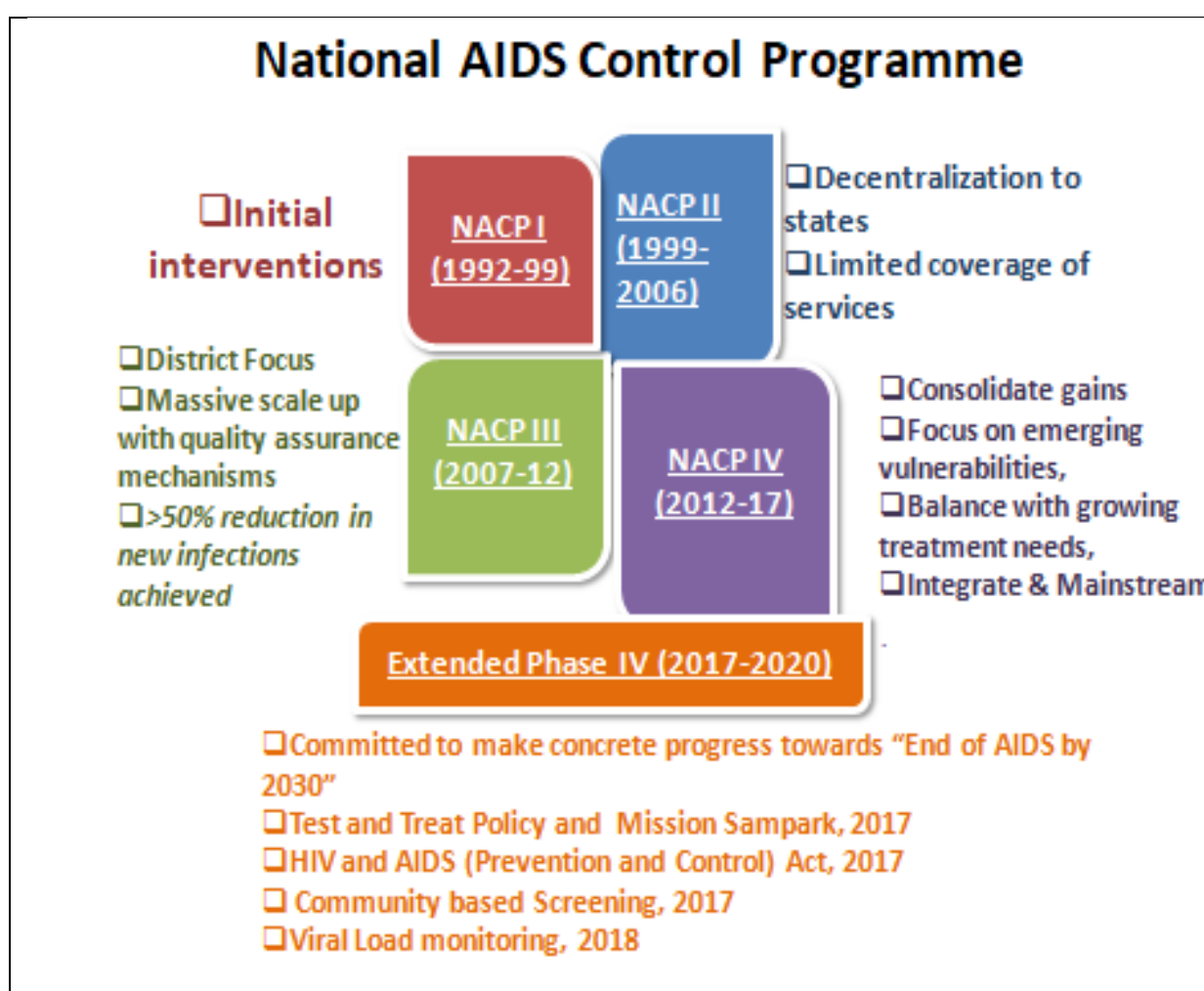
- a) Strategy 1: Intensifying and consolidating prevention services, with a focus on HRGs and vulnerable population.
- b) Strategy 2: Increasing access and promoting comprehensive care, support and treatment
- c) Strategy 3: Expanding IEC services for (a) general population and (b) high risk groups with a focus on behaviour change and demand generation.
- d) Strategy 4: Building capacities at National, State, District and Facility levels.
- e) Strategy 5: Strengthening Strategic Information Management Systems

During this phase, NACO was integrated as a Division within MoHFW.

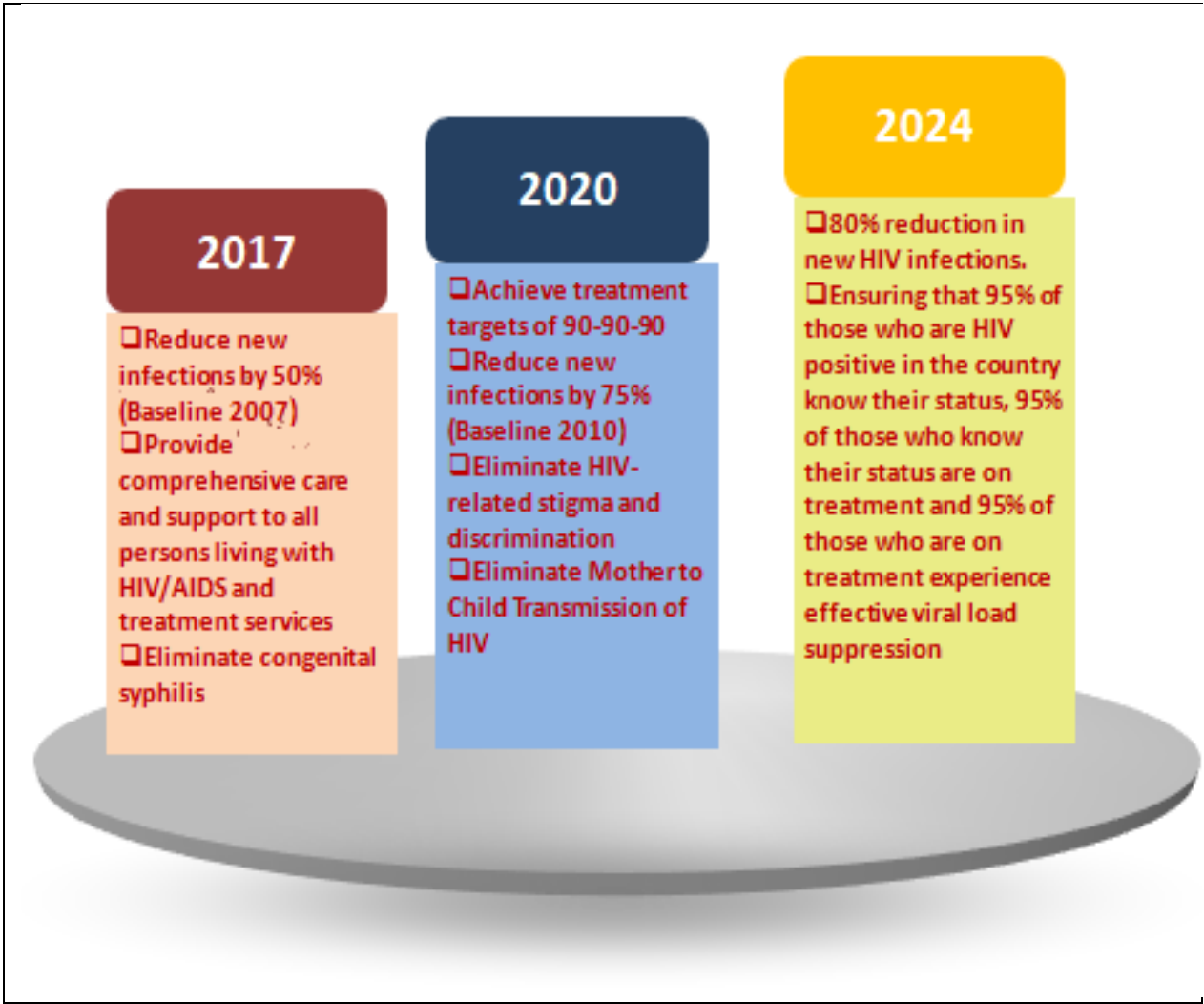
### Extended Phase IV- 2017-2020

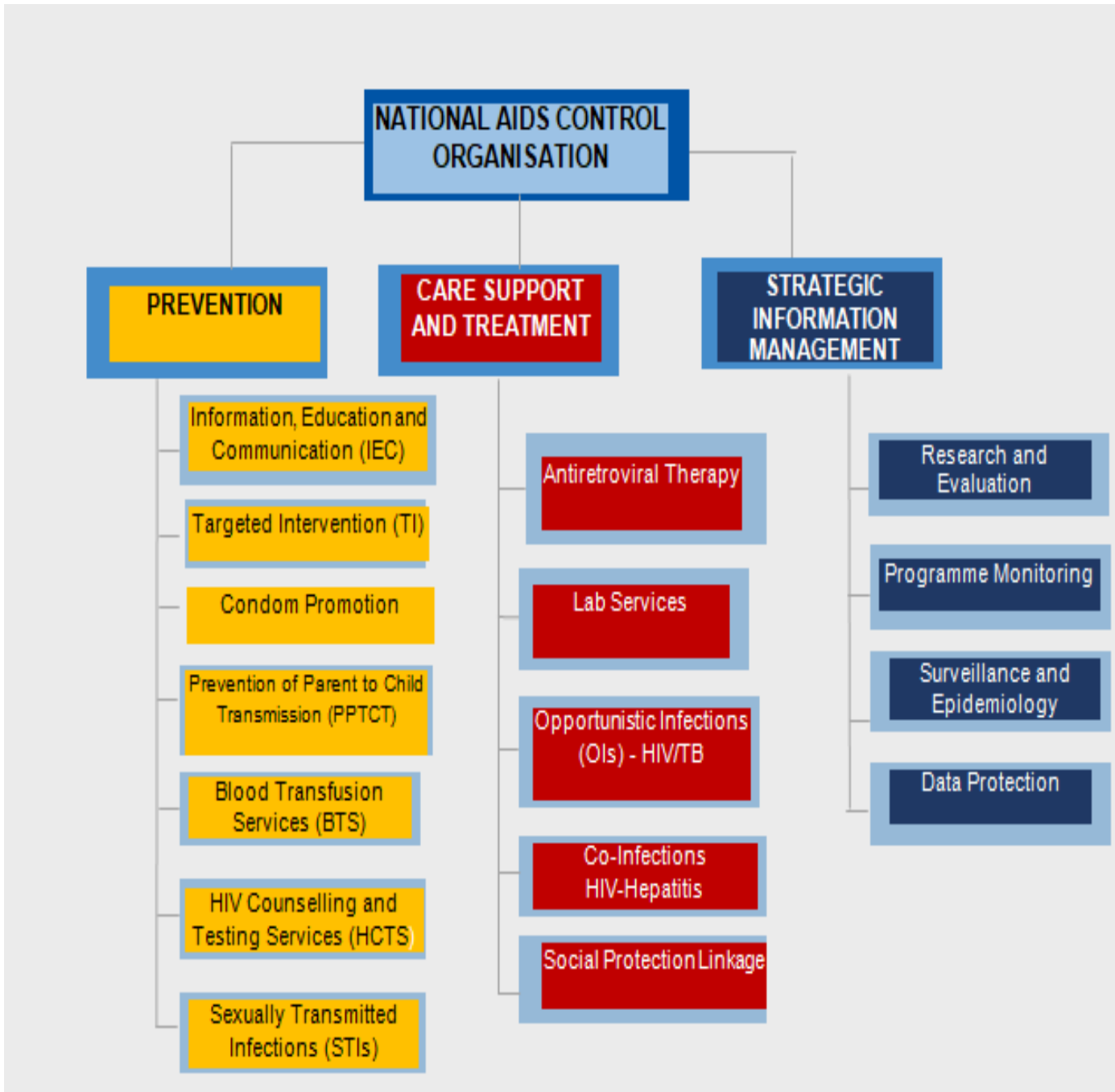
Major policy changes undertaken for implementation for the period are as follows:

- i. Committed to make concrete progress towards “End of AIDS by 2030”
- ii. Test and Treat Policy and Mission Sampark
- iii. HIV and AIDS (Prevention and Control) Act, 2017



A National Strategic plan has been developed for 2018-24 with the alignment to Sustainable Development Goals which aim to **end the epidemic of AIDS by 2030**. Other **fast-track targets** which will eventually facilitate in meeting the SDGs are as follows:





<b>ADVOCACY, PARTNERSHIPS and MAINSTREAMING</b>			
<b>Administration</b>	<b>Procurement</b>	<b>Human Resource</b>	<b>Financial Management</b>
<b>INFORMATION TECHNOLOGY</b>			

*Organizational framework of National AIDS Control Programme for Prevention, Care, Support and Treatment. Areas like Information, Education and Communication, Programme Monitoring and Research and Evaluation are cross cutting.*

## **PREVENTION**

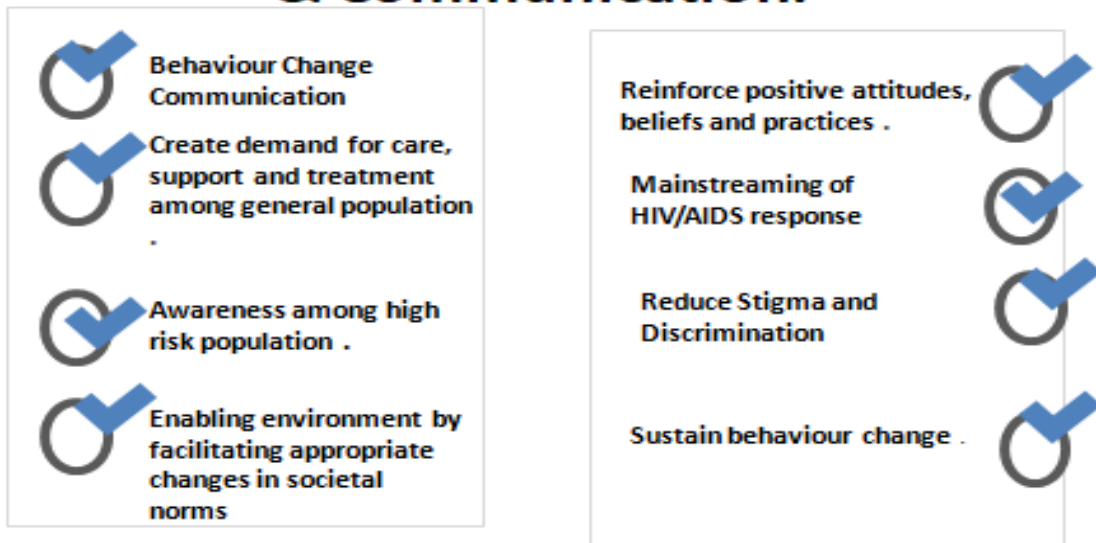
NACO since NACP II has strategically focussed on prevention front. The objective has been to generate awareness and target population which was more vulnerable and susceptible to HIV virus, thus, prevent people from getting infected by HIV virus. The key populations for HIV include Female Sex Workers, Men having Sex with Men, Injecting Drug users and Transgender/ Hijras. Bridge populations include Truckers, Migrants, Prison inmates, clients of sex workers etc. Other groups for focussed interventions include youth, women and children.

Various divisions at NACO have been involved in prevention activities:

## **Information, Education and Communication (IEC)**

The division has been in place since NACP I, Information, Education & Communication, Youth & Mainstreaming are important components of the NACP. With the expansion of services for counselling and testing, ART, STI treatment and condom promotion, the demand generation campaigns continue to be the focus of the NACP-IV communication strategy.

## Objectives of Information, Education & Communication.



### Activities undertaken by the division are as follows:

- *Outreach through mass-media:* through TV & Radio campaign on 9 Thematic Areas, cinema theatre, social media through FB, Twitter, Youtube etc
- *Outreach via mid-media:* Posters, hoardings, public displays, bus panels, etc., National Folk Media Campaign, Special events on World AIDS Day, International Youth Day, National Voluntary Blood Donation Day etc.
- *Outreach via On-ground Mobilization & Interpersonal Communication:* Adolescent Education Programme in more than 53,000 schools. Red Ribbon Clubs in colleges in 12,000 college, Out of School Youth/college at state level
- *Single window model:* is another project for delivery of social protection benefits to HIV-affected person. Over a million of social protection benefits and entitlements have been availed by both HIV infected and affected.
- *Mainstreaming:* NACO collaborates with various key Ministries/ Departments of Govt. of India and other key stakeholders with objective of multi-pronged, multi-sectoral response for risk reduction, integration of services and social protection for people infected and affected by HIV. Currently NACO has signed 16 MoUs with various Ministries and Departments of Govt. of India.
- *Social protection schemes:* objective is to link all PLHIV to different Social Protection Schemes in the state for reduction in vulnerability and mitigate the impact of HIV. Availability of social benefits to PLHIV would facilitate in improving the quality life of PLHIV and ensure social, legal and economic rights. The areas covered are of nutrition, healthcare, shelter, health insurance, legal insurance, legal aid, travel support, pension etc.

## Targeted Interventions

Targeted Intervention Division provides services for prevention of HIV among marginalised and most at risk population due to their sexual behaviour like Female Sex Workers (FSWs), Men having Sex with Men (MSM), Transgender (TG), Injecting Drug Users (IDUs) and bridge population including Truckers and Migrants in partnership with Non-Government Organisations (NGOs)/Community Based Organisation (CBOs).

Targeted interventions are a resource-effective way to implement HIV prevention and care programmes in settings with low-level and concentrated HIV epidemics. They are also a cost-effective method of reaching people who are most at risk in more generalized epidemics.

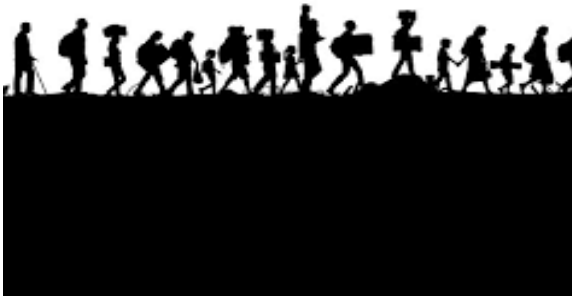
Targeted interventions are aimed at offering prevention and care services to high risk populations/most at risk population:



The Programme provides them with the information, means and skills to minimize HIV transmission and improving their access to care, support and treatment services.

Apart from the high risk population, services for prevention, care and support are also extended to the bridge population. Bridge population includes:

## Migrants



## Truckers

Major features of Targeted interventions programme are as follows:

- ✚ To work for people within the community who are most at risk of HIV and STI infection.
- ✚ To help change the behaviour and practices not the identity.
- ✚ To look at their issues from a broader perspective of interventions.
- ✚ To adapt the interventions so that they are culturally and socially appropriate to the target audience.
- ✚ Judicious use of resources in order to maximize the benefit with limited resources.
- ✚ To acknowledge that barriers to accessing health-care services exist for some populations within communities and strive towards addressing them.
- ✚ To acknowledge that people who are at risk of HIV infection are often marginalized from the broader community, stigmatized and discriminated against and work towards providing an enabling environment.

These prevention programmes are being implemented by more than 1400 NGOs/CBOs. The services provided them cover the following:

## Components of TI



NACO also reaches out to the rural HRGs and other vulnerable population with HIV/AIDS services through Link Worker Scheme (LWS) which focuses primarily on high prevalence and vulnerable districts in India.

In order to strengthen prevention activities and to achieve the fast track targets 2020 along with India's commitment to end of AIDS by 2030 some of the strategic initiatives are underway like revamping of old TI strategy, strengthening and expanding tuberculosis services from TIs as well as LWS and prison interventions and other closed setting interventions providing comprehensive HIV/TB treatment with multiple strategies including post-release social reintegration services.

**Prison Intervention:** The National AIDS Control Organisation (NACO) under its National AIDS Control Programme, categorised prisoners as one of the 'special groups'. NACO is committed to ensure equal access to HIV/TB services for people living in prisons and other closed settings such as Swadhar, Ujjawala and other State-run HOMES. NACO started the launch of prison HIV interventions as part of project Sunrise at Imphal, Manipur. Since then, NACO has rapidly scaled up the intervention across India. The intervention is currently being implemented through an integrated approach with the active involvement of key stakeholders including SACS, State Prisons department, department of Women and Child

Development, Social Welfare department and civil society organizations, to ensure sustainability.

## **Prevention of Parent to Child Transmission (PPTCT)**

The PPTCT programme aims to prevent the transmission of HIV from an HIV infected pregnant mother to her newborn baby. The programme entails counselling and testing of pregnant women in the ICTCs.

With effect from 1st January 2014, pregnant women who are found to be HIV positive are initiated on lifelong ART irrespective of CD4 count and WHO clinical Staging; their newborn (HIV exposed) babies are initiated on 6 weeks of Syrup Nevirapine immediately after birth so as to prevent transmission of HIV from mother to child and is extended to 12 weeks of Syrup Nevirapine if the duration of the ART of mother is less than 24 weeks.

### **The Goals of the PPTCT Programme**

In line with WHO standards for a comprehensive strategy, the National PPTCT programme recognises the four elements integral to preventing HIV transmission among women and children. These are:

Prong 1: Primary prevention of HIV, especially among women of child bearing age.

Prong 2: Preventing unintended pregnancies among women living with HIV.

Prong 3: Prevent HIV transmission from pregnant women infected with HIV to their child.

Prong 4: Provide care, support and treatment to women living with HIV, her children and family.

The Programme aims at reaching 95-95-95 by 2020 where 95% of estimated pregnant women shall be registered for ANC and 95% of the registered women shall be screened for HIV and 95% of diagnosed positive women shall be on ART.

## **Blood Transfusion Services (BTS)**

Blood transfusion services provides for adequate quantity of safe, quality and affordable blood and blood components to the needy. Strengthening Blood Transfusion Services has been an integral part of National AIDS Control Programme since inception (Phases I – IV)

Strategies include improving Access, Availability, Safety & Quality of Blood through:

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*HIV/AIDS Module for Ombudsman*

- Increase in Regular Voluntary Non-Remunerated Blood Donation
- Promoting Component Preparation and Quality Management Systems
- Networking & coordination between Blood Banks and e-initiatives
- Capacity Building, IEC, Monitoring & Oversight

All initial HIV sero-reactive blood donors are referred to ICTC for confirmation of diagnosis and referral to treatment. National Blood Transfusion Council (NBTC) is the apex policy making body for all matters pertaining to blood banks and blood transfusion services and is housed at NACO, MoHFW.

## HIV Counselling and Testing Services (HCTS)

HIV Counselling and testing services (HCTS) for HIV infection is the critical first step in detecting and linking people with HIV to access treatment cascade and care. These services are provided through facilities established within general health systems and community settings including private sectors.

- Integrated Counselling and Testing Centres (ICTC) for confirmed diagnosis of HIV.
- Facility Integrated Counselling and Testing Centres(FICTC) for screening of HIV.
- Community Based Screening (CBS)

**Basics of Counselling and Testing:** Counselling is a confidential dialogue between an individual and a counsellor. It aims to provide information on HIV/AIDS and bring about behaviour change in the individual. It also enables the individual to take a decision regarding HIV testing and to understand the implications of the test results.

Counselling includes the assessment of individual's risk of acquisition and transmission of HIV, facilitation of preventive behaviour, and coping mechanisms in case an individual is found to be HIV positive. More importantly, counselling is intended to address the physical, social, psychological and spiritual needs of the individual availing HCTS.

**Counselling and Testing at NACO: NACO is augmenting efforts to scale up HCTS for priority populations with a special focus on reaching the unreached. A strategic mix of HCTS has been planned to facilitate early diagnosis of HIV amongst priority populations. The aim is to maximize efficiency and cost-effectiveness while ensuring equity.**

Every effort needs to be made to ensure timely and prompt linkage of those found HIV-positive to treatment, care and support services. Likewise, all those individuals found non-reactive for HIV should be appropriately counselled, referred and linked for follow-up HIV testing, while ensuring privacy and confidentiality.

# Priority Population under HCTS

<ul style="list-style-type: none"> <li>*Infants and children</li> <li>*Patients with kala-azar</li> <li>*Persons who have undergone sexual assault</li> <li>*Accidental sexual exposure due to condom breakage.</li> </ul>	<p><b>Adolescents (10-19 years)</b></p> <p>Provider Initiated- Patients referred from OPDs for clinical suspicion of HIV due to AIDS defining illness.</p> <p>Tuberculosis patients including presumptive TB cases</p>	<p>Sexual partners / spouses of PLHIV (couples)</p> <p>Sexual and injecting partners of HRGs</p>	<p>Pregnant &amp; breastfeeding women</p> <p>STI / RTI attendees &amp; patients</p>	<p>Emergency settings (casualty):</p> <p>Patients who present with signs and symptoms suggestive of HIV/AIDS in emergency health-care setting</p>
<p><b>Occupational exposure:</b> Health-care workers exposed to infected material, with a possible risk of acquiring HIV, need to be referred to HCTS before initiating any PEP and, after completion of the PEP course</p>		<p><b>High-risk groups (HRGs):</b> HRGs comprising core groups such as FSWs, MSM, IDUs, TS/TG &amp; bridge populations such as migrants and truckers, prisons, closed settings.</p>		

## Diagnosis of HIV infection

HIV infection is diagnosed largely by the detection of antibodies against HIV in the blood of infected patients. NACO uses Rapid HIV tests at ICTC to diagnose HIV by detection of antibodies. It also gets important to understand the term window period, window period is the time duration between the potential exposure of a person to HIV virus and the time when the test would give an accurate result. During the window period a person can be infected with HIV but still test HIV negative.

- Follows acute infection with HIV, before HIV antibodies can be detected in the patient's blood stream.
- Patient is highly infectious, despite testing HIV antibody negative; HIV is replicating rapidly in all parts of the body.
- Typically up to **12 weeks'** duration but may be shorter in more sensitive HIV antibody assays (particularly those incorporating HIV p24 antigen).

## Informed Consent:

Informed consent remains one of the essential components of testing and

should always be obtained individually and in private. Even if pre-test counselling is provided in a group setting, each individual should give informed consent for testing with an opt-out option. Even HIV and AIDS Act, 2017, also mandate informed consent for HIV testing under section 5 of the Act

### ***Post Counselling***

All efforts must be made to provide same day test results and post-test counselling to all those accessing HIV services at the HCTS facilities.

Post-test counselling helps the individual to understand and cope with the HIV test result. Individual post-test counselling must be conducted irrespective of whether the result is HIV non-reactive (screening facility), HIV-negative or HIV-positive (confirmatory facility). HIV-negative clients to be given more information on safe sex, safe drug use practice and responsible behaviour. They should be encouraged to clear out doubts and raise queries if any and remain negative and go for regular testing.

### ***Confidentiality and consent***

Pre-test Counselling:

Pre-test counselling is provided to the individual before HIV testing using posters, flip charts, brochures and short video clips so as to prepare them for the HIV test and to address myths and misinformation regarding HIV/AIDS.

This can be done in two ways – (a) one on one counselling and (b) group counselling. One-on-one counselling should be done for all individuals accessing the HCTS services. Group counselling can be done when the counsellor is addressing a group such as pregnant women at ANC clinics.

#### ***Pre-test counselling points while screening the individual***

- a) Provide information on HIV and AIDS: what is HIV, what is AIDS, window period, route of transmission, prevention message, care, support and treatment services
- b) Explain the benefits of HIV testing
- c) Assure the individual that the test result and any information shared will be kept confidential
- d) Explain that the individual has the right to opt out of HIV testing and this will not affect their access to any other health-related services
- e) Obtain informed consent and document it in the relevant register
- f) Risk assessment of the individual
- g) Provide information on genital, menstrual and sexual hygiene
- h) Demonstrate the use of a condom using a model
- i) Provide information on spouse /sexual partner testing
- j) Conduct symptomatic screening for STI/RTI: Genital discharge/genital ulceration/swelling or growth in the genital area/ itching in the pubic area/ burning sensation while passing urine/ lower abdominal pain/ menstrual irregularities/ bad obstetric history
- k) Conduct symptomatic screening for tuberculosis (TB)
- l) Extend the opportunity to the individual to ask and clarify doubts

***The information may be delivered in a local language and tailored to the specific audience.***

In order to meet the fast track goal of Elimination of Mother to Child Transmission (EMTCT) by 2020 a massive scale up of HIV counselling and testing services has been undertaken specially for pregnant women. NACO has initiated Community Based Screening of HIV last year as one of the innovative strategy to reach first 90 out of the target 90:90:90 by 2020. Currently the bulk of Community Based Screening efforts are through targeting high risk groups via Targeted Interventions and other Development partners and Civil Society Organisation.

## **Sexually Transmitted Infections (STI)**

These are the infections are infections which can be transferred after having sex with an infected person. Sexually Transmitted Infections (STIs) should be suspected if a woman experiences symptoms of itching around the vagina and/or discharge from the vagina or pain in the lower belly and/or during a sexual act. While on the other hand STIs can be suspected if a man experiences symptoms of discharge from the penis, one/multiple sores at the penis, warts around the penis, pain or swelling in the groin.

It is also to be noted that among women STIs do not always show symptoms. *The chances of HIV transmission increase by 5-10 times in the presence of STIs.*

STIs are managed through a simplified syndromic case management using colour coded drug kits at Designated STI/RTI clinics located at Medical colleges and District Hospitals and at all other public health facilities.

## **CARE SUPPORT & TREATMENT**

Another important aspect of NACO along with prevention has been the care of HIV/AIDS infected and affected population along with their treatment. The Care, Support and Treatment (CST) component of the National AIDS Control Programme aims to improve the survival and quality of life of Person Living with HIV (PLHIV) with Universal access to Comprehensive HIV care.

## **Antiretroviral Therapy (ART)**

Care, Support and Treatment Services includes Free Universal Access to lifelong standardized Anti Retro Viral Therapy (ART), Free Lab Diagnostic and Monitoring services (baseline tests, CD4 testing, targeted viral load), Facilitating long term retention in care, Prevention, Diagnosis and Management of Opportunistic Infections and Linkages to Care and support services and linkage to social protection scheme.

As per National policy of “Test and Treat”, all PLHIV are initiated on life saving ART irrespective of clinical stage, CD4 count, age or population.

CST services are provided through a spectrum of service delivery models including ART Centers, Centers of Excellence (CoE), Pediatric Centers of Excellence (p-CoE), Facility Integrated ART Centers (FI-ART), Link ART Centers (LAC), Link ART Plus Center (LAC Plus and Care & Support Centers established by NACO in health facilities across the country with aim to provide universal access to free and comprehensive CST Services. There are active linkages and referral mechanism for monitoring, mentoring, decentralization and specialized care.

Provision of free antiretroviral therapy (ART) for eligible persons living with HIV/AIDS was launched on 1 April, 2004 in eight Government hospitals located in six high prevalence states. Since then, the programme has been scaled up significantly both in terms of facilities for treatment and number of beneficiaries. As per Dec 2018, app 12.7 Lakh PLHIV are availing free ART from more than 540 ART centers across the country.

## Opportunistic Infections and (HIV/TB)

Screening, Prophylaxis and Management of various opportunistic infections is an important part of comprehensive HIV care. Following intervention are done at ART centers for this

- **HIV-TB:** TB is the most common opportunistic infection among PLHIVs. All patients attending ART centers including new registrations and on follow up patients are screened verbally for 4 symptom complex. In case any one of the symptom is present patients are referred for TB testing. Those diagnosed with co-infection are initiated on Anti TB treatment from ART center followed by ART. When Tb is ruled out, Isoniazide prophylaxis is offered. NACP works in close coordination with RNTCP for managing co-infections to decrease morbidity and mortality due to TB among persons living with HIV/AIDS, to decrease impact of HIV in TB patients and provide access to HIV related care and support to HIV-infected TB patients, to significantly reduce morbidity and mortality due to HIV/TB through prevention, early detection and prompt management of HIV and TB together.
- **HIV-Kala Azar:** Kala Azar or Visceral leishmaniasis is endemic in some districts of States like UP, Bihar and Jharkhand. All PLHIVs with symptoms suggestive of Kala Azar are screened for Kala Azar and those found infected are referred for appropriate treatment.
- **Other Opportunistic Infections:** PLHIVs are regularly screened for co-infection and co-morbidities. Those diagnosed having these are treated appropriately at ART centre or are referred to concerned facility. Those who are vulnerable to opportunistic infections due to low CD4 count or any other reasons are provided with prophylaxis, for eg. Co-trimoxazole.

**Post Exposure Prophylaxis (PEP):** refers to comprehensive medical management to minimise the risk of infection among Health Care Personnel (HCP) following potential exposure to blood-borne pathogens (HIV, Hepatitis B, Hepatitis C). This includes counselling, risk assessment, relevant laboratory investigations based on informed consent of the source and exposed person, first aid and depending on the risk assessment, the provision of short term (four weeks) of antiretroviral drugs (for HIV exposure), with follow up and support.

## Laboratory

Laboratory support is provided to the HIV programme through a network of National and State Reference Laboratories located in Medical Colleges and District Hospitals. These centres oversee the quality in HIV laboratories through:

- Pre-dispatch kit evaluation by laboratories under a consortium.
- Re-testing of samples from ICTC to State Reference Laboratory (SRL)
- Providing Proficiency testing

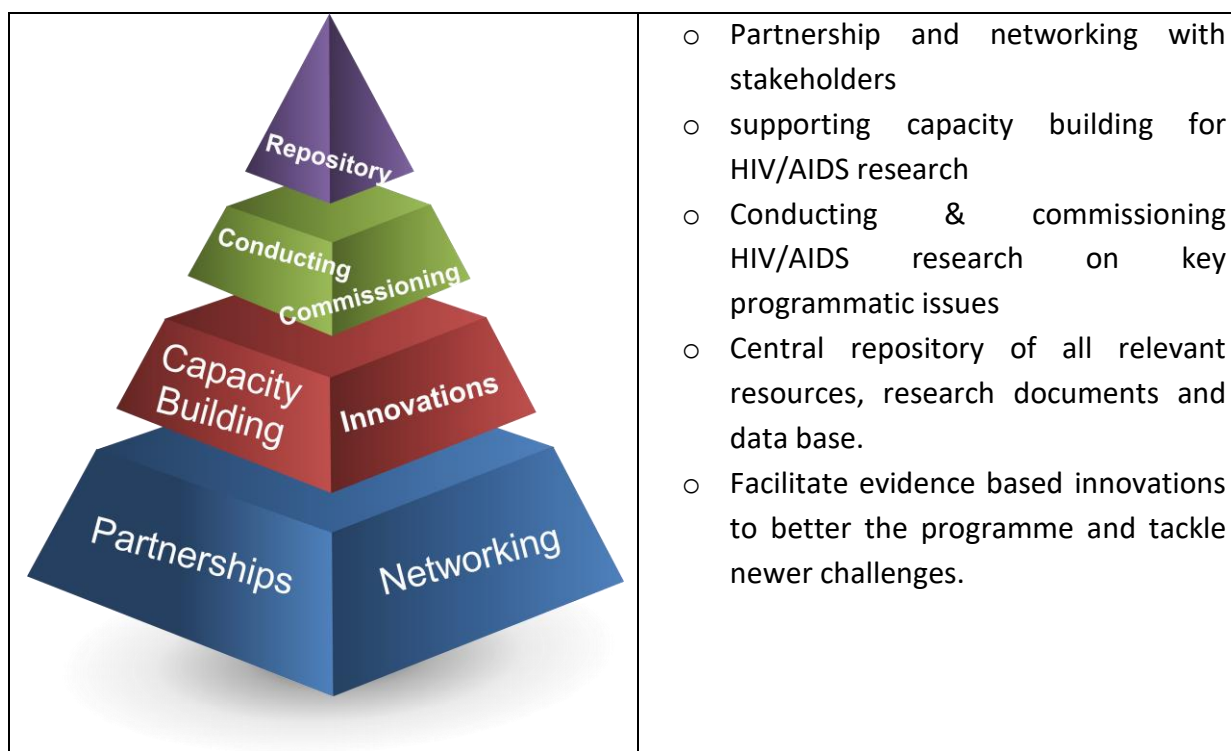
Many labs are also equipped to perform the CD4 test required to monitor the PLHIV on ART. Viral Load testing for all PLHIV once a year who are on ART is provided to monitor the efficacy and adherence to treatment. Decreasing viral loads indicate a good response, while rising viral loads indicate that the treatment is not effective and requires review. Patients are put on second and third line ART based on this test. . Viral load testing is of immense importance to monitor the effectiveness of treatment of patients taking lifelong Anti-retroviral therapy. This will optimize the utilization of 1st line regimens, thus preventing drug resistance and ensuring the longevity of people living with HIV.

## STRATEGIC INFORMATION MANAGEMENT

In order to assure a holistic fight against HIV/AIDS, evidence based Policies and Programmes have played the major role for NACO. Rigorous and scientific evidence has been central to an effective response against HIV/AIDS.

SIM has an overarching knowledge management strategy encompassing the gamut of strategic information activities starting with data generation to dissemination and effective use.

**Research and Evaluation** is another important tool of Strategic Information Management. It aims to promote, conduct and coordinate research on HIV/AIDS through:



Various studies on reaching the unreached, Pre-Exposure Prophylaxis (PrEP), self-testing, adherence issues among PLHIV, drug resistance among children and adult are being undertaken through partnerships with various research institutes.

**Programme Monitoring:** is an integrated web-based reporting and data management system to strengthen the monitoring and evaluation systems at each level. SIMS captures monthly programme monitoring data and manages users across the country for various components of HIV/AIDS Control Programme. SIMS has made real time data entry & access to the user. The online Data Item Report is available for analysis and evidence based action, timely corrective measures for programme managers and policy makers which help in monitoring at the grass root level.

**Surveillance and Epidemiology** complements in refining strategies and prioritization of focus for prevention, care and treatment interventions under NACP. HIV estimates of prevalence, incidence, mortality, human behavior, risk perception, stigma and discrimination, uptake of services, condom use etc are some of the pertinent findings of *HIV Sentinel Surveillance* and *Integrated Biological and Behavioural Surveillance*; these enable

the programme in assessing the impacts at a macro level and tailor-making annual action plans. This enhances the effectiveness and efficiency of the programme.

**Data Protection:** NACO has recently formulated ‘Data Protection Guidelines’ for organizations handling HIV related information<sup>1</sup> (in accordance with section 11 of the HIV and AIDS Act, 2017). Data protection measures include procedures for protecting information from disclosure, procedures for accessing information, provision for security systems to protect the information stored in any form and mechanisms to ensure accountability and liability of persons in the establishment. They are applicable to both public and private sector.

**SOCH and IT Platforms:** SOCH (Strengthening Overall Care for HIV-Patients) is a digital transformation project for national HIV programme to develop a patient centric, integrated, M&E systems with embedded supply chain function to assist in tracking and achieving the global HIV target of 90-90-90. It involves integration of existing standalone systems used by various program divisions to enable seamless tracking of beneficiary and inventory across HIV continuum, as well as enable electronic data interchange (EDI) with IT systems used by other programmes and departments intersecting with national HIV program at beneficiary and/ or inventory level.

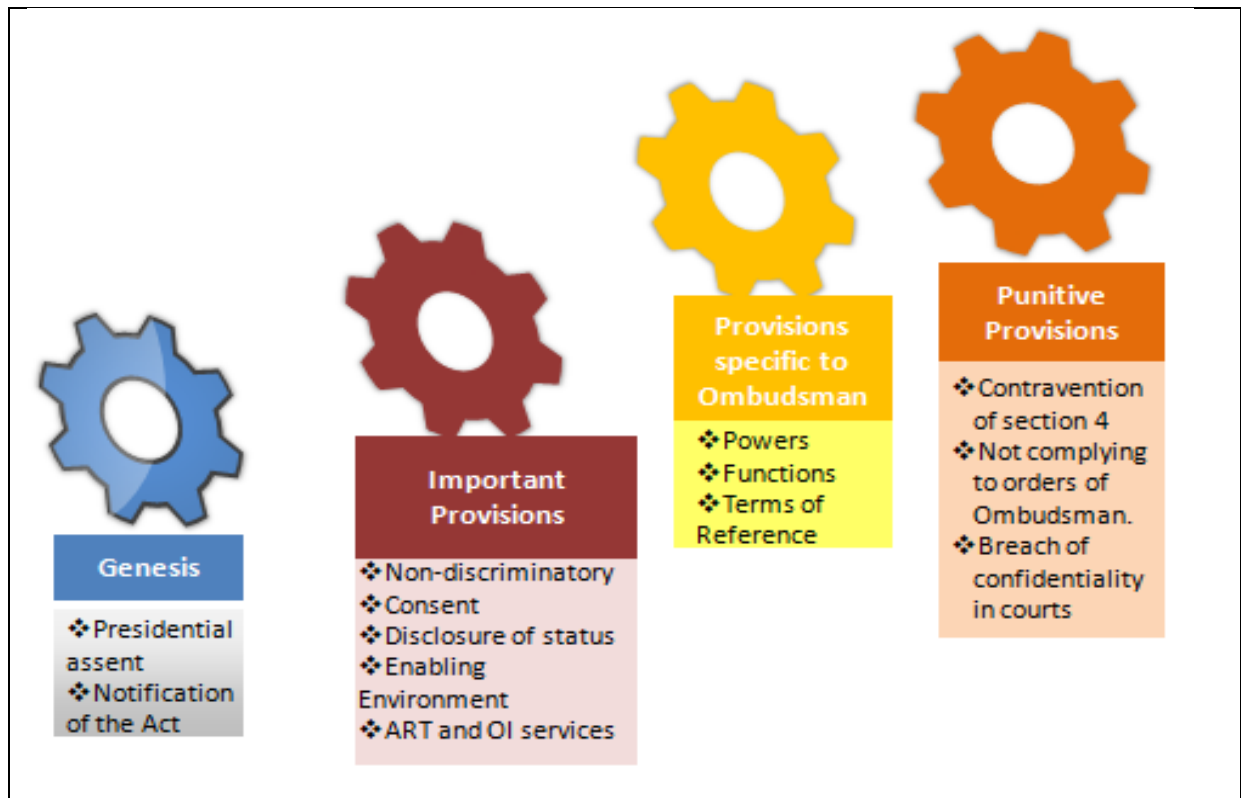
IT systems developed by NACO are used to collect programmatic data from frontline healthcare workers. Currently, five different IT systems (Strategic Information Management System (SIMS), Inventory Management System (IMS), PLHIV-ART Linkages System (PALS), EID Patient Management Tool and Excel based tool TI Management Tool (TMT)) are operational.

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<sup>1</sup> “HIV-related information” means any information relating to the HIV status of a person and includes— (i) information relating to the undertaking performing the HIV test or result of an HIV test; (ii) information relating to the care, support or treatment of that person; (iii) information which may identify that person; and (iv) any other information concerning that person, which is collected, received, accessed or recorded in connection with an HIV test, HIV treatment or HIV-related research or the HIV status of that person.

## CHAPTER- III

### The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act, 2017



#### **Genesis of the Act:**

The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome Bill, 2014 was passed by the Parliament and it received Presidential assent on 20th April, 2017. The HIV and AIDS (Prevention and Control) Act, 2017 was notified on e-gazette on 21st April, 2017.

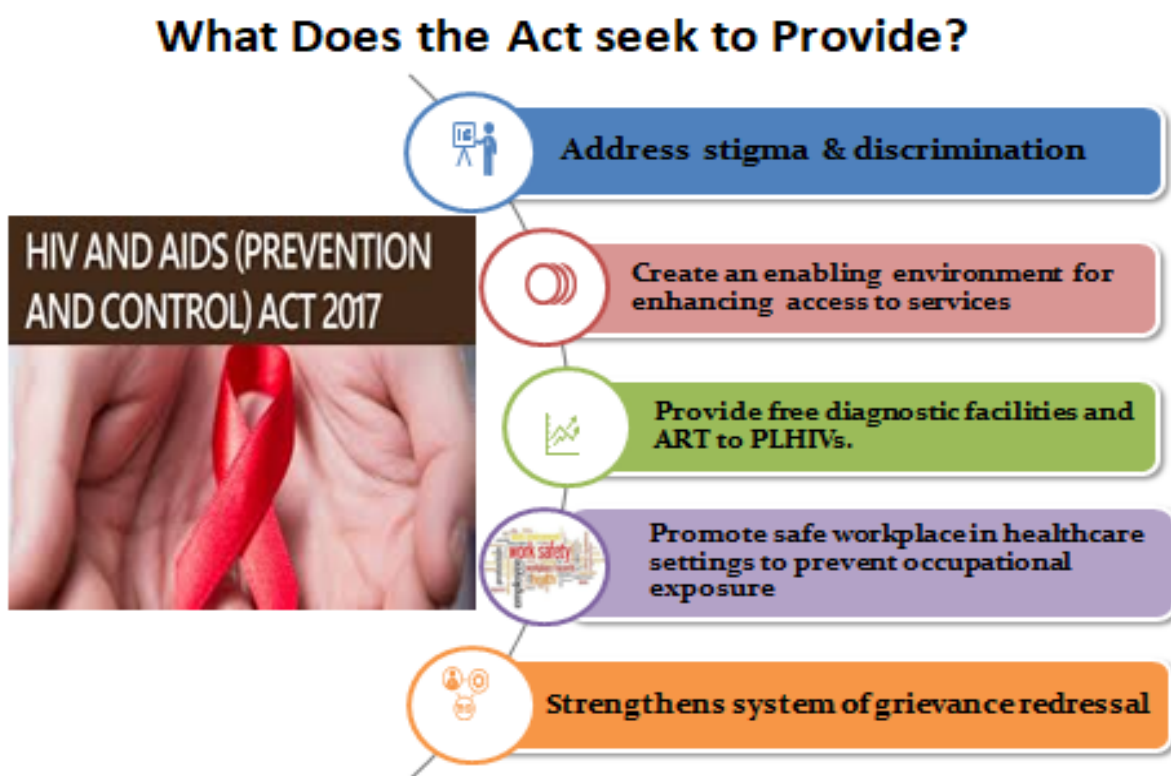
Passing of the Act has brought many policy decisions in relation to HIV and AIDS under the legal ambit. It has been hailed as landmark legislation, first of its kind in the health sector in specific to HIV/AIDS. This has been an outcome of relentless efforts, commitment and hard work of civil society members, legal experts, community members, NACO officials etc. for more than a decade. The Act has come into force from 10th September, 2018.

For effective implementation of the Act, subordinate legislations have to be drafted. Rules

and Guidelines are to be prepared by both Central and State Governments under:

- ✚ Section 46- The Central Government may, by notification, make guidelines consistent with this Act.
- ✚ Section 47- The Central Government may, by notification, make rules to carry out the provisions of this Act.
- ✚ Section 49- The State Government may, by notification, make rules for carrying out the provisions of this Act.

### Important Provisions of the Act:



## **Address stigma & discrimination<sup>2</sup>: (Section 3 and 4)**

- The Act prohibits acts of discrimination by any person against HIV positive persons (in education, health, public facilities, property-rights, employment, movement, eligibility to stand for & hold public office etc.)
- The Act also penalizes propagation of feelings of hatred, discrimination or physical violence related to any protected person.

## **Create an enabling environment for enhancing access to services (Section 5, 8, 11, 22)**

- Informed consent<sup>3</sup>, a pre-requisite for HIV testing.
- No compulsion to disclose HIV status.
- Provides for confidentiality of HIV related information<sup>4</sup>
- Provides for obligation of the Central /State Governments for promotion of strategies for reduction of risk and outlines the fact that such activities shall not invite civil or criminal liability.
  - (i) Provisions of information, education and counselling services relating to prevention of HIV and safe practices;
  - (ii) The provisions and use of safer sex tools, including condoms;
  - (iii) Drug substitution and drug maintenance; and
  - (iv) Provision of comprehensive injection safety requirements.

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“discrimination” means any act or omission which directly or indirectly, expressly or by effect, immediately or over a period of time,—

- (i) Imposes any burden, obligation, liability, disability or disadvantage on any person or category of persons, based on one or more HIV-related grounds; or
- (ii) Denies or with holds any benefit, opportunity or advantage from any person or category of persons, based on one or more HIV-related grounds, and the expression “discriminate” to be construed accordingly.

<sup>3</sup>“informed consent” means consent given by any individual or his representative specific to a proposed intervention without any coercion, undue influence, fraud, mistake or misrepresentation and such consent obtained after informing such individual or his representative, as the case may be, such information, as specified in the guidelines, relating to risks and benefits of, and alternatives to, the proposed intervention in such language and in such manner as understood by that individual or his representative, as the case maybe;

<sup>4</sup>“HIV-related information” means any information relating to the HIV status of a person and includes—

- (i) information relating to the undertaking performing the HIV test or result of an HIV test;
- (ii) information relating to the care, support or treatment of that person; (iii) information which may identify that person; and
- (iv) any other information concerning that person, which is collected, received, accessed or recorded in connection with an HIV test, HIV treatment or HIV-related research or the HIV status of that person;

- Formulate IEC programs that are age-appropriate, gender-sensitive, non-stigmatizing and non-discriminatory.

### **Provide free diagnostic facilities and ART to PLHIVs (Section 14&15)**

Provides for obligation of the Central /State Governments for:

- Anti-Retroviral Treatment/management of Opportunistic Infections.
- Welfare schemes for HIV-affected person.

### **Promote safe workplace in healthcare setting to prevent occupational exposure. (Section 19)**

- Every establishment where there is significant risk of occupational exposure to ensure safe working environment:
  - a. Universal Precautions<sup>5</sup> to all persons working in such establishment who may be occupationally exposed to HIV; and
  - b. Training for the use of such Universal Precautions;
  - c. Post Exposure Prophylaxis to all persons working in such establishment who may be occupationally exposed to HIV or AIDS

### **Strengthen system of grievance redressal (Section 20, 21, 23, 24, 25, 26)**

- Complaint Officer: At establishment<sup>6</sup>s of more than 100 persons (20 in case of healthcare settings) for redressal of grievances. He shall dispose of complaints of violations of the provisions of this Act in the establishment.
- Ombudsman: At State level to enquire into violation of provisions of the Bill in relation to healthcare services. The Ombudsman shall, upon a complaint made by any person, inquire into the violations of the provisions of this Act, in relation to acts of discrimination.

### **Provisions specific to Ombudsman**

**Section 23:** Every State Government shall appoint one or more Ombudsman,—

(1) The terms and condition of the service of an Ombudsman appointed shall be such as may be prescribed by the State Government.

(2)The Ombudsman appointed shall have such jurisdiction in respect of such area or areas as the State Government may, by notification, specify.

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<sup>5</sup>“Universal Precautions” means control measures that prevent exposure to or reduce, the risk of transmission of pathogenic agents (including HIV) and includes education, training, personal protective equipment such as gloves, gowns and masks, hand washing, and employing a few work practices.

<sup>6</sup>“establishment” means a body corporate or co-operative society or any organisation or institution or two or more persons jointly carrying out a systematic activity for a period of twelve months or more at one or more places for consideration or otherwise, for the production, supply or distribution of goods or services;

**Section 24:** (1) The Ombudsman shall, upon a complaint made by any person, inquire into the violations of the provisions of this Act, in relation to acts of discrimination mentioned in section 3 and providing of healthcare services by any person, in such manner as may be prescribed by the State Government.

(2) The Ombudsman may require any person to furnish information on such points or matters, as he considers necessary, for inquiring into the matter and any person so required shall be deemed to be legally bound to furnish such information and failure to do so shall be punishable under sections 176 and 177 of the Indian Penal Code.

(3) The Ombudsman shall maintain records in such manner as may be prescribed by the State Government.

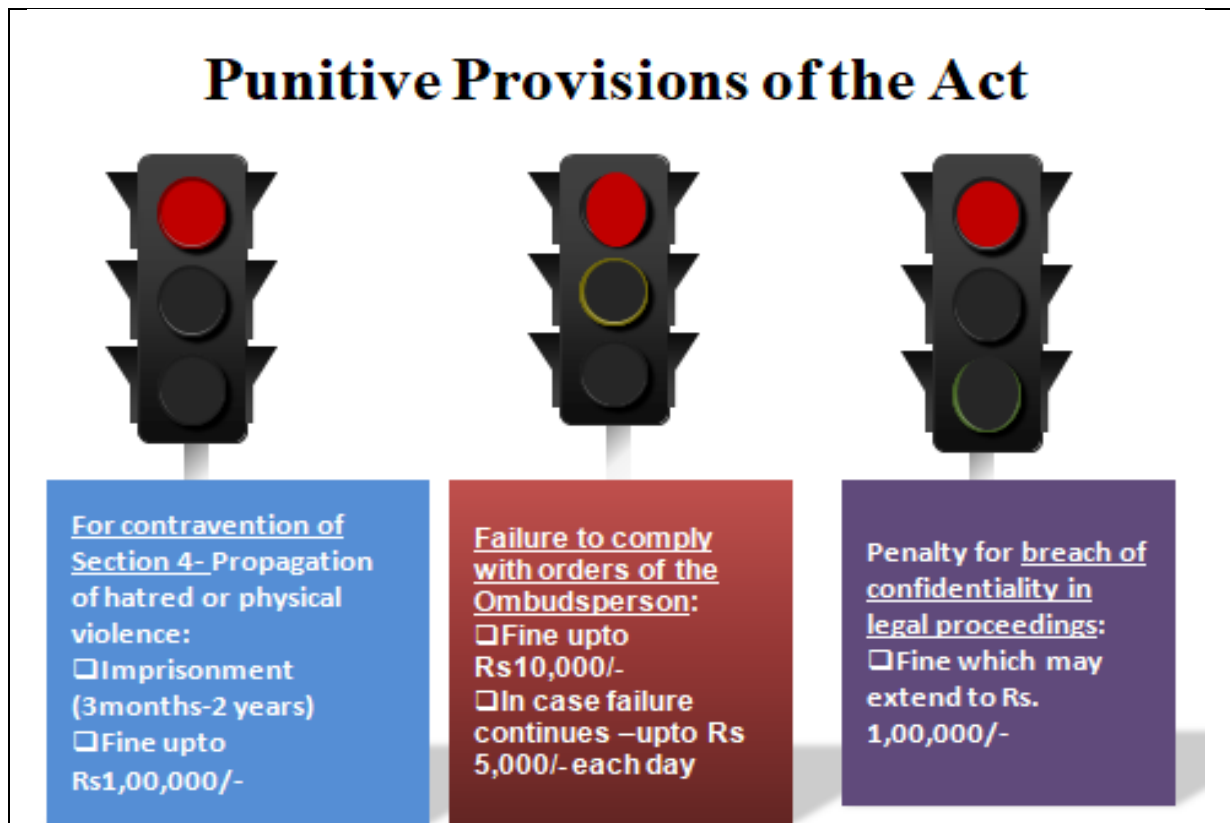
**Section 25:** The complaints may be made to the Ombudsman under sub-section (1) of section 24 in such manner, as may be prescribed, by the State Government.

**Section 26:** The Ombudsman shall, within a period of thirty days of the receipt of the complaint under sub-section (1) of section 24, and after giving an opportunity of being heard to the parties, pass such order, as he deems fit, giving reasons therefore:

*Provided that in cases of medical emergency of HIV positive persons, the Ombudsman shall pass such order as soon as possible, preferably within twenty-four hours of the receipt of the complaint.*

**Section 27:** All authorities including the civil authorities functioning in the area for which the Ombudsman has been appointed under section 23 shall assist in execution of orders passed by the Ombudsman.

**Section 28:** The Ombudsman shall, after every six months, report to the State Government, the number and nature of complaints received, the action taken and orders passed in relation to such complaints and such report shall be published on the website of the Ombudsman and a copy thereof be forwarded to the Central Government.



### Manner of maintaining records by Ombudsman<sup>7</sup>

(1) The Ombudsman shall -

- (a) immediately on receipt of a complaint, record it by assigning a sequential unique complaint number in a register maintained solely for that purpose in physical or computerized form;
- (b) On receipt of the complaint, acknowledge it including by sending the unique complaint number by SMS or e-mail to the complainant where available;
- (c) Record the time of the complaint and the action taken on the complaint in the register; and
- (d) Maintain the register of complaints in a manner that ensures confidentiality of data

(2) The Ombudsman shall comply with data protection measures in accordance with section 11 of the Act.

<sup>7</sup> These are part of model State rules as required under section 49 of the Act and the Ombudsman should refer to respective state specific rules for detailed information.

## **Manner of making complaints to Ombudsman**

(1) Any person may make a complaint to the Ombudsman within whose jurisdiction the alleged violation took place, within (as time mentioned in State specific rules) from the date that the person making the complaint became aware of the alleged violation of the Act.

*Provided* that the Ombudsman may, for reasons to be recorded in writing, extend the time limit to make the complaint by a further period of (as mentioned in State specific rules), if he is satisfied that circumstances prevented the complainant from making the complaint within the stipulated period.

(2) All complaints shall be made to the Ombudsman in writing in accordance with the form as specified in respective state rules.

*Provided* that where a complaint cannot be made in writing the Ombudsman shall render all reasonable assistance to the complainant to reduce the complaint in writing.

(3) In cases of medical emergency, the Ombudsman or his assistant may visit the complainant at the location of the alleged violation or any other convenient place to enable written documentation of the complaint.

(4) The Ombudsman may receive complaints made in person, via post, telephonically, or through electronic form through the Ombudsman's website.

## **Provisions related to the Complaints Officer**

**Section 20 and 21:** Every establishment consisting of one hundred or more persons, whether as an employee or officer or member or director or trustee or manager; shall designate the Complaints Officer who shall dispose of complaints of violations of the provisions of this Act in the establishment, in such manner and within such time as may be prescribed. In case of healthcare establishments the number hundred is substituted by twenty; which means every healthcare setting having twenty or more people shall designate a Complaints Officer.

## CHAPTER-IV

### HIV at Workplace and Stigma and Discrimination

#### **HIV and Stigma and Discrimination**

*“Stigma and Discrimination is an affront to human rights and puts lives of people living with HIV and key population in danger”*

*-UNAIDS, 2017*

HIV and AIDS is not only a disease but a stigmatised disease. One of the reasons for stigma is the lack of correct knowledge of HIV. The greatest fear is that of transmission which arises out of myths and misconception. This is worsened in societies where health literacy is poor and traditional healers/quacks are approached for treatment.

Understanding Stigma: *Stigma can be defined as;*

*‘Shame and dishonour surrounding a situation which is unacceptable and against the basic **norms, values and ideals** of the society/community. It varies in magnitude from being benign to vehement but each one has a wider ripple effect.’*

Stigma is expressed in various forms like language, gestures, behaviour, denial of services, harassment, violence etc. Stigma can be broadly characterised into external and internal stigma; the former includes the societal perception while the later defines self-perception and both can stem out of the socio-cultural milieu and engrained value systems.

**Andre Betellie**, a famous sociologist said “It is hard to deny that India in many spheres is still governed by traditional norms and values. Values and norms are ascribed and not acquired” highlighting that the perceptions in Indian society emanate from already existing norms.

It has been a challenge to change these perceptions and provide a non-stigmatised and discrimination free environment to PLHIV. Though Article 15 of our constitution prohibits any kind of discrimination but the long existing societal notions are difficult to change.

According to Integrated Biological and Behavioural Surveillance (IBBS), 2014-15, 46% Injecting Drug Users (IDUs) have reported to have been treated disrespectfully by family, friends, neighbours etc.

The socio cultural norms prevailing in the society considers sex as a taboo. As the predominant route of HIV transmission in India is through the sexual route, society has a tendency to negatively morally appraise the person with HIV.

- Research by the International Centre for Research on Women outlines the possible consequences of HIV-related stigma as:
  - **loss of income and livelihood**
  - **loss of marriage and childbearing options**

- **poor care within the health sector**
- **withdrawal of care-giving in the home**
- **loss of hope and feelings of worthlessness**
- **loss of reputation**

-(ICRW) (2005) <sup>8</sup>

HIV and AIDS Act, 2017 has out-rightly prohibited discrimination against HIV affected and infected population. People living with HIV cannot be denied employment on the basis of their HIV status. HIV test cannot be the basis for expulsion of PLHIV from job. Healthcare providers are also prohibited from discriminating positive patients.

Under the HIV and AIDS Act, people living with HIV have been ascertained many other legal and constitutions rights like right to movement, right to contest elections, right to reside, right to access public spaces , prohibition of isolation or segregation etc. The Act is seen as an important milestone which will facilitate India in meeting one of the fast track targets of elimination of stigma and discrimination against HIV/AIDS by 2020.

### **Health settings**

HIV related stigma and discrimination prevents the infected and affected people from accessing health services. Discriminatory attitudes and behaviours towards the infected people have direct negative consequences on the quality of their life. Discriminatory attitudes towards HIV/AIDS infected communities are associated with the actual infection, the behaviour led to infection and the judgemental attitude of the providers. Some socially marginalized groups, such as men who have sex with men (MSM), injection drug users (IDUs), female sex workers (FSWs) and Transgender communities face more stigma and discrimination. This “double stigma” influences the attitudes of service providers and affects all infected people, regardless of their route of infection. 25.6 % Injecting Drug Users perceived that they had been treated differently in the health facility (IBBS, 2014-15). The discriminatory attitude at the hands of doctors or health staff in relation to HIV/AIDS has a layered impact; the patients confide into them their health problems expecting diagnosis and treatment. However, here the caregivers violate their right to confidentiality, right to health and right to privacy which along with tarnishing their relationship prevents them from seeking further treatment.

Sub-section (c) of section 3 under HIV and AIDS Act, 2017 prohibits discrimination against the protected person on the basis of denial or discontinuation of, or unfair treatment in healthcare setting. Section 26 of the Act offers the Ombudsman to pass order within twenty-four hours in case of medical emergency.

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<sup>8</sup>[\*HIV-related stigma across contexts: common at its core'\*](#)

### **Education institutions**

Good quality education is one of the utmost goals for parents and the government in order to ensure bright future and responsible citizens. Access to quality education for children and youth is the best way to address HIV stigma and discrimination within a generation. Education can also give children affected with HIV a better understanding of HIV and equip them with life skills to cope with the challenges it brings. Discrimination under such settings is tantamount to abrogating a child's fundamental/human/basic right to a 'sound future' including livelihood. In this context, the rising cases of denial of education to HIV affected children are a matter of grave concern. If this discrimination continues, then a large number of children will be excluded from schools and mainstream society and be pushed to languish at the margins of our society. This can only be achieved when there is an integrated curriculum and a sensitised staff.

Sub-section (b) of section 3 prohibits discrimination against the protected person on the basis of denial or discontinuation of, or unfair treatment in, educational, establishments and services thereof. In case of contravention of this section, person infected and affected with HIV can file a complaint to Ombudsman and seek redressal.

### **Establishments**

Health has been one of the prerogatives for assuring perceptible economic and social development in today's fast growing world. Health and economy have been hands in gloves with one another, countries who have aimed at ensuring universal access to health, equity and raising quality of care have excelled. It gets imperative for the country's policy-makers to create economic opportunities and ensure that the national labour force is capable of seizing such opportunities.

The presence of HIV afflicted individuals in establishments often leads to discrimination, marginalization and unfair treatment. They are made to quit their jobs and are forced to live in abject poverty with immediate ripple effect on their close family members and children in terms of poor expenditure on education and health. The HIV status shouldn't be a negative factor in the professional development of an individual. Sub-section (b) of section 3 prohibits discrimination against the protected person on the basis of unfair treatment in, in relation to employment or occupation. Section Sub-section (l) of section 3 prohibits HIV testing as a prerequisite for obtaining employment, or for continuation of the same. In case of contravention of this section, person infected and affected with HIV can file a complaint to Ombudsman and seek redressal.

## CHAPTER-V

### Miscellaneous

#### **Guardianship**

A guardian is someone who is chosen or appointed to make legal decisions for a minor or any individual who is incapable of making such decisions on their own.

As per sub-section 2 of section 4 of the Guardians and Wards Act, 1890;

“guardian” means a person having the care of the person of a minor or of his property, or of both his person and property.

However, Section 32 of HIV and AIDS Act, 2017 says that a person below the age of eighteen but not below twelve years, who has sufficient maturity of understanding and who is managing the affairs of his family affected by HIV and AIDS, shall be competent to act as guardian of other sibling below the age of eighteen years for the following purposes,

namely:—

- a) admission to educational establishments
- b) care and protection
- c) treatment;
- d) operating bank accounts
- e) managing property
- f) any other purpose that may be required to discharge his duties as a guardian.

*For the purposes of this section, a family affected by HIV or AIDS means where both parents and the legal guardian is incapacitated due to HIV-related illness or AIDS or the legal guardian and parents are unable to discharge their duties in relation to such children.*

It is usually seen that children of HIV infected parents are deprived of lots of benefits due to unavailability of a legal guardian. Thus, here there is an exception of granting guardianship right to a child below 18 years who has sufficient maturity and understanding.

#### **Sex, Sexuality/Sexual Orientation and Gender**

Gender and sex are often used interchangeably in colloquial terms but they both have very different meanings attached to them. The term ‘**sex**’ refers to the biological indicators/characteristics like chromosomes, sex organs (vagina and penis) which determine whether an individual is a male or a female. It might not be limited to binaries of male or female but also intersex (variations in sexual characteristics).

The term **gender** lays down the characteristics that are inculcated in an individual through their socialisation with the society. These can be behaviours, attributes, social activities which have been sanctioned by the society and are considered appropriate. They might vary society to society and region to region. These are also not limited to binaries of being feminine or masculine but others too (eg- transgenders and hermaphrodites).

Word sexuality can be defined as one's sexual orientation and sexual expression. This could be physical, emotional, romantic attraction, feeling and behaviour. Being a heterosexual, homosexual, bisexual, asexual are all examples of one's sexuality.

India is undergoing a change towards a more progressive transformation coming from legal activism in India. In 2009 under the Naz Foundation v. Government of NCT of Delhi, a landmark case was decided by a two-judge bench of the Delhi High Court, which held that treating consensual homosexual sex between adults is not a crime and criminalising it is a violation of fundamental rights protected by Indian Constitution. Though in 2013, section 377 was reinstated via Naz Foundation judgement, 2013 (Suresh Kumar Koushal and another v. NAZ Foundation). Soon after, under National Legal Services Authority v. Union of India, 2014, Hon'ble Supreme Court declared transgender people to be a 'third gender'. It also affirmed that the fundamental rights under Part III of the Constitution of India shall be equally applicable to them too.

Another legal hallmark witnessed was on 6th September 2018, when the Hon'ble Supreme Court unanimously ruled in *Navtej Singh Johar v. Union of India* that Section 377 was unconstitutional. This not only decriminalizes consensual sex among same sexes but also provides a legally viable environment for both self and social acceptance. This would enable the population to come out in open about their sexuality and sexual orientations and it will also improve the uptake of medical care and thus will make this population less vulnerable to contracting and spreading HIV and other sexually-transmitted diseases.

## **Annexure:**

List of Guidelines for further reference:

- i. *National Guideline on HIV Counselling and Testing Services*
- ii. *Compendium, National Blood Policy and Guidelines, 2018*
- iii. *Guidelines for Blood Donor Selection and Blood Donor Referral*
- iv. *National Guidelines for the Enumeration of CD4*
- v. *National Guidelines for HIV Testing (Addendum 1 and 2)*
- vi. *Data Protection Guideline of National AIDS Control Programme*
- vii. *Link Workers Scheme Operational Guidelines*
- viii. *Operational Guidelines for implementing HIV Targeted Interventions among men who have sex with men in India*
- ix. *Policy, Strategy and Operational Plan, HIV intervention for Migrants*
- x. *Targeted Interventions under NACP III Operational Guidelines- volume II- Migrants and Truckers*
- xi. *Operational Guidelines for Employer Led Model*
- xii. *Opioid Substitution Therapy under National AIDS Control Programme, clinical practice Guidelines for treatment with Buprenorphine*
- xiii. *Operational Guidelines for implementing Targeted Interventions among Hijras and Transgender people in India*
- xiv. *Guidelines for Prevention of Parent to Child Transmission (PPTCT) of HIV using Multi Drug Anti-retroviral Regimen in India.*
- xv. *Information Education Communication, Operational Guidelines*
- xvi. *Operational Guidelines for Programme Managers and Service Providers for Strengthening STI and RTI Services*
- xvii. *National Guidelines for Anti-Retroviral Treatment Services, India*
- xviii. *Guidelines for Prevention and Management of Common Opportunistic Infections or Malignancies among HIV-Infected Adult and Adolescent.*
- xix. *Targeted Interventions under NACP III, Operational Guidelines Volume I, Core High Risk Groups*

They are available at <http://naco.gov.in/>

## CASE STUDIES

### Case 1:

#### Case of discrimination at social/community level:

Dhruv (fictitious name) is a very naughty student of class 2 at a nearby government school in a small village. He aims to become an astronaut and go to the space. His father, Mr G works as a bearer at a nearby hotel and his mother works as a domestic help at five other households. It was Dhruv's birthday, which meant a family lunch and lots of sweets for Dhruv.

Dhruv along with his family was enjoying his day at a nearby market where his father, Mr G came across a health-camp; many people from his village had come to get themselves tested for HIV for free. On insistence of his friend, Mr G decided to get tested and was found reactive and later tested positive for HIV at nearby centre. The test result was displayed at the notice board of community health center of the village.

People around came to know about the HIV status of Mr G and called for a social boycott. He and his family were denied access to bathing ghats and wells. Two households where Dhruv's mother worked as domestic help asked her to discontinue her services. Mr G and his family were socially ostracised and denied participation at public gatherings and community celebrations.

They were forced to leave their house and shifted to Dhruv's uncle's place. There they came in contact with an outreach worker who worked at a NGO nearby. The NGO was a targeted intervention site for State AIDS Control society. The counsellor counselled Dhruv and her mother to get tested for HIV. Both of them were negative.

#### Food for thought:

##### Anomalies in the case which contravene the provisions in the HIV and AIDS Act

1. Display of test report on the notice board (Section 8)
2. HIV being the reason for removal of Mr G's wife from work at two households (Section 3)
3. HIV being the reason for discrimination of Mr G's family (Section 3)

**Further course of action:** The counsellor and Programme Manager helped Mr G file a complaint to the Ombudsman of the State. The Ombudsman directed the Sarpanch of the village to take cognisance of the discrimination and rectify the mistake. All those behind the discrimination were made to undergo counselling sessions and were fed with correct information undoing all the myths and misconceptions around HIV/AIDS. ANMs and Asha workers were also sensitised and given the responsibility of generating right awareness.

**Outcome:** Dhruv on his return to his village received a warm welcome where people had realised their mistake and felt guilty of ill-treating the family. Mr G has joined a nearby NGO and during his free time works as an advocate for rights of people living with HIV. He has been regular at taking medicine and wants to see Dhruv become an astronaut.

**Case 2:**

**Case of discrimination at school**

Mr A works at a zari factory far from his state, he works tirelessly and seldom takes any day off. He only has one dream that is to give best education to her two daughters (Pari and Shrishti) and help them fulfil their dreams of becoming a doctor and a civil servant. Pari is a student of class three while Shrishti studies in class five. Shrishti is exceptionally brilliant at studies while Pari loves dancing and playing.

It was October and Mr A's favourite time. As customary, festivals were approaching and it was time for Mr A to visit his family back at his native town. While leaving for his hometown he became a part of a good deed where he donated blood to his friend who had recently met with an accident.

Mr A and family were all gearing up for the upcoming celebrations; sweets, new clothes, decorations and lights. One evening Mr A received a phone call, where he was informed about his blood being reactive and after a confirmatory test he was detected HIV positive. The call was made from the hospital where he had donated the blood. It was a difficult time for Mr A and his family. He consulted one of his friends and decided to follow the instructions of the doctor and take medicines regularly.

When things had started to fall back on track for Mr A, one afternoon his two daughters came home sobbing, they had been expelled from the school. Mr A went back to the school, met the principal and class teacher. He begged asking them to take her girls back and that without education they would have no future. The principal called her security and asked them to shun him out. The class-teacher also looked helpless. Later in the evening, Shrishti narrated an account of harrowing stories where both the sisters were bullied and asked to sit separately and were made to stand outside the assembly line and also the class for hours.

**Food for thought:**

Anomalies in the case which contravene the provisions in the HIV and AIDS Act

1. Mr A's friend disclosed his HIV status to other people in the village. **(Section 8)**
2. HIV was the reason for discrimination and expulsion of Shrishti and Pari from the school **(Section 3)**

3. HIV was the reason of ill-treatment meted to Mr A on his visit to the school. (**Section 3**)
4. The Principal not abiding by the orders of the Ombudsman (**Section 38**) (*drawing from the outcome mentioned below*)

**Further course of action:** Mr A along with help from his colleagues back at workplace filed a complaint to Ombudsman. Ombudsman directed the principal to reinstate the kids. She along with the class-teacher were counselled and placed at a nearby NGO and asked to do voluntary work for a month. This was to be done post the school hours in order to ensure that their absence does not affect the functioning of the school. The friend of Mr A was also placed at the same NGO for a fortnight and sensitised to the Government AIDS prevention programme.

**Outcome:** The Principal was hesitant to reinstate the kids and refused at first go but later agreed after paying fee for non-compliance to Ombudsman's orders. The Principal now along with two more teachers run a successful Adolescent Education Programme (AEP) of NACO. They have enrolled all the children of class IX and XI of the school into the curriculum.