



*Empowered lives.  
Resilient nations.*

---



**Lessons  
from the  
HIV  
Programme**

---

**for an  
Effective  
Development  
Response**

---

the 1990s, the number of people in the UK who are aged 65 and over has increased from 10.5 million to 13.5 million, and the number of people aged 75 and over has increased from 4.5 million to 6.5 million (Office for National Statistics 2000).

There is a growing awareness of the need to address the needs of older people, and the need to ensure that they are able to live independently and actively in their own homes. This has led to a number of initiatives, including the development of the concept of 'age-friendly' environments (World Health Organization 2002).

The concept of 'age-friendly' environments is based on the idea that the environment should be designed to meet the needs of older people, and to enable them to live independently and actively in their own homes. This includes a range of factors, such as the availability of public transport, the availability of social services, and the availability of housing that is suitable for older people.

The concept of 'age-friendly' environments is also based on the idea that the environment should be designed to be inclusive, and to enable older people to participate in the community. This includes a range of factors, such as the availability of social services, the availability of housing that is suitable for older people, and the availability of public transport.

The concept of 'age-friendly' environments is also based on the idea that the environment should be designed to be safe, and to enable older people to live independently and actively in their own homes. This includes a range of factors, such as the availability of public transport, the availability of social services, and the availability of housing that is suitable for older people.

The concept of 'age-friendly' environments is also based on the idea that the environment should be designed to be accessible, and to enable older people to live independently and actively in their own homes. This includes a range of factors, such as the availability of public transport, the availability of social services, and the availability of housing that is suitable for older people.

The concept of 'age-friendly' environments is also based on the idea that the environment should be designed to be supportive, and to enable older people to live independently and actively in their own homes. This includes a range of factors, such as the availability of public transport, the availability of social services, and the availability of housing that is suitable for older people.

The concept of 'age-friendly' environments is also based on the idea that the environment should be designed to be empowering, and to enable older people to live independently and actively in their own homes. This includes a range of factors, such as the availability of public transport, the availability of social services, and the availability of housing that is suitable for older people.

The concept of 'age-friendly' environments is also based on the idea that the environment should be designed to be enabling, and to enable older people to live independently and actively in their own homes. This includes a range of factors, such as the availability of public transport, the availability of social services, and the availability of housing that is suitable for older people.



*Empowered lives.  
Resilient nations.*

# **Lessons from the HIV Programme**

---

**for an Effective  
Development Response**





# CONTENTS

---

ABBREVIATIONS .....	I
FOREWORD .....	II
PREFACE .....	III
ACKNOWLEDGEMENTS .....	IV
POST SCRIPT .....	V
INTRODUCTION .....	1
<b>SECTION 1 - A BRIEF BACKGROUND</b> .....	3
<b>SECTION 2 - SALIENT FEATURES OF INDIA'S RESPONSE TO THE EPIDEMIC</b> .....	11
<b>SECTION 3 - SUMMARY OF LESSONS/FINDINGS</b> .....	53
ANNEXURE .....	58
CONCLUSION .....	59





## ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
AusAID	Australian Agency for International Development Assistance
CBO	Community-based Organisation
DFID	Department for International Development
FSW	Female Sex Worker
Gol	Government of India
HIV	Human Immunodeficiency Syndrome
HRG	High Risk Group
IDU	Injecting Drug User
M&E	Monitoring and Evaluation
MSM	Men who have Sex with Men
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NGO	Non-Governmental Organisation
NRHM	National Rural Health Mission
PLHIV	People Living with HIV
PPTCT	Prevention of Parent to Child Transmission
RTI	Reproductive Tract Infection
SACS	State AIDS Control Society
SIMS	Strategic Information Management System
SIMU	Strategic Information Management Unit
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
STRC	State Training Resource Centre
TRG	Technical Resource Group
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WSW	Women in Sex Work

# Lessons from the HIV Programme

## for an Effective Development Response

### FOREWORD

Ever since the first case of HIV was identified in 1986, India has shown strong political will, commitment and urgency in addressing the problem. This focus has aided the evolution of one of the world's most comprehensive Aids control programmes. The National AIDS control Programme in India has gone beyond just generating an HIV response—it has paved the way for some of the most successful experiments in social sector response. Due to India's consistent support to the national HIV response in the last two decades and more, the annual incidence of HIV infection among adults has fallen by about 57% between 2000 and 2011.<sup>1</sup> However, success can be the biggest enemy for a programme of this nature as it carries the risk of complacency. India must continue to strive and explore new boundaries.

Numerous factors have contributed to the success of the programme in India, including the use of evidence for planning and the creation of timely and enabling policies, implementation of robust systems, structures for managing the national response, participation and involvement of civil society, investment in technical quality and programme design, and facilitation of community participation and ownership.

There are several lessons that can be learnt from the HIV response in India, the most important being the success of the national Aids control Programme in being able to contain the progression of the epidemic despite the complexities, geographical inaccessibility, and challenging health infrastructure in the country. While these lessons continue to strengthen the programme, they can also be used as guidelines for the development sector at large, in order to address cross cutting issues such as nutrition, tribal health, water, sanitation and hygiene, and gender equity.

I would like to congratulate the UNDP India Country Office and Swasti, a Health Resource Centre, for investing in the process of gathering evidence and compiling lessons gained from experts, underlined by the objective of achieving broader development goals. Every attempt has been made through this document to distil insights and lessons from the successes and failures of the national HIV response. I hope this document will inspire and contribute to guiding development programmes for achieving greater outcomes and impacts in India.



**J.V.R. Prasada Rao**

*UN Secretary-General's Special Envoy for AIDS in Asia and in the Pacific*

---

1 HIV Sentinel Surveillance 2010–11, A Technical Brief, NACO.



## PREFACE

From an early stage, HIV has been considered as a behavioural, social, and economic development issue rather than just a medical issue. The threat of the medical, social and economic repercussions of AIDS on an individual, community and national level has forced the country to think differently in its response to the epidemic. This has helped establish and accelerate a multi-sectoral response to AIDS.

In India and across the world, remarkable progress has been made towards combating HIV and AIDS over the past two decades—the number of people infected with HIV and cases of AIDS-related deaths have reduced and there is a significant increase in the number of people seeking and receiving treatment. The tables below illustrate statistics that justify this claim:

This publication was conceptualised at a time when the Government of India was planning the Fourth Phase of the National AIDS Control Programme. The idea behind it is to paint a comprehensive picture of the AIDS response programme, rather than merely document best practices or create an evaluation report. This document, therefore, records the lessons the programme has to offer, given its multiple approaches and stakeholders.

It also provides a host of information—strategies implemented, constraints faced, insights, perspectives, programme partners, and lessons from the government, civil society, and academic, corporate, media and community partners at the local, state, and national levels in India—all captured at a critical juncture in the journey of the AIDS response.

With this publication, we hope to stir reflection and to encourage the HIV sector to maintain its momentum and build on its progress so far. We also hope that these lessons contribute to strengthening the responses to other development challenges such as malnutrition, maternal and child health, sanitation, and climate change. This publication is intended for professionals working in the development sector including HIV, Water and Sanitation, Livelihoods, Public Health, and similar areas, who can read, introspect, and examine what all worked for and against the response. The document has been purposely written in a narrative style, bereft of jargon, for easy reading. I would like to thank the team that worked on this report and all the contributors for their energy, time, and reflections on the last 26 years of HIV programming in India.

DDG IEC/ AS

NACO Representative



## ACKNOWLEDGEMENTS

UNDP would like to thank the multitude of people who gave their time and contributed to this report. First and foremost, the government and non-government officials, representatives of donor agencies, civil society organisations including community-based organisations and expert programme implementers, and people living with HIV. A full list of those consulted is provided in the appendix. Additionally, we would like to acknowledge the contributions and the leadership shown by the National AIDS Control Organisation, which has been at the forefront of the HIV programme in India. This publication has made extensive use of reports and publications by NACO, various State AIDS Control Societies, HIV programme implementers and development partners.

## DISCLAIMER

The United Nations Development Programme (UNDP), India Country Office, commissioned this publication. The views expressed in this report do not reflect the views of the UNDP or that of the National AIDS Control Organisation (NACO). The response to AIDS in India is spread over two decades and is very diverse. It's quite possible that some of the events, organisations, and developments got inadvertently omitted in the report. Such regrettable oversight might have happened due to the vastness of the work.



## POST SCRIPT

India's experience in HIV prevention and control, as analysed in this report, presents us with many important lessons for the next phase of the global AIDS response, and for health and development more broadly. The proposed Sustainable Development Goals (SDGs) embody the bold aspirations of the international community to end the tyranny of poverty, ensure a life of dignity for all and secure the planet for future generations. Delivering on these ambitious, interconnected goals will require us to do things differently.

The post-2015 development agenda presents us with a platform for applying the lessons from HIV for sustainable development. More than three decades of experience of responding to an epidemic have taught us that HIV cannot be addressed by the health sector alone. Strengthening governance, institutional capacities, partnerships, civil society, mainstreaming, community engagement and enabling legal and policy environments while scaling up evidence and human rights based programmes, can help to address challenges faced in other health and development programmes. Investing in smart cross-sectoral strategies will help deliver on an ambitious new sustainable development agenda and achieve shared gains for HIV, health, and development. For example, reducing gender inequality and gender-based violence can help women and girls to negotiate if, when, and with whom to have sex, and to protect themselves from HIV. Tackling the exclusion of men who have sex with men, transgender people, sex workers and people who use drugs is critical to accelerating progress on HIV prevention and control. Addressing economic inequalities through social protection and economic empowerment can reduce poverty and vulnerability to HIV, and help to keep people living with HIV healthy and contributing to communities and economies. All of these are also important human rights and development objectives.

The lessons are clear. Now it falls to us to apply them if we hope to realise the vision of the SDGs—a more prosperous, fair, and sustainable world, and one free from the scourges of discrimination and AIDS.

# Lessons from the HIV Programme

## for an Effective Development Response

### INTRODUCTION

Home to an estimated 1.21 billion people, India is the second most populous country in the world, accounting for 17% of the world's population. It is also vast in terms of geography and is characterised by large diversities in geographical regions, socio-cultural groups and health needs. Given India's size, diversity and limited resources, innovative models and approaches have played a critical role in addressing emerging health issues, including large public health programmes to tackle HIV and AIDS.

The AIDS epidemic was detected in India in 1986, and since then, concerted efforts have been undertaken to address and contain the spread of the epidemic. The National AIDS Control Programme (NACP), which was established in 1992 with support from the World Bank and the World Health Organization (WHO), has evolved methodically to meet the emerging needs over a period of 28 years. Various institutes, different services and a large network of service outlets have been established for the implementation of the programme across the country, along with the use of sound epidemiological knowledge and a changing epidemic situation.<sup>2</sup>

Government and development partners, including bilateral, multilateral, and private donors, have invested considerably in terms of both technical and financial resources and also demonstrated a strong and sustained leadership to combat the disease. Additionally, the government and civil society have also undertaken innovative programming in partnership with the communities most affected by HIV to ensure a response that is most effective.

The HIV programme has evolved over the last couple of decades, with NACP making rapid strides in developing need-based strategies, policies, programmes, and projects to strengthen the national response to the most complex epidemic in recent times. Several mechanisms have been evolved for review, assessment, course correction and future planning to meet changing requirements over time. These efforts have resulted in a focused response towards the prevention of the spread of HIV in India and led to unprecedented gains, with the adult prevalence rate of 0.38% in 2001-03 through .034% in 2007 to 0.26% in 2015.<sup>3</sup>

Given the success of the HIV programme in India, there are important lessons to be learnt, which may have far-reaching relevance across sectors such as nutrition, health and climate change. Thus, the intent of this report is to draw attention to the lessons from India's successful response to HIV and promote cross-learning to address challenges in other development sectors, so as to enhance the outcomes in these sectors.

Using a predetermined framework consisting of the components listed below, this publication focuses on analysing the lessons learnt, success factors and limitations, guiding principles and approaches used:

---

2 AM Kadri<sup>1</sup>, Pradeep Kumar<sup>2</sup>, 'Institutionalization of the NACP and Way Ahead', *Indian Journal of Community Medicine*, 2010.  
3 NACO, *India HIV Estimation 2015, Technical Report*.

## Lessons from the HIV Programme for an Effective Development Response

---

- Role of leadership and political will
- Enabling legal and policy environment
- Programme design, management, and system
- Governance and accountability mechanisms
- Partnerships and mainstreaming
- Community engagement

This report is divided into three sections:

- The first section details the background to the HIV epidemic in India and the evolution of the programme.
- Section two highlights the key aspects of India's response to address and control the epidemic, and the lessons learnt in the process.
- The last section deals with some of the major public health programmes which are in place to respond to persistent diseases that affect large populations in India, and also provides insights on how the lessons from the HIV programme could be useful to address the challenges faced in other large public health/development programmes.

## SECTION 1 - A BRIEF BACKGROUND

### 1.0 NATIONAL HIV RESPONSE

#### 1.1 UNDERSTANDING THE HIV EPIDEMIC IN INDIA

The HIV epidemic began in India with the identification of the first case of HIV among female sex workers in Chennai in 1986.<sup>4</sup> Since then, the number of infected people has grown steadily, and in the 1990s, India witnessed an upsurge in HIV incidences and prevalence in some pockets of the country, primarily in the south, west and the north-east. In 2005, the HIV burden was estimated at 5.2 million and India was considered to be home to the second highest number of People Living with HIV (PLHIV), after South Africa. The other trends that were observed were: movement of the disease from High Risk Groups (HRGs) to the general population; feminisation of the epidemic, with a large number of women being infected; spread of the disease from urban to rural areas; emergence of HRGs in states other than the high HIV prevalence states; and high vulnerability observed amongst the youth.<sup>5</sup>

However, more recently, India has demonstrated an overall reduction of 57% in the annual new HIV infections among adult population, from 2.74 lakh in 2000 to 1.16 lakh in 2011, reflecting the impact of various interventions and scaled-up prevention strategies under the National AIDS Control Programme (NACP). According to the HIV Estimations 2015, the estimated number of people living with HIV/AIDS in India was 20.89 lakh, with an estimated adult (15–49 age group) HIV prevalence of 0.26% in 2015.<sup>6</sup> Today, India carries the world's third largest burden of HIV, following South Africa and Nigeria.

##### 1.1.1 POPULATION MOST AFFECTED

HIV/AIDS has been seen to disproportionately affect the poor and vulnerable groups. In India, the epidemic remains largely concentrated among vulnerable populations at high risk of HIV, although it has also affected other segments of the population. Groups identified as being at risk can be categorised as female sex workers (FSWs), men who have sex with men (MSM), and injecting drug users (IDUs). Out of these, there has been a declining trend amongst FSWs (5.06% in 2007 to 2.67% in 2011), and MSM (7.41% in 2007 to 4.43% in 2011), while the prevalence among IDUs has remained stable (7.23% in 2007 to 7.14% in 2011).<sup>7</sup>

Transgender people (TG) have also emerged as a risk group with high vulnerability and high levels of HIV, at 8.82%.<sup>8</sup> Further, in certain regions of the country, evidence has indicated the role of bridge populations, such as migrants and long distance truckers, in fuelling the HIV epidemic by carrying the infection from high risk populations to the general population. The prevalence rate amongst the general population still remains low, with a significant decline among antenatal clinic attendees who are considered as a proxy for the general population (0.49% in 2007 to 0.29% in 2011–15).<sup>9</sup>

4 E.A. Simoes et al., 'Evidence for HTLV-III infection in prostitutes in Tamil Nadu (India)', *Indian Journal of Medical Research*, 85 (April 1987), 335–8.

5 Dr. S.Y. Quraishai, 'HIV/AIDS and INDIA: A Road Map', ppt, 18–20 March 2005.

6 India HIV Estimation 2015, Technical Report.

7 HIV Sentinal Surveillance, Technical Brief (2014-15).

8 HIV Sentinal Surveillance, Technical Brief (2014-15).

9 HIV Sentinal Surveillance, Technical Brief (2014-15).

### 1.1.2 STATES WITH HIGH AND LOW HIV PREVALENCE

HIV is diversely spread across states and districts in India. Six high prevalence states, namely, Maharashtra, Karnataka, Andhra Pradesh, Tamil Nadu, Manipur and Nagaland, account for approximately 66% of the HIV burden in the country. Sustained initiatives of the Government and stakeholders under the third phase of NACP (NACP-III) have resulted in reduced adult prevalence estimates in these states. At the same time, however, reverse trends are emerging in some of the low prevalence states such as Punjab, Rajasthan, Odisha, Kerala, Jharkhand, Uttar Pradesh, Assam and Meghalaya, which are now showing an increase in HIV prevalence,<sup>10</sup> thus pointing towards a continuously changing distribution of the HIV epidemic in India. The low prevalence states in India account for approximately one third of the country's HIV burden. Among sex workers, there is a decline in the south Indian states, indicating a possible impact of interventions, while rising trends are evident in the north-east suggesting a dual nature of the epidemic that is now driven both by injecting drug use and sexual transmission (NACO, 2010).

### 1.1.3 MODES OF TRANSMISSION AND DRIVERS

The primary drivers of the HIV epidemic in India are unprotected paid sex/commercial sex work, unprotected anal sex between men, and contaminated injecting equipment of injecting drug users. The infection is spread through the bridge population, who acquire the HIV infection from core transmitters and pass it on to their sexual contacts that have no HIV risk behaviour, e.g. spouses. More than 90% of women have acquired HIV infection from their husbands or their intimate sexual partners—they are at increased risk of HIV, not due to their own sexual behaviour, but because they are partners of men who are within an HRG (see figure below).

### DYNAMICS OF HIV TRANSMISSION:



According to the National AIDS Control Organisation (NACO), the transmission route is still predominantly sexual (87.4%), and the other routes of transmission by order of proportion are: perinatal (4.7%), unsafe blood and blood products (1.7%), infected needles and syringes (1.8%) and unspecified and others (4.1%).<sup>11</sup>

### 1.1.4 FACTORS CONTRIBUTING TO THE SPREAD OF THE EPIDEMIC

Lack of awareness, poverty, and gender inequality are some of the factors that continue to propel the transmission of this epidemic in India. Sex work by women, men, MSM and TGs, primarily as a source of economic sustenance, and the movement of people from rural to urban India in search of better livelihood options, the transmission of infection by men with multiple partners to monogamous women, are some of the manifested outcomes of the above stated factors which also contribute to the spread of the HIV epidemic. Besides, transmission by the sexual route being the most dominant mode evokes

10 HIV Sentinel Surveillance, Technical Brief (2014-15).

11 UNGASS, India Country Report.

a moral bias in society, which stigmatises infected people and constrains them from taking appropriate measures to seek the necessary services. Listed below are some of these factors that add to the spread of the disease in India.

**Migration, Urbanisation and Mobility:** HIV prevalence is showing a steady increase in rural areas, although as per data the HIV epidemic is more pronounced in urban areas (0.35%) than in rural areas (0.25%).<sup>12</sup> A major cause for the increase of HIV transmission in rural areas is the migration of people in large numbers from rural to urban areas in search of better livelihoods. Migrants and mobile population are exposed to unique pressures, constraints and living environments. The isolation from their communities and families enhances their vulnerabilities and increases the likelihood of engaging in risky behaviour.

Male migrants, who make up the largest clientele of sex workers, are a key bridge population. More than 80% of the migrants in Karnataka and Andhra Pradesh reported having visited a sex worker in the last 12 months.<sup>13</sup> Studies, too, validate the role of migrants as a bridge population, transmitting HIV between urban and rural areas and between high risk and low risk groups.<sup>14</sup>

Besides migration, mobility of people too enhances the risk of HIV transmission. Being mobile, in itself, is not a risk factor for HIV/AIDS, but the situations encountered and the behaviours possibly engaged in during mobility, increase the risk of HIV. A number of studies from India have reported a high vulnerability of truckers to HIV transmission with many engaging in high-risk behaviours—an estimated 36% of clients of sex workers are truckers. Long absences from home, marital status, alcohol use, income levels have been identified as some of the reasons for visiting sex workers.<sup>15</sup>

The impact of mobility and migration is evident in the growing feminisation of the HIV epidemic in India. Women account for 40.5% of HIV-affected people in India.<sup>16</sup> As stated earlier, the largest proportion of infected women are those who have acquired HIV from their husbands or intimate sexual partners, rather than due to their own high-risk sexual behaviour. The impact on women has a wider implication as it increases the risk of transmission of HIV from mother to child. 6.54% of the people living with HIV are children and in 2015 children accounted for 12% of total new infection<sup>17</sup>

**Stigma and Discrimination:** HIV/AIDS related stigma and discrimination is underpinned by many factors, including a lack of understanding of the epidemic, misconceptions about the way HIV is transmitted, the incurability of AIDS, lack of access to treatment, fear of being infected, association with behaviours (such as sex between men and injecting drug use) that are already stigmatised in many societies, the low status of women in many societies, other cultural and traditional dogmas and norms.

HIV related stigma has had far-reaching negative implications on individuals living with HIV, such as refusal of access to HIV prevention, care, and treatment services to those who need it, and non-disclosure of HIV status to employers for fear of discrimination,<sup>18</sup> among others. The shame associated with AIDS also makes people particularly vulnerable to blame and social exclusion. Even those who are not, themselves, infected, but are associated with those who are, such as spouses, children, and caregivers, suffer discrimination. The concentration of the epidemic in the country among HRGs like MSM, FSWs and IDUs, which are already isolated and stigmatised, poses a particularly challenging problem.

---

12 Government of India, *National Family Health Survey (NFHS), Key Findings (2005-06)*, 19.

13 Government of India, 2010, *UNGASS Country Progress Report 2010*, 13 March, 23–24.

14 N. Saggurti et al., 2008, 'HIV risk behaviours among contracted and non-contracted male migrant workers in India: potential role of labour contractors and contractual systems in HIV prevention', *AIDS*, 22(5):127–36.

15 NACO, 2009, 'Targeted Interventions for Truckers: Operational Guidelines'.

16 India HIV Estimation 2015, Technical Report.

17 India HIV Estimation 2015, Technical Report.

18 United Nations Development Programme (UNDP), 2006, *The Socio-Economic Impact of HIV and AIDS in India*, 135.

# 1.2 EVOLUTION OF HIV PROGRAMMING IN INDIA

## 1.2.1 BEFORE NACP

Ever since the first case was identified, India's has responded to the HIV/AIDS challenge with a great deal of promptness. At initial very early stage, an AIDS Task Force was set up under the Indian Council of Medical Research (ICMR), in addition to a National AIDS Committee (NAC) headed by the Secretary under the Ministry of Health & Family Welfare to carry out surveillance to track new cases and take steps to prevent an epidemic.<sup>19</sup>

Soon after, in 1990, the Government launched a Medium Term Plan between 1990 and 1992, in four states: Tamil Nadu, Maharashtra, West Bengal and Manipur, and four metropolitan cities: Chennai, Kolkata, Mumbai and Delhi.<sup>20</sup> This Plan was supported by the World Health Organization (WHO), with an annual budget of about US\$2 million,<sup>21</sup> and it facilitated targeted Information, Education and Communication (IEC) campaigns, and the establishment of a surveillance system and safe blood supply.<sup>22</sup>

## 1.2.2 PHASE I

The Government of India's response to the HIV/AIDS epidemic can be captured through a series of five-year National AIDS Control Plans. The first phase, NACP-I, was implemented during 1992–1999 with an IDA Credit of US\$ 84 million, had the objective of slowing down the spread of HIV infections so as to reduce morbidity, mortality and the impact of AIDS by initiating a major effort in the prevention of HIV transmission.<sup>23</sup>

The specific objectives were: (i) to involve all States and Union Territories in developing HIV/AIDS activities with a special focus on the major epicentres of the epidemic; (ii) to attain a satisfactory level of public awareness on HIV transmission; (iii) to develop health promotion interventions among high risk behaviour groups; (iv) to screen all blood units collected for blood transfusions; (v) to decrease the practice of professional blood donation; (vi) to develop skills in clinical management, health education and counselling, and provide psycho-social support to HIV sero-positive persons, AIDS patients and their associates; (vii) to strengthen the control of sexually transmitted diseases (STDs); and (viii) to monitor the development of the HIV/AIDS epidemic in the country.

In order to strengthen the management capacity, a National AIDS Control Board (NACB) was constituted and an autonomous National AIDS Control Organisation (NACO) was set up for project implementation.<sup>24</sup> NACP-I substantially achieved its specific objectives and often exceeded the original targets. Nationwide capacity-building in the managerial and technical aspects of the programme was a major focus during the implementation period. Maximum efforts were oriented towards integrating relevant project activities with the health care system.

This period also witnessed experimentation and modelling based on experience and evidences from multilateral and bilateral agencies such as WHO, Norwegian Agency for Development Cooperation (NORAD), Department for International Development (DFID), United States Agency for International

---

19 *NACO Annual Report 2012–13*

20 *NACO Annual Report 2013–14*.

21 World Bank, *Project Performance Assessment Report, India National AIDS Control Project (Credit 2350), Report No. 26224 (2 July 2003)* 1–2.

22 *NACO Annual Report 2013–14*.

23 Independent Evaluation of NACP: John Hopkins University, USA; IIM Calcutta; Indian Institute of Health Management Research, Jaipur.

24 *NACO Annual Report 2013–14*.

Development (USAID), etc. From sexually transmitted infection (STI) clinics in brothels, to healthy highway projects and targeted interventions (TIs), the AIDS response was taking a very interesting shape. Around this time, the policy decision to allow bilateral/multilateral and other external agencies to directly support the country's AIDS response led to the formation of organisations such as the AIDS Prevention and Control Project (APAC), which was the result of a tripartite partnership between the NGO Voluntary Health Services, USAID and the Tamil Nadu AIDS Control Society. This paved the way for the states to form semi-autonomous bodies like State AIDS Control Societies (SACs) to fast-forward and channelise much needed management and technical assistance. Also, in this phase, professional blood donation was curbed by the setting up of a National Blood Transfusion Authority.

### 1.2.3 PHASE II

The increasing incidence of HIV/AIDS necessitated the expansion of the response to widen the ambit. Thus, NACP-II was initiated in 1999, with the key objectives to reduce the spread of HIV infection and to strengthen India's capacity to respond to HIV/AIDS on a long-term basis, with an overall budget of US\$ 460 million. Based on the experience gained in Tamil Nadu and a few other states, along with observations on the evolving trends of the HIV/AIDS epidemic, the focus was shifted from raising awareness to changing behaviour, and the decentralisation of programme implementation to the state level, with greater involvement of NGOs.<sup>25</sup>

By this time, India also had sufficient strategic information to infer that more than 90% of the infection was transmitted by HRGs. Thus, greater emphasis was placed on TIs for highly vulnerable sections of the population, which were implemented through more than a thousand NGOs. The other focus areas of this Phase included national coverage of the blood safety programme; the establishment of over 800 voluntary counselling and testing centres; a successful prevention of parent to child transmission programme; upgrading of over 800 STD clinics; a successful condom promotion programme, including social marketing; the establishment of approximately 150 community care centres and drop-in centres; and making Antiretroviral Therapy (ART) available through a large number of centres.

SACs were established to support decentralised planning and implementation, and the management of information systems was streamlined. Another major achievement of this phase was the setting up of a reliable HIV surveillance system, which has the largest coverage in the world.<sup>26</sup> NACP-II also saw the reaffirmation of the government's commitment to the prevention of HIV through significant policy changes. The National AIDS Prevention and Control Policy (NAPCP) was released during this period, with the objective of providing a strong policy environment to strengthen the country's response to the epidemic.

Further, there was the establishment of a high level political forum called the National Council on AIDS (NCA), presided over by the Prime Minister and the Council to mainstream HIV control into the work of all organs of government, private sector and civil society, and lead a multi-sectoral response to HIV/AIDS in the country.<sup>27</sup> The call by the top leadership for a multi-sectoral response led to its inclusion in the NACP strategy, which expanded the scope of the programme. India also actively endorsed international commitments such as Millennium Development Goals (MDGs)<sup>28</sup> and the United Nations General Assembly Special Session (UNGASS) which exhorted nations to address the HIV epidemic in a mission-like mode.

---

25 NACO, Annual Report 2013–2014.

26 Independent Evaluation of NACP: John Hopkins University, USA; IIM Calcutta; Indian Institute of Health Management Research, Jaipur.

27 World Bank Report

28 UNDP Millennium Development Goal, Goal 6. Available at <http://www.undp.org/mdg/goal6.shtml>

### 1.2.4 PHASE III

NACP-III, launched in 2007, was the most dynamic phase of the response, as it consolidated and scaled up successful and innovative models during the development stage as well as through the course of implementation of the plan. The primary goal of this phase was to halt and reverse the HIV epidemic over five years (2007–2012) through the integration of programmes for HIV prevention, care, support and treatment. The stated guiding principles included equity; legal, ethical and human rights; and participation of People Living with HIV (PLHIV) and civil society.<sup>29</sup> NACP-III was formed at a point of time when the country was in the midst of a policy change, with the election of a new government, which had included health as one of its seven development goals. Acknowledging the fact that HIV/AIDS was possibly the most complex public health challenge facing India, the government decided to look at all feasible modalities to curtail the spread of HIV, by learning from successful approaches which were evolving locally, nationally and globally.<sup>30</sup>

A key focus of NACP-III was the North-eastern states, especially vulnerable groups—MSM and IDUs.<sup>31</sup> This phase focussed on scaling up and improving service delivery, and establishing robust monitoring and evaluation (M&E) systems at all levels; evidence based planning, programme implementation with innovative elements and comprehensive financial management. This phase also adopted the strategy of mainstreaming and partnership development with various stakeholders, with emphasis on the 'Three Ones' (one Agreed Action Framework, one National HIV/AIDS Coordinating Authority and one Agreed National M&E System).<sup>32</sup>

The major structural reform under NACP-III was the establishment of the District AIDS Prevention Control Unit (DAPCU) under the leadership of District Collectors. DAPCU plays a pivotal role in monitoring and coordination of service delivery in the district and a key role in the integration of NACP with the National Rural Health Mission (NRHM), and in mainstreaming HIV/AIDS. This phase saw considerable momentum, building on lessons in the earlier two phases. It benefited from strong leadership, with a public health professional at the helm, bringing in a strong health systems focus and integration with other health issues.

### 1.2.5 PHASE IV

NACP-IV was launched in February 2014 with the promise to integrate it with other national programmes and align it with the Twelfth Five Year Plan goals of inclusive growth and development. Having initiated the process of reversal in several high prevalent areas with continued emphasis on prevention, the next phase of NACP will focus on accelerating the reversal process and ensuring integration of the programme response. The main objective of NACP-IV (2012–2017) is to reduce new infections and provide comprehensive care and support to all PLHIV, and treatment services for those who require it. Its proposed strategies include intensifying and consolidating prevention services; increasing access to comprehensive care; and giving support and treatment. NACP-IV aims at consolidating the gains of the programmes so far, scaling up of programmes, and integrating HIV services with health systems in a phased manner. It also lays emphasis on social protection and on the mainstreaming of HIV among other sectors.

---

29 NACO, 2006, *Strategy and Implementation Plan: National AIDS Control Programme Phase III (2006–2011)*, 30 November.

30 Mid-term Evaluation of 10<sup>th</sup> Plan Health Chapter: 2002–2007.

31 UNGASS Country Progress Report—India, 2008.

32 Monitoring and Evaluation Toolkit: HIV, Tuberculosis and Malaria and Health Systems Strengthening. Part 1: The M&E system and Global Fund M&E requirements. The Global Fund to Fight AIDS, Tuberculosis, Malaria. Third Edn. 2009.

## Lessons from the HIV Programme for an Effective Development Response

The box below highlights some of the critical milestones of India's AIDS response so far:

Table 4: Critical Milestones of AIDS Response in India

1986	First case of HIV detected in India; The AIDS Task Force was instituted by the Indian Council of Medical Research to track the epidemic; The National AIDS Committee, headed by the Secretary, Ministry of Health, was established to address the issue.
1990	The development of a medium-term plan for AIDS control (1990–1992), with a focus on four states: Tamil Nadu, Maharashtra, West Bengal, and Manipur, and four metropolitan cities: Chennai, Kolkata, Mumbai, and Delhi. The plan facilitated targeted IEC campaigns, establishment of a surveillance system, and safe blood supply.
1992	Creation of the National AIDS Control Organisation and State AIDS Control Cells; Launch of the National AIDS Control Programme, Phase-I (1992–999).
1999	Launch of the second National AIDS Control Programme (1999–2006) in November 1999; Mandated creation of State AIDS Control Societies; Strategy for Greater Involvement of People with HIV/AIDS; Provision of Anti retroviral Treatment (ART).
2002	Adoption of the National AIDS Prevention and Control Policy; Adoption of the National Blood Policy; Constitution of the Forum of Parliamentarians on HIV and AIDS.
2004	Roll-out of free ART in the country.
2005	Setting up of National Council on AIDS, chaired by the Prime Minister.
2007	Launch of the third phase of the National AIDS Control Programme (2007–2013) in July 2007.
2012	NACP-III dissemination summit for sharing good practices, innovations and impact, organised by NACO in New Delhi on 25–27 April 2012. Over 500 delegates from the government, civil society, vulnerable communities, national and international funding organisations, SACS, Technical Support Units, etc., participated in the event.
2012	The first 'Inter-ministerial Conference for Mainstreaming HIV in India' organised by Department of AIDS Control and United Nations Development Programme (India) was held in New Delhi on 18–19 December 2012. The conference aimed at bringing together all concerned ministries and departments on a common platform to facilitate greater understanding and coordination through comprehensive deliberations around the key issues related to mainstreaming HIV. Over 300 delegates participated in the conference deliberations, including representatives from 23 ministries, 16 public sector undertakings, 25 state governments, communities of vulnerable populations, PLHIV, civil society partners and development partners.
2013	The first international conference on HIV Sensitive Social Protection, UNDP, with the Department of AIDS Control (DAC), hosted a global conference on HIV sensitive social protection in December 2013, highlighting advances in India's HIV related social protection work and how it can be made more effective for people affected by HIV. The sessions brought together more than 200 national and international participants from 12 countries including India. The conference hosted a knowledge fair, technical sessions and developed a road map for social protection work in the DAC-led South–South exchange initiative.
2014	Launch of National AIDS Control Programme-IV with a renewed commitment to sustain the impact achieved in the HIV prevention and treatment efforts in India.
2016	Mid term assessment of NACP IV undertaken

## 2.0 THE FRAMEWORK

In order to glean innovative approaches and lessons to be learnt, the information collected was distilled and analysed through a comprehensive framework. This framework analysis was critical to ensure a systematic approach. The framework below captures all the essential elements of the HIV programme in areas that are fairly common to any developmental context. Using this framework, national and state level consultations were held with a wide range of stakeholders who have played critical roles and contributed to the country’s response to HIV. This process helped to distil the lessons learnt from the HIV response.



Figure 1: India’s HIV Response Framework

## SECTION 2 - SALIENT FEATURES OF INDIA'S RESPONSE TO THE EPIDEMIC

### 3.0 GUIDING PRINCIPLES AND APPROACHES

#### 3.1 GUIDING PRINCIPLES

The HIV response in India has largely followed guiding principles that have been globally adopted and endorsed.<sup>33</sup> This has helped develop and implement a comprehensive national response by incorporating best practices and developing policies and guidelines, while promoting aid effectiveness and harmonisation.

##### 3.1.1 THE THREE ONES

**Issue:** Maximising limited resources and avoiding duplication of efforts are most crucial for an effective outcome, especially in a vast and populated country like India.

**Efforts:** Aligning itself with global efforts to maximise programme outputs, India adopted the unifying credo of the 'Three Ones' principles in 2006. This coincided with the pre-launch of the third phase of the National AIDS Control Programme, therefore setting the stage for the next phase of India's response to HIV. The 'Three Ones' principle was first articulated at the International Conference on AIDS and STIs in Africa (ICASA), held in Nairobi in 2003, with the intent to harmonise the global response to HIV. The 'Three Ones' principle called for one action plan that would provide a basis for coordinating the work of all partners; one coordination authority, with a broad-based multi-sectoral mandate; and one M&E framework.<sup>34</sup>

The adoption of the 'Three Ones' principles helped in avoiding duplication of resources and efforts; brought together various actors to collaborate within an agreed programme framework and work towards maximising impact; initiated periodic joint reviews; and leveraged the potential of various stakeholders involved with HIV response in the country

##### 3.1.2 GREATER INVOLVEMENT OF PLHIV

**Issue:** Greater involvement of PLHIV in the HIV/AIDS response increases the effectiveness of the programme by providing an opportunity to design programmes and interventions best suited to those infected and affected.

**Efforts:** The Paris Declaration adopted by global leaders in 1994 was the first to articulate the need for greater involvement of PLHIV.<sup>35</sup> The Government of India (GoI) introduced Greater Involvement of PLHIV (GIPA) as a guiding principle in HIV programmes and issued a policy to this effect in 2010, although it was not encapsulated in the main National AIDS Control Policy of India.

33 Government of India, NACP-III, 3.

34 Joint United Nations Programme on HIV/AIDS (UNAIDS), 'Three Key Ones' Key Principles. Conference Paper 1, Washington Consultation, 25 April 2004, available at [http://data.unaids.org/una-docs/three-ones\\_keyprinciples\\_en.pdf](http://data.unaids.org/una-docs/three-ones_keyprinciples_en.pdf)

35 *The Paris Declaration*, The Paris AIDS Summit (adopted on 1 December 1994), 2, [http://data.unaids.org/pub/externaldocument/2007/theparisdeclaration\\_en.pdf](http://data.unaids.org/pub/externaldocument/2007/theparisdeclaration_en.pdf)

The adoption of this policy facilitated the development of PLHIV networks in the country, which grew from just a handful of individual leaders to large networks of PLHIV at national, state, and district levels. It also provided a large platform for the involvement of PLHIV to advocate for their rights for better access to stigma-free, quality treatment and care. As a result, there are now district level networks in more than 300 districts and more than 200 drop-in centres that are functioning through these networks.

The adoption of GIPA also enabled the effective and meaningful involvement of PLHIV in the NACP strategy, as they began to participate in all areas, right from decision making to implementation at the grassroots level, leading to greater impact. The results of this capacity building measure are evident today as we witness their representation in various committees of national importance, such as the National Council on AIDS, State Councils on AIDS, Technical Resource Groups (TRGs), Country Coordinating Mechanism, and Grievance Redressal Committees at the state level.

### 3.1.3 SOCIAL OWNERSHIP AND COMMUNITY INVOLVEMENT

**Issue:** Increasing access and ensuring that services and interventions reach those who need them the most require a wide network of service delivery at the grassroots. Engaging community-based organisations (CBOs) has been one of the most effective methods to achieve this.

**Efforts:** Initiated after suggestions and feedback from the World Bank—the primary funder for the first National AIDS Control Programme<sup>36</sup>—the effectiveness of community involvement was demonstrated by other donors and funders, such as DFID and USAID. The involvement of civil society organisations (CSOs) in the country's AIDS response promoted a sense of ownership among the community, through civil society representation and participation in planning and implementation. This has been one of the key guiding principles of NACP and has largely contributed to the success that has been achieved in the prevention, care, and support operations around AIDS in the country.

### 3.1.4 EQUITY AND IMPACT MITIGATION STRATEGIES

**Issue:** Principles of equity guarantee access to prevention, care, and treatment services to those who need it the most. HIV/AIDS disproportionately affects poor and vulnerable groups who are less well informed about HIV, with high concentration among young working adults with significant household

level impacts (loss of bread winner), and a corresponding loss of skills, with rapid attrition in the labour force, which in turn has a direct impact on productivity.<sup>37</sup> AIDS also causes significant loss of income. This ranges from 10% of household income to 66% in the case of incapacitation due to HIV/AIDS.<sup>38</sup> The growing adverse impact of HIV and AIDS on women and children has been documented in several places, including the NCAER/UNDP study.

**Efforts:** Ensuring equity has been the basis of most health related policies globally, and it is also the underlying principle governing India's response to HIV/AIDS. Thus, NACP lays emphasis on ensuring equitable access to prevention services for the most disadvantaged and vulnerable groups. Efforts have been made to ensure that the right prevention information is available to all, regardless of gender, age, ethnicity, and sexual orientation.

The TI programme, which is being implemented in partnership with civil society bodies, is an effort by the government to extend access to all those who need it, especially women. Besides providing subsidised

---

36 World Bank, *Project Performance Assessment Report, India National AIDS Control Project (Credit 2350)*, Report No. 26224 (2 July 2003) 3.

37 Mid term Evaluation of 10<sup>th</sup> Plan Health Chapter: 2002–2007.

38 [http://www.undp.org/content/dam/india/docs/socio\\_eco\\_impact\\_hiv\\_aids\\_%20india.pdf](http://www.undp.org/content/dam/india/docs/socio_eco_impact_hiv_aids_%20india.pdf)

services, intervention sites are being set up close to where the poor and disadvantaged are located. This includes urban slums, which are home to a large migrant population, so as to improve their access to services.

Over the course of its phased intervention, NACP has moved from addressing risks and vulnerabilities to including impact mitigation interventions. Through the adoption of a multi-sectoral approach, Gol is making efforts to extend the benefits of existing welfare schemes to PLHIV in order to mitigate the impacts of the deprivation of their right to a dignified life. Gol has is attempting to improve services through interventions such as Community Care Centres(CCCs) and Link ART Centres.

### 3.1.5 CREATING AN ENABLING ENVIRONMENT

**Issue:** HIV/AIDS largely affects communities and populations that are perceived as being engaged in behavioural patterns that transgress the norms of accepted social behaviour. Thus, those infected and affected are subjected to social stigma, which in turn prevents these populations from accessing care and treatment services, thereby undermining the impact of the programme. Therefore, the creation of an enabling environment wherein people infected and affected by HIV can access services and lead a life of dignity, free from stigma and discrimination, is an essential principle of the programme.

**Efforts:** In order to foster an enabling environment, NACP encouraged the review and reform of structural constraints, legal procedures and policies that impede interventions aimed at marginalised populations.<sup>39</sup> Some efforts in this direction include the promotion of GIPA, the establishment of PLHIV networks and civil society forums, and facilitating non-stigmatising legislation. Capacity building measures were also taken at all levels to ensure effective advocacy against discrimination and a rights-based approach towards the HIV mitigation programme.

Aggressive multimedia mass mobilisation campaigns with the support of PLHIV were used to generate strong community dialogue: spots on TV and radio with messages by celebrities; folk media performances in rural areas; sensitisation of various stakeholders, from the grassroots level to policymakers; involvement of positive speakers through advocacy workshops; revisions in or repealing of existing penal laws, such as

ITPA and Section 377, has also paid dividends. Social assessments were carried out on the basis of which tribal populations were also included in the plan.

### 3.1.6 EVIDENCE-BASED AND RESULT-ORIENTED PROGRAMMING

**Issue:** Evidence-based programme interventions provide scope for innovation and flexibility, and help deliver efficient, result-based outcomes. This becomes even more critical when a large scale response needs to be mounted with limited resources. In such cases, efficient planning can greatly help maximise outcomes.

**Efforts:** India's response to the evolving HIV epidemic is largely based on evidence generated from multiple sources.<sup>40</sup> This has helped to revise estimates, provide data for programme design and also undertake mid-course correction as required. Right from the beginning, regular and systematic sentinel surveillance, behavioural and biological surveys, etc., have been instrumental in designing the right programme at the right time for the right people. Besides, HIV was also added to the third wave of the National Family Health Survey (NHFS), which is a population-based survey to collect information on health related indicators, including maternal and child health, to corroborate the estimates. The programme has largely benefitted from the focus on strategic information management and is one of the few national programmes known to be designed entirely based on evidence.

---

39 World Bank Appraisal Report No: 36413 IN, March 2007.

40 NACO, 2006, M&E Monograph.

### 3.2 APPROACHES

#### 3.2.1 RIGHTS-BASED APPROACH

**Issues:** The gross violation of rights of those infected and affected, and the high degree of stigma and discrimination associated with HIV underscore the need for a rights based approach. Further, the marginalised sections of the population that are most at risk of acquiring HIV—such as MSM, TGs, FSWs, and IDUs—are not only stigmatised but also criminalised, because of the Indian punitive laws (many of which are legacy laws), affecting their rights and access to services. Women, too, shoulder a disproportionate share of the impact due to the socio-cultural environment.

**Efforts:** The national programme emphasises the need to work in partnership with PLHIV networks and other stakeholders towards creating an enabling environment by addressing issues of stigma, discrimination, and other legal and ethical concerns.<sup>41</sup> The efforts undertaken in this direction include adoption of GIPA to facilitate the inclusion of PLHIV within the programme development process, sensitisation of service providers and policy makers through consistent advocacy, undertaking multimedia campaigns in both rural and urban India, repealing of old laws that prevent effective intervention among HRGs, the provision of legal clinics, and the drafting of the HIV bill.

#### 3.2.2 MULTI-SECTORAL APPROACH

**Issue:** The magnitude of the AIDS epidemic and its implications on significant developmental goals such as the social and economic growth of the nation have made it clear that an effective response to HIV cannot solely be the responsibility of the health sector. Therefore, it was felt that a multi-sectoral approach would help streamline the existing responses of various development processes and government/non-government responses in order to address the direct and indirect causes and impact of the epidemic in a cost-effective and efficient manner.

**Efforts:** At a global level, the Joint United Nations Programme on HIV/AIDS (UNAIDS) was created in acknowledgement of this need. In India, too, the government recognised the need for a multi-sectoral approach, which was articulated in its National AIDS Prevention and Control Policy (2002). This approach was further boosted in 2005, when Golset up the National Advisory Council, with representation from several ministries, to ensure a multi-sectoral response to the disease. NACP-III also declared mainstreaming and partnerships as part of its core strategy, calling forth the support of all stakeholders—government, non-government and the private sector.

This approach helped to mainstream HIV within the responses of other sectors, including the government and the private sector, by leveraging social security schemes provided through various ministries to PLHIV. Multinational, national and public sector units, including railways and armed forces, have started providing care and treatment services to their employees and people around these HIV related facilities including ART.

#### 3.2.3 GREATER INVOLVEMENT OF CIVIL SOCIETY

**Issues:** CSOs have immense potential to be at the forefront of addressing multiple medical, social, legal, ethical and policy issues. Their outreach to marginalised and vulnerable groups offers great scope for innovation and rapport-building, ensuring a local and more appropriate response. Moreover, interventions designed and planned by communities are rooted in local contexts and realities, and therefore are more likely to succeed because of greater participation and a sense of ownership.

---

41 Government of India, NACP-III, 26.

**Efforts:** The National AIDS Prevention and Control Policy (2002) emphasised that the government would involve CSOs on a large scale, from policy to grassroots work, in its response to the epidemic, and this approach has significantly contributed to the success achieved by the national programme today. The Global Fund-supported initiatives have also focused on building on existing efforts by encouraging the formation of CBOs to strengthen services for care and treatment.

Programmes implemented by donor partners like DFID and USAID together with CSOs, have demonstrated the advantages of partnering with CSOs. This approach has been integrated into the government's response by engaging CSOs for the implementation of TIs (programmes specifically directed towards prevention of HIV infection amongst vulnerable populations). The commitment, flexibility and swiftness with which CSOs have responded, as well as their acceptability among the affected communities, have proved that they are better placed to achieve breakthroughs in the case of hard-to-reach communities, and provide prevention, treatment, care and support services. In fact, CSOs have successfully implemented many innovative approaches, such as Oral Substitution Therapy, and helped integrate HIV and sexual reproductive services for women. Initiatives involving PLHIV networks, and most of the interventions for care treatment, such as TIs and ART, have been implemented by CSOs as per the need of the community.

### 3.2.4 DECENTRALISATION

**Issues:** The emerging complexity of the HIV infection and its spread from urban to rural areas mandated the need to look at a decentralised structure and thereby extend the programmes to the district level. Health being a state subject, this approach ensured a better response as it could be planned, implemented and monitored as per the needs of the states, which were socio-culturally diverse.

**Efforts:** Given the localised prevalence of HIV in certain geographical areas of the country, SACS were formed very early on as part of the response. These devolved the responsibility of implementing NACP at the state level. As the infection moved from urban to rural areas, this was followed by further decentralisation through the formation of District AIDS Prevention and Control Units (DAPCUs) at the district level. Further, a North East Regional Office (NERO) was set up for the first time to address responses specifically tailored for the unique nature of the HIV epidemic of the region. DAPCUs function through District Collectorates and the District Magistrates oversee the implementation. Similarly, at the village level, local governance structures such as the Panchayati Raj Institutions are beginning to play a prominent role in the NACP programme

### 3.2.5 EMPOWERMENT APPROACH

**Issue:** Empowering individuals and communities to take ownership of programmes in order to achieve the most effective HIV responses, and taking concrete action to address social and structural barriers to their broader health and human rights, is an extremely successful way of enhancing programme outcomes.

**Efforts:** Partnerships were formed with core communities and PLHIV networks to increase programme saturation and reach hidden populations. CBOs were promoted to raise awareness about rights, as well as to increase outreach and advocacy. Drop-in centres were established to provide safe spaces and the formation of collectives that determine the range of services as well as adherence to safe practices was promoted. Capacity-building exercises were aggressively carried out to empower them to implement, monitor and manage interventions, and they were co-opted into several advisory and technical groups to provide inputs for the improvement of programmes.

Communities developed the strength to represent themselves and their concerns at national and international forums and actively engage in decision making committees. The empowerment approach

also promoted a sense of ownership and increased adherence to prevention measures, such as condoms and safe needles. Marginalised communities thereby got the opportunity to be recognised, and this also helped to fight the stigma and discrimination they faced.

### 3.3 THE NEED FOR A STRONG AND COMMITTED LEADERSHIP

**Issues:** Governments are driven by political priorities; hence, sustained political advocacy becomes essential to generate political support and interest in developmental issues, get decisions taken and have them implemented. HIV/AIDS is not only a public health concern but an enormous development issue that requires concerted efforts from all quarters to ensure an effective response, which can be evinced only through a strong political leadership and mandate.

**Efforts:** There has been comprehensive and concerted support from political leaders and policymakers at all levels—be it the grassroots level, the state, the national and even international level—to accelerate the response to HIV and to end the epidemic.

In India, the strong civil society movement and the impact of the global leadership in addressing HIV motivated political representatives to break their silence and address the issue. In 2001, an international HIV/AIDS conference organised in New Delhi brought together, for the first time, the then Prime Minister Mr. Atal Bihari Vajpayee and the leader of Opposition, Ms. Sonia Gandhi, to jointly extend their support to spearhead the HIV response in the country. This conference also brought together the Chief Ministers and Health Ministers of the high HIV prevalence states.

Support has been evinced from the entire political class, cutting across party lines. Former Prime Minister Mr. Atal Bihari Vajpayee, who led the National Development Alliance (NDA) government in 2001, declared that, 'We must recognise that the fight against HIV/AIDS requires greater courage and commitment. It requires leadership that is ready even to go against the stream of public opinion.' Some of the efforts that were undertaken under his government include the representation of India at the 2001 United Nations General Assembly on AIDS (UNGASS) meeting, through a high level delegation led by the then Leader of the Opposition, Ms. Sonia Gandhi. Chief Ministers, especially from high HIV prevalence states, were requested by the central leadership to review the HIV/AIDS situation regularly.

Similar commitment was displayed by the succeeding United Progressive Alliance (UPA) government led by Prime Minister Mr. Manmohan Singh, when he took charge in 2005. He stated, 'The National AIDS Control Programme must move out of the narrow confines of the health department and become an integral part of all government departments and programmes to create a national response, which alone can help reverse the epidemic.'

The intent of the Government to address HIV/AIDS on priority basis was seen through the inclusion of HIV/AIDS as a priority in the Five Year Plans, which articulate India's strategy for national progression for the ensuing five-year period. In 2005, the Government strengthened its commitment to battling the HIV epidemic by setting up the National Council on AIDS (NCA) under the chairmanship of the Prime Minister, and whose membership included 31 central ministers, six state chief ministers and civil society representatives. This body was mandated to provide the highest political attention and support to the implementation of the national HIV control framework, especially in order to mainstream HIV control into the work of all organs of the government, private sector and civil society, and lead a multi-sectoral response to HIV/AIDS in the country.

The states were also directed to establish State Councils on AIDS, along the pattern of the National Council on AIDS, to be chaired by the Chief Minister, with the Minister of Health as Vice Chair.<sup>42</sup> The State Council, with

---

42 World Bank Appraisal Report, March 2007.

representation from various departments of the government and civil society, was to set policy guidelines, review the state's performance, including mainstreaming by key departments. Ms. Sonia Gandhi, leader of the Congress Party, also wrote to the Chief Ministers belonging to the party and reviewed the HIV/AIDS response within Congress-ruled states during meetings with the Chief Ministers on a regular basis.<sup>43</sup>

State-level initiatives to address HIV/AIDS were driven through the directives issued by the Chief Ministers of the states. For instance, Mr. Chandra Babu Naidu, former Chief Minister of Andhra Pradesh, dedicated one day of every session of the State Assembly to discussing HIV/AIDS. He also promoted life skills education, including reproductive health in schools and pushed for condoms to be distributed free wherever alcohol was being sold as well as at all official functions.<sup>44</sup> The state of Tamil Nadu took the decision to transform its State AIDS Control Cell into a semi-autonomous State AIDS Control Society (SACS), which became a model for other states to follow.<sup>45</sup> The national response to HIV and AIDS was not only supported by the top leadership at the national and state level, but also by local self-government bodies such as the Zilla Parishads (district level governance bodies) and the Gram Panchayats (village level governance bodies), which have been crucial in executing the HIV response at the village and community level, while addressing the social stigma and discrimination associated with HIV.

A Parliamentary Forum was also constituted, which was represented by parliamentarians and policy makers. This was an effort to sensitise policy makers who had access to Parliament about issues related to HIV/AIDS. This Forum was expected to play a critical advocacy role by activating the executive and the legislature towards framing appropriate laws and policies to protect the rights of PLHIV.

Complementing the Parliamentary Forum at the national level, a Legislator's Forum on AIDS was also set up in 13 states across the country. This was an important initiative which strengthened the HIV response by engaging legislators and policy makers to influence effective policy changes at the state level.

Most recently, in 2011, UNAIDS India, in collaboration with the Indian Ministry of Health and Family Welfare and the Forum of Parliamentarians on AIDS, co-hosted a National Convention on HIV for 500 elected government representatives who were addressed by the Prime Minister, senior political leaders such as the Health Minister, Rural Development Minister and the Deputy Chairman of the India's Planning. The participants pledged their sustained support for the HIV/AIDS response and drafted a note on their role in reducing HIV related stigma and discrimination.<sup>46</sup>

### 3.4 LEGAL AND POLICY ENVIRONMENT: HOW IT ENABLED THE HIV RESPONSE

**Issues:** While there have been developments in the policy environment that have enabled and facilitated the HIV response in the country, the legal empowerment process has not managed to keep pace. Those who are most at risk of acquiring HIV—also considered the main drivers of the infection, including populations such as sex workers, MSM, transgender people and drugs users—are also subject to certain criminal laws because of their behaviours. This poses a challenge in the implementation of HIV prevention programmes among these populations, thus undermining the very agenda of the programme. Besides, the impact is being increasingly seen amongst women and children who are being deprived of their basic rights to a dignified life. A strong legal framework along with an enabling policy environment are absolutely crucial to protect human rights, promote gender equality and ensure universal access to care, treatment and prevention services for all those who need them. Therefore, there is a need to create human rights-based legal frameworks for a more effective national HIV response.

---

43 Parliamentarians' Forum on HIV/AIDS (PFA), 'About PFA', last updated on 2 May 2012, <http://www.pfaindia.in/aboutus.html>

44 Asia Pacific Leadership Forum on HIV/AIDS and Development (APLF), *Act Now; Asia-Pacific Leaders Respond to HIV/AIDS* (no date), 21, [http://data.unaids.org/publications/External-Documents/apfl\\_actnow\\_en.pdf](http://data.unaids.org/publications/External-Documents/apfl_actnow_en.pdf)

45 World Bank, *Project Performance Assessment Report, India National AIDS Control Project* (Credit 2350), Report No. 26224, 2 July 2003, 5–6.

46 NACO, 2012, *India Report NCPI*, 3.

The enforcement of the fundamental rights enshrined within the Indian Constitution, which entitles every human being to a life of dignity, has been inadequate to protect the rights of PLHIV. Further, the HIV Bill is yet to be legislated, has led India to endorse international political and legal commitments and declarations, such as the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social, and Cultural Rights (ICESCR), Convention for the Elimination of All Forms of Discrimination Against Women (CEDAW), Convention on Rights of the Child, etc., which have helped to honour the rights of the HIV-affected and infected populations.<sup>47</sup>

**Efforts:** The development of the NACP in 2002 articulated the Government of India's commitment to the HIV response by defining a multi-sectoral response, including the large-scale involvement of NGOs from policy level to grassroots level, and the review and reform of criminal laws to ensure that they are in tandem with international human rights obligations. In addition, the policy highlights the government's commitment to strengthen anti-discrimination laws and ensure that legislative measures are undertaken to protect the vulnerable.<sup>48</sup> Some states have developed their own policies. Manipur was probably the first state that launched an HIV/AIDS Policy in 1996, preceding the national policy.<sup>49</sup>

**National Policy on HIV/AIDS and the World of Work:** In 2009, the Ministry of Labour and Employment adopted a national policy on HIV/AIDS and the World of Work. This was developed by the Ministry of Labour and Employment in collaboration with NACO and technical support from International Labour Organization (ILO). The key areas included: collaborations with corporate groups/large companies in the public and private sector to develop and implement HIV/AIDS workplace policies. This policy initiated a business response to prevent HIV/AIDS in the world of work and catalysed the process of reaching out to the bridge populations in the informal sector through collaborative efforts between NACO and trade unions.

**Policy for Greater Involvement of PLHIV (GIPA):** This policy was drafted and adopted with the intent of meaningfully engaging with PLHIV in order to reduce the spread of HIV and mitigate its impact in India, and thus enhance the AIDS response. The basic purpose of this policy was to get PLHIV voices on board, protect their rights, secure their access to necessary services, care and support, and ensure that their interests are represented. According to NACO, currently 35 central and state social security schemes have been modified for PLHIV and 29 directives have been issued by State Councils on AIDS in favour of PLHIV.<sup>50</sup>

**National Blood Policy:** Ensuring the widespread availability of safe and quality blood is a critical component of the National AIDS Prevention and Control Programme. A National Blood policy formulated by NACO was adopted by Gol in April 2002. The transfusion of unsafe blood and blood products accounted for 2.07% of the HIV infections in the country in 2004–05, as opposed to over 9% of AIDS cases in 1999.

## LEGAL REFORMS:

**Repealing of the incarceration law:** In the initial years following the discovery of the HIV virus in India, certain laws were drafted by some states that violated the human rights of infected or affected individuals. However, concerted efforts by civil society and affected communities resulted in reforms in Indian legislation favouring an active response to AIDS. These reforms began with the *Lucy D'Souza vs Goa State* case in the Mumbai High Court, and were supported by overseas development assistance.<sup>51</sup> This particular case led to the repealing of the law that incarcerated HIV-positive people for life out of fear that they would spread the infection to others.

---

47 UNDP, 2001, *Law Ethics and HIV/AIDS in South Asia*, 41, <http://www.undp.org/content/dam/aplaws/publication/en/publications/hiv-aids/law-ethics-and-hiv-aids-south-asia/35.pdf>

48 Government of India, *National Aids Prevention and Control Policy*, 15 April 2003, para 6.1.

49 Manipur State AIDS Control Society, Home: Welcome to Manipur State AIDS Control Society (2012), <http://manipursacs.nic.in/> (accessed on 19 December 2012).

50 NACO, 2012, *India Report National Commitments and Policies Instrument*, 8.

51 UNDP, 2001, *Law, Ethics and HIV/AIDS in South Asia*, 13.

**Decriminalisation of Section 377:** MSM and TGs have been legally penalised in India because of existing laws, which also makes it difficult to implement HIV prevention programmes among them. In 2010, the Delhi High Court delivered a landmark judgment by repealing Section 377 of the Indian Penal Code, thereby decriminalising same-sex relations between consenting adults. Based on a case filed by a leading NGO, the judgement was the first in India to directly guarantee rights for homosexuals. It overturned a 149-year-old British colonial law which described sex between members of the same gender as an 'unnatural offence'.<sup>52</sup> However, this was overturned in the Supreme Court in December 2013.

**TRIPS reforms for cheaper drugs:** Despite the pressure on India to endorse drug patent laws such as Trade-Related Aspects of Intellectual Property Rights (TRIPS), proposed by the World Trade Organization (WTO), India was able to incorporate in its national legislation many of the flexibilities allowed under the TRIPS agreement, thereby managing to achieve a significant reduction in ART prices.<sup>53</sup> These reforms have helped protect access to medicines and uphold the human rights of the affected and infected populations. This success could not have been achieved without the relentless advocacy by members of the civil society.

**Gender reforms:** NACP is now working towards drafting a policy for Gender Mainstreaming, keeping in mind the impact on women. Gender has also been included as a guiding principle in NACP-IV. TGs, who have long been marginalised and deprived of their rights, have successfully fought for their recognition beyond the accepted norms of he/she, With Gol introducing 'Other' as a gender option in 2005. This has been implemented in passport application forms, election/ voter ID cards and was also included in the census of 2011. In 2008, the Government of Tamil Nadu also established a Transgender Welfare Board to protect the rights of the TGs, with the State Social Welfare Minister as its president. This is the first such initiative in India and a pioneering one in the Asia Pacific Region,<sup>54</sup> The state of Maharashtra has also set up a similar board.

### 3.4.3 RESPONDING TO THE INTERNATIONAL CALL FOR ACTION

India's AIDS response has been ensconced within the significant global declarations to halt and reverse the epidemic. Its participation in and endorsement of these calls for action have, in many ways, provided clear directions for an effective response and also instigated the government to gather momentum. Some of the most important developments are listed below.

**Millennium Development Goals:** In 2000, the adoption of Millennium Development Goals (MDGs) by the largest gathering of world leaders at the United Nation Headquarters in New York, set targets including halting and reversing the spread of HIV and ensuring universal access to treatment of HIV/AIDS for all those who need it. These goals were endorsed by 189 nations, including India. Under this declaration, these nations committed to a new global partnership, thereby placing the issue on the international agenda.

**United Nation General Assembly Special Session (UNGASS):** In June 2001, India also participated in UNGASS, which was specifically dedicated to HIV/AIDS. This meeting, attended by the Heads of States and representatives of Governments proposed a Declaration of Commitment, which was unanimously adopted at that session, setting out a series of national targets and global actions to reverse the epidemic.<sup>55</sup> The declaration guided country level responses by setting targets, refining governance mechanisms, mandating the collection of data and reporting on progress.<sup>56</sup>

52 <http://www.thehindu.com/todays-paper/tp-national/tp-newdelhi/india-could-be-showcased-globally-for-hiv-reforms/article505418.ece>

53 Patent Reform in India: The campaign to protect public health, <http://www.ipngos.org/NGO%20Briefings/Patents%20Act%20amendment.pdf>

54 UNDP, 2010, *Hijras/Transgender Women In India: HIV, Human Rights and Social Exclusion*, 12, [http://indiagovernance.gov.in/files/hijras\\_transgender\\_in\\_india\\_hiv\\_human\\_rights\\_and\\_social\\_exclusion.pdf](http://indiagovernance.gov.in/files/hijras_transgender_in_india_hiv_human_rights_and_social_exclusion.pdf)

55 Bulletin of the World Health Organization, Bull World Health Organ vol.79 n.12 Geneva Jan. 2001; [http://www.scielo.org/scielo.php?pid=S0042-96862001001200006&script=sci\\_arttex](http://www.scielo.org/scielo.php?pid=S0042-96862001001200006&script=sci_arttex)

56 UNGASS, 2001, Declaration of Commitment on HIV/AIDS.

In 2006, UN member states met to review the progress achieved by nations in realising the targets set out during the UNGASS meeting in 2001. A political declaration on HIV/AIDS was unanimously adopted by the member states, which reaffirmed the 2001 Declaration of Commitment on HIV/AIDS and the MDG of HIV reversal, besides further refining the goals and providing the countries a framework for focussed action towards achieving universal access to comprehensive prevention programmes, treatment, care and support by 2010.

Ten years into the landmark UNGASS meeting, leaders came together at the 2011 UN General Assembly High Level Meeting on AIDS. The Political Declaration on HIV/AIDS recorded new commitments and bold new targets across the globe. The Outcome Framework (2009–2011) and the revised investment framework (2011) were the other international frameworks which guided the response.

**Three Ones Principle:** As stated earlier, India has committed to the Three Ones' principle, which was accepted at the International Conference on AIDS and STIs in Africa (ICASA), held in Nairobi in 2003, which has provided greater clarity to its national response to AIDS.

**GIPA** was the outcome of the 1994 Paris Summit, whereby, as a signatory government to the Paris Declaration, India undertook the initiative to endorse and implement it in India.

India has also endorsed several other international political and legal commitments and declarations, such as the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social, and Cultural Rights (ICESCR), Convention for the Elimination of All Forms of Discrimination Against Women (CEDAW), Convention on Rights of the Child, etc., which have helped to honour the rights of HIV-affected and infected populations.<sup>57</sup>

The Programme of Action of the International Conference on Population and Development (1999), the Beijing Declaration and Plan of Action (2000), are some of the other internationally acknowledged declarations which reinforced the call to action on HIV.

These international commitments and instruments have contributed greatly in influencing the response to AIDS in India, driving the attention of both donors and the government to meet the country's international obligations on ensuring universal access to treatment and upholding human rights.

### 3.5 DESIGNING THE RIGHT RESPONSE

**Issues:** Given the size of India's population, even a minimal increase of 0.1% would not only have a tremendous impact on the AIDS burden in India, but would also reflect globally. Given the diverse epidemiological situation of HIV across the country, tackling this public health problem requires a suitably diverse response. India has been very proactive in responding to the AIDS crisis. Issues such as lack of awareness, absence of accurate data on infection rates, gender inequality and poverty are some of the crucial obstacles to a streamlined response to the epidemic. There is also the concentration of the epidemic in certain states and among certain groups of individuals, deemed HRGs. Further, 'bridge populations', such as truckers and migrants, act as carriers of HIV from HRGs to the general population.

**Efforts:** Over the years, the government has responded with dynamism to contain the epidemic and prevent new infections. Soon after the first case was detected, Golput in place a National AIDS Committee to carry out surveillance to track new cases and take steps to prevent an epidemic. Large-scale communication efforts were initiated in an effort to prevent the transmission of the disease, which also focused on blood safety. As the number of cases continued to rise, India established its National AIDS

---

<sup>57</sup> UNDP, 2001, *Law, Ethics and HIV/AIDS in South Asia*, 41, <http://www.undp.org/content/dam/aplaws/publication/en/publications/hiv-aids/law-ethics-and-hiv-aids-south-asia/35.pdf>

Control Programme (NACP) in 1992 with support from the World Bank and the World Health Organization (WHO). This period also witnessed the implementation of focused programmes by bilateral partners like DFID (Andhra Pradesh, Gujarat, Kerala, Orissa and West Bengal) USAID (Tamil Nadu), CIDA (Karnataka and Rajasthan), and others, which contributed to the state and national level efforts.

In April 1999, the second phase of NACP (NACP-II) commenced, bringing about a paradigm shift in the national response to the epidemic. The programme was implemented through a decentralised mechanism of State AIDS Control Cells, which were set up in all the states of India. NACP-II focused on mapping populations at risk and covering them through TIs to prevent HIV transmission. Further, a comprehensive programme was initiated, which included Voluntary Counselling and Testing Centres (VCTCs) and STD clinics. Other highlights of NACP-II include: nationwide Behaviour Sentinel Surveillance (BSS) surveys; prevention of Parent to Child Transmission (PPTCT) programme; and Computerized Management Information System (CMIS) and Computerized Project Financial Management System (CPFMS).

The third phase of NACP (NACP-III), which was initiated in 2007, was the most dynamic phase of the programme, which introduced a package to integrate the programmes for prevention, care, support and treatment. The focus was on: the saturation of coverage of HRGs with TIs; scaled up interventions among the general population; providing greater care, support and treatment to a larger number of PLHA; strengthening the infrastructure, systems and human resources at the district, state and national levels; and strengthening strategic information management systems throughout the nation. Listed below are some of the successful strategies adopted by India to enhance its response:

### 3.5.1 USING EVIDENCE TO BUILD AN EFFECTIVE RESPONSE

**Issue:** The systematic gathering of data through scientific research such as behavioural and health sentinel surveillance, experiential knowledge and best practices, helps to generate the information required to design an effective response.

**Efforts:** The evolution of NACP was based on methodological and evidence based research. The programme was designed on the basis of all available information on the epidemiological situation in India.<sup>58</sup> This approach, it was hoped, would be helpful in preventing new infections and reduce the long-run costs and burden on health systems. Over the last decade and half, India has substantially increased its data sources to mount an evidence-based response to contain the HIV epidemic. The generation, analysis and use of data for planning has shifted from the national level to the state, district and, most recently, the sub-district level, at least in the priority states. NACO and its partners have developed and applied new methodologies specifically configured to provide district level information, to inform the fine-tuning of NACP-II and the design of NACP-III.

The evidence used includes results of HIV Sentinel and Behavior surveillance studies, analysis of epidemiological or survey data, modelling and syntheses of existing evidence. Surveys such as HIV Surveillance Survey (HSS), Behavioural Surveillance Survey (BSS), mathematical and statistical models,<sup>59</sup> National Family Health Survey (NHFS 3), along with mapping and size estimation, helped to define the disease burden, which showed that 99% of the population was uninfected and that HIV remains highly concentrated in key populations at higher risk of infection. Therefore, priority was given to prevention efforts, and widening the coverage of groups with high risk of infection through TIs.<sup>60</sup> Besides scientific evidence, other forms of evidence, such as best practice evidence also influenced the decision process.

58 A.M. Kadri,<sup>1</sup>Pradeep Kumar,<sup>2</sup>2010, 'Institutionalization of the NACP and Way Ahead',

59 M&E Monograph; NACP-III;[www.nacoonline.org](http://www.nacoonline.org); NACO, 2008, *HIV Sentinel Surveillance and HIV Estimation in India 2007:A Technical Brief*.

60 World Bank Appraisal Report No: 36413 IN, March 2007; NACO, 2006, *Strategy and Implementation Plan: National AIDS Control Programme Phase III (2006–2011)*, 30 November.

Experiential knowledge was gathered from the field, based on successful interventions, especially with respect to vulnerable populations at high risk of being infected.<sup>61</sup>

Prior to the initiation of any programme under NACP-III, the innovative measure of geographical mapping was introduced for evidence based planning and implementation of TI programmes. This exercise helped

achieve a geographical and social overview of sites, profiling of different categories of HRGs and their mobility patterns, and available services. It was undertaken in 17 states and resulted in strengthening TI services. For the first time, a line list of HRGs was introduced, thus contributing to a robust estimate (with identification) of individuals. Despite the country's geography and diversity, this massive exercise provided clear evidence for the up-scaling of the TI programme from about 1,000-plus in NACP-II to over 2,100 in NACP-III. In some states, the population estimates of HRGs increased three to seven times over. The quality of the evidence gathering has been varied. This did have implications on the design and quality of the interventions.

### 3.5.2 LEARNING FROM SUCCESSFUL MODELS

**Issues:** NACP exemplifies how an effective programme can be evolved by improving on, consolidating and scaling up need-based, successful and innovative models developed in response to HIV/AIDS. These models have been primarily implemented by NACO and/or SACs. However, a significant number have also been implemented by various development partners—either independently (within the framework of NACP), or in partnership with national/state programmes.

**Efforts:** The TI model, which proved that by identifying sub-populations with high risk of HIV infection and preventing further transmission through direct interventions, can contribute towards lowering of HIV prevalence and incidence, was first demonstrated by DFID, during Phase II of the programme, as part of their support to the government. During this phase, TIs were implemented through a large number of NGOs who were in close proximity with these sub-populations, in the states of Gujarat, West Bengal, Orissa, Andhra Pradesh and Kerala. In Tamil Nadu, APAC pioneered TIs on the ground, with support from USAID. An evaluation of the TI programmes in five states<sup>62</sup> and two external evaluations undertaken in 22 states during 2002–03 observed that TIs play a critical role in reducing the spread of the epidemic and therefore, interventions must focus on groups at highest risk and cover them fully. NACP-III acknowledged this success and scaled up the programme manifold.

The comprehensive approach to HIV prevention through community empowerment, which was later termed as collectivisation, was pioneered successfully through the Sonagachi model in West Bengal, funded by DFID. Apart from Sonagachi, various other models such as the Pragati model (Bangalore, by Swasti), Saksham model (Vijayawada, by CARE), Ashodaya model (KHPT, Mysore) were rich and diverse, with several learnings for the national programme. These models encouraged the participation of HRG communities themselves in tackling problems related to AIDS, advocating for their rights, and safeguarding the interests of their community members. Today this collectivisation process is part of the national response, prompting HRGs and PLHIV communities to form networks at the national, state and district level.

The Healthy Highway project, which was launched in 1996 with the support of DFID, covered the country's major national highways and aimed to reduce the prevalence of STDs (and HIV) among

---

61 NACO, 2006, *Strategy and Implementation Plan: National AIDS Control Programme Phase III (2006–2011)*, 30 November, [http://www.nacoonline.org/upload/Publication/Strategy%20and%20Implementation%20Plan%20NACO%20Programme%20Phase%20III%20\(2006-2011\)%202006.pdf](http://www.nacoonline.org/upload/Publication/Strategy%20and%20Implementation%20Plan%20NACO%20Programme%20Phase%20III%20(2006-2011)%202006.pdf)

62 DFID 2003b.

truck drivers and sex workers by modifying their high-risk behaviour. Lessons from this project, which was implemented across 19 states with the help of 38 NGO partners, helped in designing the next phase of NACP. Besides, innovative interventions amongst MSM, TGs and IDUs, which needed more careful thinking and modelling were undertaken by a number of agencies including DFID, USAID, UNDP and Futures Group, to name a few, and have been inducted into the national programme.

The Avahan Programme, which came much later in 2003, built on these initiatives and was implemented in six states: Tamil Nadu, Karnataka, Andhra Pradesh, Maharashtra, Nagaland and Manipur. Apart from TIs, Avahan also provided prevention services to men at risk and long-distance truckers on a large scale.<sup>63</sup> The Orchid Project in Manipur and Nagaland, too, set many trends in addressing the needs of IDU populations. This project also brought to scale the Oral Substitution Therapy (OST), the efficacy of which had been earlier demonstrated by DFID, and which was later included within the national response. The Orchid Project also successfully employed nurses to effectively deliver STI services to cover the shortfall of doctors.

The initiatives by HIV/AIDS Alliance India addressed the requirements of HRGs, particularly MSM and TGs more clearly, right from defining their identities, undertaking mapping to get an estimate on the size, tailoring appropriate and sensitive services, besides empowering them through the formation of CBOs. Positive Action for the Health of People Living with HIV/AIDS (Pathway), implemented by Project Concern International, which provided comprehensive community and home-based care and support for PLHIV in the high prevalence states of Maharashtra, Tamil Nadu, and Andhra Pradesh and in the north-eastern states of Manipur and Nagaland, was a beacon for strengthening the national response. In addition, civil society also developed successful models where HIV and AIDS treatment, care and support were provided as a whole. For example, In partnership with the Clinton HIV/AIDS Initiative, Project Concern International procured paediatric ART for 10,000 children, linked children living with HIV/AIDS to the nearest ART centres, and provided home-based care and support to those children who required it.<sup>64</sup>

These are only a few of the manifold innovations which have been undertaken by various stakeholders. Lessons and models developed by various partners over time have been incorporated into the national response by NACO, and on the basis of these, a series of Operational Guidelines (list appended at the end of the report) have been developed, which have been used to support the scale-up of these best practices in all states.

### 3.5.3 UNIFORMITY AND QUALITY OF INTERVENTIONS

**Issues:** Ensuring the uniformity and quality of the HIV programme, with its many components, may prove to be a challenge, given the diverse needs and the large scale of operations. Moreover, being largely implemented in partnership with NGOs and other community bodies, which have varying capacities, there may be issues with standardising the services.

**Efforts:** As stated above, guidelines were developed based on the lessons learnt from the previous phases of the programme. These were used to support the scaling-up of interventions in all states, in a uniform and consistent manner, while ensuring quality.

---

63 Bill & Melinda Gates Foundation, 2008, *Avahan: The India AIDS Initiative the business of HIV prevention at scale*, New Delhi, 10, [http://www.gatesfoundation.org/avahan/Documents/Avahan\\_HIVPrevention.pdf](http://www.gatesfoundation.org/avahan/Documents/Avahan_HIVPrevention.pdf)

64 Aarogya, Project Concern International/India (PCI), 2012, *Saving Lives and Building Healthy Communities*, <http://aidssupport.aarogya.com/gujarati/showcasing-initiatives/project-concern-international-india-pci/all-pages> (accessed on 19 December 2012).

### 3.6 PROGRAMME INTERVENTIONS

#### 3.6.1. PREVENTION

**Issues:** Multiple surveys, mapping and surveillance exercises at the end of NACP-II indicated that 99% of the population was uninfected. Therefore, the focus of NACP-III was to prevent new infections in all sub-populations and prevent the spread from HRGs to the general population. A package of clearly defined and inter-linked HIV prevention services, with easy-to-access delivery points, was envisaged to enhance utilisation.<sup>65</sup>

**Efforts:** TI became a key focus area within NACP, given the concentration of the HIV infection amongst certain sub-populations. As stated earlier, several models implemented across HIV prevalence states had already demonstrated its direct impact on the prevention of HIV amongst HRGs. Thus, Phase II of the programme saw a major scale-up of TIs, implemented directly by the government or with support of donor/partners. At the end of Phase II, it was clear that India's epidemic could be handled only if we manage to establish a comprehensive TI programme.

Phase III of NACP saw more variation and innovation within the programme aimed at adapting the programme as per need, and to promote access. Capacity building and community empowerment activities were undertaken to enhance community ownership and consolidate available resources. The Truckers' Initiative was revised to include an innovative peer-based outreach programme through a network of ex-truckers and helpers, to bring about behavioural change.

The HIV prevention strategies emphasised behaviour change communication, condom promotion, and treatment and counselling of patients. These services were implemented by the SACs in partnership with a number of NGOs and CBOs. This strategy of reaching out to hard-to-reach communities through their members—as in the case of the Manas Bangla Project in West Bengal, which was an umbrella network of dedicated CBOs/NGOs for MSM/TG—gathered steam in Phase III.

The vulnerability associated with STIs and the close link between STIs and HIV made the Government undertake several modifications in the programme. This included the provision of a standardised package of STI/ Reproductive Tract Infection (RTI) services through syndromic case management by public health facilities and preferred private practitioners. One of the innovative approaches considered for this was the provision of night clinics to make it flexible as per the needs of the affected communities.

Condom use for HIV prevention has been extensively promoted within NACP, including social marketing schemes. Recognising the vulnerability and weak negotiating skills of women, a female condom programme was initiated in eight states. This innovative approach provides a choice to women, especially FSWs, to ensure safe sex behaviour, reducing their vulnerability. In addition to this, Condom Vending Machines and special condoms for the MSM population were also introduced within the programme.

The Blood Safety programme under NACP seeks to reduce and eliminate HIV infection through blood transfusion, by ensuring HIV-free, good quality blood. Towards this end the infrastructure was strengthened and testing of all blood samples was made mandatory; blood storage centres were established, also with in primary health care centres (PHCs), to increase access to blood in all areas in the country; the use of safe and tested blood in hospitals was promoted in hospitals and other clinical facilities; all efforts were made towards ensuring safe blood transfusion by raising awareness and through capacity building.

---

65 NACO, 2008, *NACP-III: To halt and reverse the HIV epidemic in India*.

Pre- and post- counselling, along with free HIV testing facilities were also provided under the national programmes, at the peripheral and referral institutions of the government. Currently, there are 5,223 Integrated Counselling and Testing Centres (ICTCs). These services are also being expanded within PHCs and Community Health Centres (CHCs) in rural areas, private sector facilities and mobile clinics. The main functions of an ICTC include HIV diagnostic tests, counselling and promoting behavioural change, and referral for care and treatment services. The ICTC services are accessed by voluntary clients (those who visit the ICTC on their own), and extend to provider-initiated client testing, including patients with signs/symptoms of HIV infection, patients with STI/ RTI/ Tuberculosis (TB) and pregnant women visiting antenatal clinics.<sup>66</sup>

Mechanisms were put in place to ensure that reports could be collected the same day. Capacity building of counsellors through peer-based psychosocial support and supportive supervision was made a regular exercise. Community Care Centres (CCCs) played a major role in creating an enabling environment by providing quality care to PLHIV in an otherwise highly stigmatised environment. They continue to operate at low costs and are managed by NGOs to provide counselling and monitoring of adherence to medication, treatment of opportunistic infections, nutritional advice, care at home, and referrals.

CCCs were also linked to ART centres, thereby enhancing access and adherence to treatment, care, and psychosocial support. These centres, which were started in Phase II, have now been scaled up across the country to provide for children and to provide palliative care for the infected and those dying of AIDS. CCCs have played a role in raising awareness about HIV and decreasing the stigma and discrimination among healthcare providers.

Realising the need for providing integrated health services to enhance and improve programme outcomes, the screening of HIV-TB co-infection and cross referrals was initiated to ensure early identification and reduction of morbidity. The convergence of HIV and Reproductive and Child Health (RCH) services, as demonstrated under the DFID-funded Challenge Fund, was included in the national programme. This move resulted in boosting institutional deliveries and also helped identify HIV-positive women who were enrolled under the PPTCT programme. This move activated a strong referral system, enabling regular follow-ups of pregnant women, and encouraged the uptake of PPTCT services. The vulnerability of people with STIs and the close link between STI and HIV made the Government undertake several modifications in the programme. These included the provision of public private partnerships as well as adapting clinic timings to suit the needs of the users.

### 3.6.2 CARE, SUPPORT AND TREATMENT

**Issues:** Prevention without the provision of a strong care, support and treatment continuum undermines the efficiency of disease control. As the number of PLHIV increased, NACP recognised the need for care and support. In addition, it was also understood that PLHIV require regular follow up, support to ensure their adherence to the treatment regime. Palliative care, which is a low-cost and effective strategy for PLHIV, can be delivered only through the provision of home-based care. Besides medicines, they also need psychosocial support from their families and communities to extend their longevity and enable them to lead a dignified life. The availability of and access to ART is also very important to promote adherence and reduce drug resistance.

**Efforts:** The care, support and treatment (CST) component under NACP has been steadily strengthened over a period of time, to ensure reduction of AIDS related mortality. The programme has responded to the needs of PLHIVs by providing psychosocial support to infected and affected individuals, especially

---

66 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3026121/?report=printable>

to marginalised women and children, as well as ensuring access to affordable and sustainable treatment services. Acknowledging that prevention will be effective only if the provisions for treatment are made available, the ART regime was launched in 2004. It provided renewed hope for PLHIV, most of whom had not been able to undertake treatment due to the prohibitive costs of these drugs.

Access and adherence to treatment became one of the key thrusts under the national programme, thus shifting the focus towards identifying and strengthening institutions and referral linkages for HIV testing, ART centres and procurement of antiretroviral (ARV) drugs. Simultaneously, there was an emphasis on capacity building of health service providers across the ranks, to ensure quality of ART delivery. The national response was also scaled up to provide ARV services through Link ART Centres, by bringing them closer to the community and promoting adherence. CCCs, too, were innovatively modified to act as bridges between the patient and ART centres. They also provided counselling through strong outreach services, referrals and palliative care. Standardised treatment provision was also experimented with, by engaging private care providers to meet the rising demands.

The programme also now focuses on the management of opportunistic infections, including the control of TB among PLHIV, safety measures, positive prevention and impact mitigation. To ensure quality services, activities such as monitoring for adherence and quality, assessment of lab services, and a mechanism for certification and accreditation of services in both public and private sectors was developed. Home-based care, which is effective in ensuring adherence to treatment, and rehabilitation of PLHIV, also became an integral part of the CST strategy.

The provision of ART was made through several initiatives which have made it accessible and affordable. Some of the efforts taken in this direction are listed below:

- Advocacy by PLHIV networks and other CSOs, coupled with global efforts in this direction, resulted in a considerable reduction in the cost of medicines and led to improved access.
- Political commitment by global leaders in the form of the 2001 UNGASS Declaration, followed by the political support provided by Gol, WHO's '3 by 5' initiative, and UNAIDS support in 2003, strengthened the demand for providing free drugs.
- The National Paediatric ART initiative, which was launched in 2006, boosted the much-needed treatment for children.

### 3.6.3 BUILDING CAPACITY

**Issues:** A critical mass of well-trained human resources is the backbone to an elaborate organisational structure. Until Phase II of the programme, skills such as diagnosis and clinical management were recognised and honed. However, building the capacity of leadership and strategic management, programme management, particularly in the areas of logistics and supply, finance, information management, collaboration and partnership development, behaviour change, community participation and NGO management, remained a low priority. Further, the expansion of the programme up to district level underscored the need for capacity building.<sup>67</sup>

**Efforts:** Recognising the need for skilled and competent human resources at all levels of programme implementation, i.e. national, state, district and community, public and private health systems, non-governmental organisations (NGOs) and civil society, NACP-III focused on strengthening the skill development of health care providers, and CSOs at the national, state and district levels, in order to meet

---

67 NACO, 2006, *Strategic Implementation Plan*.

the challenges of scaled-up interventions without compromising on quality. The programme looked at strengthening training infrastructure, identifying resource persons, developing guidelines and also providing mentoring facilities to ensure sustainability.

State Training Resource Centres (STRCs) were designed to provide uniform and quality training to TI project staff so as to strengthen their capacity for planning and implementing TIs effectively. They work closely with states and Technical Support Units (TSUs) to develop the capacity of partner organisations. STRCs also work with NGOs and CBOs to harness learnings and best practices from each state. Regional STI Training, Reference and Research Centres were also strengthened in order to provide necessary laboratory support and generate scientific evidence to ensure good quality services. The Centre of Excellence (CoE) was set up to facilitate the provision of tertiary level treatment, training and mentoring, and operations research; operational guidelines and manuals were prepared and disseminated to tackle all the technical areas. STRCs/TSUs were made responsible for the TI training programmes. Training modules were developed for all functionaries at the TI level.<sup>68</sup>

The capacity development of public health institutions was also undertaken, in order to mainstream HIV within their activities—for instance, the nurse practitioner’s model project in Andhra Pradesh, which built the capacity of nurses for handling HIV cases at PHCs—thus improving service delivery in rural areas. Further, there was the initiation of institutional strengthening and capacity building of in-service nurses in public sector institutions, with the support of GFATM Round 7, through the Indian Nurses Council, aimed at improving service delivery on a large scale.

The trainings ranged from programme management, outreach planning, financial management, counselling in TIs, to auditing, quality planning and risk management. Specific trainings were also conducted under the Integrated Biological and Behavioural Surveillance (IBBS). While the Basic Services Division trained its personnel on whole blood testing, PPTCT multi-drug regimen and full-site sensitisation, apart from regular induction and refresher trainings of their counsellors and lab technicians, the Laboratory Services Division trained State Reference Labs (SRL) staff on the new version of ISO.<sup>69</sup>

In order to build the capacity of and strengthen specific programme components, such as the condom programme and truckers’ intervention, NACO set up Technical Resource Groups (TRGs), whose key role was to support NACO and SACS in the scale-up of these technical areas. For the condom programme, social marketing organisations were set up across the country, focusing on 227 high prevalence districts. This approach helped in strengthening thematic areas with inadequate capacity and systems too weak for effective implementation. Additionally, 18 TRGs (~200 experts) were formed to provide technical advice to divisions for all major programmatic areas (Counselling, Condoms, STI, TIs, M&E, Training).

NACP-III also focused on developing a sustainable model of capacity building by making provision for TSUs to mentor SACSs and TI implementing NGOs in the states. The effectiveness of the TSU model was successfully demonstrated during Phase II of the programme in the DFID-supported states. The primary role of TSUs was to enhance the technical capabilities of SAACs, NGOs and CBOs towards the effective implementation of the AIDS response. TSUs were instrumental in enhancing the capacity of organisations, which, in turn, helped in scaling-up interventions such as TIs, establishing M&E systems and processes, capacity building of NGOs and CBOs, and providing supportive supervision.

---

68 NACP-IV, Technical Working Group.

69 NACO Annual Report 2013–14.

Capacity building and empowerment of PLHIV were undertaken in order to enable and institutionalise GIPA. Some of the concrete steps undertaken in this direction include:

- Supporting the formation of national level networks such as the Indian Network of Positive People (INP+P), Positive Women's Network (PWN), and state level and district level networks in the six high HIV prevalence states;
- Training of PLHIV on positive living and life skill courses, to pave the way for a positive outlook;
- The formation of Support Groups at state and district levels, particularly in high HIV prevalent states and districts, with a focus to empower PLHIV. These groups provided them a platform to share problems, fight stigma, and unite to fight for their rights;
- Building the capacity of PLHIV to get involved in HIV related projects, which became a source of income and sustenance;
- Enabling PLHIV to negotiate with ministries offering social protection schemes and leverage them effectively.

### 3.6.4 USE OF MEDIA AND TECHNOLOGY

**Issues:** Strategic communication is a critical element in the HIV response as it plays a key role in HIV prevention by generating awareness among the general population; motivating behaviour change among at-risk populations; generating demand for care and treatment services; and promoting an enabling environment by reinforcing positive attitudes to address the stigma and discrimination around HIV. Concerted efforts need to be made to emphasise behaviour change and optimal utilisation of services in order to meet the overarching goal of NACP-III. The communication strategy of NACP-III aims at building upon and reinforcing the gains of NACP-II, while directing the focus more specifically to the scaled-up synergy between communication response and service delivery at all levels, by integrating communications as something that cuts across all programme components.

**Efforts:** The need for effective communication cuts across all programme areas and has been an integral part of the HIV response right from its initiation. Several mediums, including newspapers, electronic media, radio, mid and mass media campaigns have been used extensively to create awareness and behaviour change, promoting demand for HIV related services and reducing stigma and discrimination. All campaign programmes were evidence based and used particular evidence of knowledge levels among audiences. The campaigns made a significant shift in the tone and tenor of their messages to make condoms more acceptable and to normalise condom use.<sup>70</sup> Many of these campaigns were produced in partnership with donors/partners and other communication and technical organisations with expertise in communication, and reflected good benchmarks in terms of research and content.

The focus was on behaviour change communication and peer-led Inter Personal Communication (IPC), which was useful in accessing hard-to-reach HRGs and migrant populations. 'Seena Tan Ke' is an example of a peer-led approach, combined with a synchronised multi-media approach. This programme sought to promote the uptake of services by branding service centres, and demonstrated the utility of increasing outreach by supplementing IPC with alternate communication mediums. Migrant populations were the focus of the radio show 'Kitne Door Kitne Paas'. The efficacy and outcomes of IPC initiatives were tracked and measured through tracking tools developed by partner organisations including the AVAHAN initiative. Communication materials, including pamphlets, posters, flip charts, training manuals, group discussion tools, etc., were developed.

---

70 Condom Monograph NACP-III India.

## Lessons from the HIV Programme for an Effective Development Response

---

Several initiatives were launched at the national and state levels to address youth and women. Communication programmes such as the Red Ribbon Club (RRC) and the Adolescent Education Programme (AEP) helped generate accurate knowledge on HIV and enhance risk perception among youth. These projects were aimed at building the capacity of students as peer educators and change agents by developing their skills in leadership, negotiation and team building. Innovative mass media campaigns, such as 'Angan ke Paar' and 'Babli Boli', focused on rural women. SHGs were also mainstreamed.

Large-scale social mobilisation campaigns were used to generate demand for services, reduce barriers and increase awareness. Some of the notable mass media campaigns are detailed below.

- The Red Ribbon Express (RRE) was a broad-based multimedia mass mobilisation campaign, implemented by NACO through multi-sectoral collaboration with various ministries. This campaign created an enabling environment by facilitating greater access to HIV services and increasing awareness regarding other programmes such as blood safety, condom usage, safe needle practices, especially in small towns and villages across 24 states in India. Large-scale efforts at media advocacy ensured consistent and continued media coverage during the campaign period.
- The success of RRE prompted several national and state level initiatives, such as 'Zindagi Zindabad' and 'Vaazkhai Vaazhatharkeor' (Life is to Live). These campaigns were oriented towards rural areas, with special focus on migrants, while also targeting youth and women.
- 'Buladi' was a 360 degree surround campaign, based on mix media, targeted at the general population. This campaign initiated a sustained effort for more prolonged message visibility and exposure to motivate behaviour change, and had an iconic brand ambassador in the form of a rag doll called Buladi. The commonplace, unassuming yet homely name evoked the personality of a conscious, strong-willed middle class lady with whom the target could culturally identify and the campaign was hugely successful in achieving its targets.

Large campaigns have been initiated for condom promotion in keeping with data and strategic communication guidelines for motivating behaviour change. The condom normalisation campaign, especially the work undertaken by BBC World Service Trust, set new benchmarks for the use of evidence-based innovative strategies. The 'Joh Bola Wohi Sikander' campaign directly addressed the goals of preventing HIV among general and high risk populations. State specific campaigns such as the 'Unda Mee Daggara' campaign in Andhra Pradesh, which advocated carrying condoms on one's person, had a high rate of recall and comprehension.

The 'BindaasBol' campaign attempted to reduce the embarrassment surrounding condom purchase; the campaign saw a 22% increase in consistent condom usage with spouse in its initial phase ('Yehi hai Sahi'). The Chunnilal ads portrayed light-hearted openness between spouses on condoms and broke through the clutter by projecting the condom user as a caring husband who has incorporated condoms into his routine behaviour. These campaigns took the opportunity to move potential users further along the continuum of normalisation, harnessing social support and beliefs, rather than focusing on individual behaviour.

As part of this broader integration with NRHM and health initiatives of other ministries, co-branding of media campaigns was undertaken. Additionally, HIV messages were also included in long-running television serial dramas like *Kalyani* and *Kyunki Jeena Isi ka Naam Hai*, which address other, broader health issues and have emerged as recognisable and well-liked media vehicles. *Kyunki...* was launched in April 2008 in collaboration with the Ministry of Health and Family Welfare, UNICEF, NACO and other partners. Its aim is to generate behavioural results in support of key government initiatives. Adopting the entertainment education format on an ambitious scale, the programme reached families, caregivers and health workers with messages relating to health, education, protection, HIV/AIDS and equality.

Advocacy efforts, too, have been undertaken as part of the communication strategy. The mainstreaming of HIV/AIDS for a multi-sectoral response was one such attempt which aimed at shifting focus from awareness generation to creating an enabling environment. Several ministries and departments mainstreamed HIV/AIDS issues into their policies and programmes. This helped leverage existing plans and schemes within these ministries to make them available to those infected and affected by HIV. Additionally, advocacy and social mobilisation initiatives with key populations and stakeholders helped to gain momentum by sensitising and orienting policy makers, religious leaders, law enforcement agencies, media and government officials, as well as the key populations.

Media advocacy was also used as a tool to mainstream HIV and create an enabling environment in the six highprevalence states through intensive workshops. This led to an increase in both the quantity and quality of reporting. As a result of these media advocacy initiatives, there was a 62% increase in the coverage of HIV and key populations since 2005 and a 20% increase in such coverage since 2007. Advocacy training manuals have been developed in partnership with BMGF under the AVAHAN programme to address the gaps in operationalising various advocacy initiatives. The usage patterns of such manuals need to be tracked to ascertain the outcomes of developing such material.

North-eastern states of Manipur, Mizoram and Nagaland were specifically targeted through multimedia campaigns, with a strong attempt at community mobilisation. These campaigns used sports and music concerts, celebrities, television and radio to attract young people. Celebrity endorsement was another technique which has been used considerably to reduce stigma and discrimination.

The programme also adapted itself to using new emerging technologies such as internet and mobile phones. These platforms were used to remind people to adhere to safe behaviour practices as well as to go for STI/HIV tests. A two-month-long internet campaign called 'Know Your Status' was initiated in 2007 on three websites, Yahoo, Indiatimes and Rediff. These campaigns made the HIV campaign interactive, allowing internet and mobile phone users to respond to questions asked by celebrities. Treatment and counselling helplines were also set up to enable people to access information and services confidentially. Further, internet platforms like Yahoo Media were also used to influence policy, such as the HIV Bill, NACP Policy, Section 377 and ITPA, among others.

Tools like spot analysis, contact mapping, mapping of geographic and social networks, site load mapping, seasonal calendars, force field analysis, peer education card and performance cards, and peer calendars are innovative and meaningful ways of enhancing the effectiveness of the IPC approach for Behaviour Change Communication (BCC).

### 3.6.5 MONITORING AND EVALUATION, SURVEILLANCE AND RESEARCH

**Issues:** A well designed programme relies on the availability of accurate and systematic data as it generates evidence necessary to develop appropriate policies and implementation plans, and these contribute towards achieving a greater impact on the epidemic in the country. This is even more relevant in the context of India, given its size and diverse cultures and requirements. It is therefore critical that a public health problem like HIV is addressed through evidence based planning, in order to maximise resources and optimise programme output.

**Efforts:** NACP has always pushed towards a systematic process of data collection and analysis. The process adopted consists of vigorous M&E, surveillance and research. SIMS was established to provide evidence related to inputs, outputs, outcome and impact, and to manage the strategic information within the national programme. SIMS operates at the national and state levels. The Strategic Information Management Unit (SIMU) of NACO addresses strategic planning, M&E, surveillance and research.<sup>71</sup>

---

71 NACO, 2008, *NACP-III: To halt and reverse the HIV epidemic in India*.

SIMU was responsible for generating and managing crucial information on the entire spectrum of the HIV epidemic and the data generated through SIMU provided a snapshot of trends and progress in the programme. Another key function of SIMU is to promote data use for policymaking, programme planning, implementation and review at national, state, district and reporting unit levels. This has helped the states and programme managers to respond with course correction measures and improve programme efficiency. Standardised indicators used by SIMS at all levels resulted in the generation and compilation of data across regions simultaneously. This eased the reporting process as the data was accepted by international bodies.

The Computerised Management Information System (CMIS) is another routine reporting system which is based on real-time data analysis, validation, and triangulation, thereby providing programme managers with the information needed for immediate decision making at all levels. Monthly reports are also currently compiled through CMIS.

### HIV/AIDS RESEARCH

Research is a vital component of SIMS and covers a wide diversity of areas such as epidemiological, social, behavioural, clinical and operational research. Each of these has a strong role to play in providing direction to the programme strategies and policies. Research studies have helped in understanding the strengths and weaknesses of various interventions and have also contributed to re-modelling them for greater effectiveness.<sup>72</sup> Research studies are being conducted in the country with the direct support of NACO, as well as through partnerships with academic and other research organisations to ensure good quality, rigorous research.

The other steps taken by NACO to strengthen the research component are:

- Constitution of a Research Ethical Committee to control and manage various studies that are being conducted in the country related to HIV and high-risk behaviour;
- Setting up of a TRG to advise on and guide the process;
- Promoting the Network of Indian Institutions for HIV/AIDS Research (NIIHAR), with a current membership of 42 reputed institutions, to motivate research on HIV/AIDS themes within the research agenda in the country;
- Provision of research fellowships for MD/MPhil/PhD students with the idea of building the capacity of young researchers in the country for conducting HIV/AIDS-related research studies.

### SURVEILLANCE: HIV SENTINEL SURVEILLANCE

One of the most significant outcomes of NACP is the establishment of a robust and credible HIV Sentinel Surveillance (HSS) system, which is the largest HIV surveillance system in the world. The impressive expansion and improvised strategies adopted by HSS in India also makes it one of the best in the world.<sup>73</sup> HSS helps the national programme to track the levels and trends of the HIV epidemic in different geographical regions and population groups.<sup>74</sup> Initially, when the system started in 1992, the sites were restricted only to high prevalence states or states where the epidemic was more visible. In 2006, however, HSS expanded to all the states in the country and today there are 1,359 sentinel sites spread across different states. HSS has contributed to better evidence collection and understanding of the epidemic,

---

72 NACO Annual Report: 2013–14.

73 NACO, ME Monograph.

74 NACO, 2012, *HIV Sentinel Surveillance Technical Brief 2010-2011*.

which has provided insights for developing appropriate policies and strategies. The classification of districts into A-B-C-D<sup>75</sup> categories, based on HSS data, has helped the programme to focus better and has also ensured proper utilisation of resources.

### BEHAVIOUR SENTINEL SURVEILLANCE

Behaviour Sentinel Surveillance (BSS) is yet another attempt by NACO to track behavioural indicators, which measure the efficacy of prevention efforts in the country. The first BSS study was commissioned in 2001. The study, focused on tracking BSS, was intended to shift the focus of prevention efforts from output to achieving outcomes. The critical learning was that during the implementation of programmes, most interventions focus on delivering outputs and services without paying much attention on understanding outcome level changes being achieved by the project.

### ANNUAL EVALUATION OF TIS AND JOINT REVIEW MISSION

Several SACs conduct an annual evaluation of their TI programme to assess whether the NGOs implementing TI interventions are on track and to track their progress as per the annual plan chalked out at the beginning of the year. This provided the SACs with insights to amend the design if required and consolidate gains and share lessons. The evaluations also became a critical tool to make a decision on the re-contracting of NGOs. Besides these intervention level reviews and evaluations, the national programme is also regularly evaluated through joint review missions, wherein all the key stakeholders of the national programme participate in reviewing the programme, assessing performance, and consolidating learnings. These reviews and missions provide an opportunity for reflection on the viability and effectiveness of various strategies and to take corrective action.

### MID TERM ASSESSMENT OF NACP IV

The year 2016 marked the 30 year milestone in the India's response to HIV/AIDS since the detection of its first case in 1986. NACO recently concluded the mid-Term Appraisal for NACP-IV. The Mid Term Appraisal of NACP IV was conducted under the overall technical guidance and oversight of steering committee, chaired by Secretary & DG, NACO. Four Technical Sub Committees were constituted with representation from a wide range of stakeholders. The appraisal was an exhaustive one which ensured the participation of community and specialists from various fields. The main objectives of the Mid Term Appraisal was to review the progress of phase IV against the target, provide recommendations for the planning of NACP V and creating synergy with India's commitment to the Sustainable Development Goals.

### NATIONAL INTEGRATED BIOLOGICAL & BEHAVIOURAL SURVEILLANCE

The National Integrated Biological & Behavioural Surveillance (IBBS) was implemented with a strategic focus on strengthening HIV surveillance among HRGs and bridge populations. The broad objective of the National IBBS is to generate evidence on risk behaviours among HRGs to support the planning and prioritisation of programme efforts at the national, state and district levels.

## 3.8 INSTITUTIONAL STRUCTURES AND ARRANGEMENTS

**Issues:** The emerging need to address the rapidly evolving HIV epidemic in the country has entailed a high degree of adhocism as it requires competencies that are not always available within the programme. For example, NACP-II, which was designed only for prevention, had to expand its strategy to include care and treatment among other services. Thus, the urgency to address such unplanned requirements and the provision of experts to address these needs necessitated an effective framework of governance.

---

75 This prioritises the districts according to the prevalence of HIV (burden of disease), according to which different packages of services/funding are allocated.

**Efforts:** In 1987, the National AIDS Committee was set up, which was headed by the Secretary, Health, under the Ministry of Health and Family Welfare (MoHFW). The AIDS Control programme has, since, evolved over the years, responding to the needs and adapting itself to meet the demands of the epidemic. Some of the factors that have necessitated change in the programmatic approach include the dynamic epidemiological situation; the engagement of multiple donors and funders; policy changes in the international commitment to HIV/AIDS; varying political support across both national and state levels; the need for greater involvement of HIV-positive people; a call for integration of vertical programmes within the NRHM framework; decentralisation; the need for a multi-sectoral approach; the need to increase efficiency of governance and accountability.

Thus, the three organised phases of NACP have seen significant changes in the structure and institutional arrangements that are responsible for the management of the AIDS response in the country. NACO has the primary responsibility of implementing the NACP policy framework across the country. It is supported by the National Technical Support Unit (NTSU) and TRGs, which advise on specific intervention areas such as blood safety, laboratory services, ART, etc.

At the state level, NACP is managed by the SACS with the support of TSUs, and through outsourcing and contracting of services, the required management skills have been mobilised at the national and state levels. During NACP-III, systems for surveillance, management and financial monitoring were developed, providing a solid foundation for scaling up the programme.<sup>76</sup>

### 3.8.1 UNDERSTANDING LESSONS IN PROGRAMME MANAGEMENT

#### 3.8.1.1 STRUCTURES

##### DEPARTMENT OF AIDS CONTROL–NACO

The National AIDS Control Organisation (NACO) provides leadership to the HIV/AIDS Control Programme (NACP) in India, implementing the national plan within a single monitoring system.<sup>77</sup> NACO was set up in 1992 as a semi- autonomous body headed by a senior officer from the Indian Administrative Service (IAS) of the rank of an Additional Secretary. During Phase III of NACP, the charge was taken over by a Secretary to the Government of India, as NACO became an independent department under a Ministry called the Department of AIDS Control. This helped to sustain a focused effort by ensuring visibility, power, and strong leadership. The Secretary is assisted by the Joint Secretary, six Deputy Directors General, one Assistant Director General, one Joint Director, one Director, one Deputy Secretary and two Under Secretaries. Brief outlines of the different structures that manage the AIDS Control programme in India and the lessons emerging from them are detailed below.

NACO's is an administrative structure responsible for implementing NACP, which is the largest vertical programme yet to be integrated within the NRHM framework. This unique structure was mandated for several reasons. The speed at which HIV/AIDS was spreading within the country and its implications called for a response on a mission basis. This was possible only through a structure which had sufficient flexibility to make quick decisions and respond immediately to the emergency situations at hand.

Secondly, evidence pointed towards certain sub-populations whose behavioural patterns were subject to punitive measures. These sub-populations, such as sex workers, MSM, IDUs and TGs, were also the primary drivers of the HIV infection in the country. This made it clear that the HIV epidemic cannot be addressed like some of the other public health diseases, such as TB and Polio, given the sensitivities associated with it. Thus, it was crucial to control the epidemic by bringing these groups together within

---

76 <http://www.performance.gov.in/sites/default/files/document/strategy/AIDS.pdf>

77 NACO, 2006, Institutional Assessment.

the prevention framework, despite legal restrictions. The semi-autonomous nature of NACO helped bypass these bottlenecks and design an innovative response to contain the epidemic.

### STATE AIDS CONTROL SOCIETIES

For effective implementation of NACP, SACSs have been set up in each state, under the overall charge of the Secretary, Health. Each SACS is headed by a Project Director, who is an IAS officer or a Senior Medical Officer of the state. In addition, there is a regular post of an Additional Project Director, who is the technical head for the SACS. Below these two senior positions, there are the posts of Joint Director, Deputy Director and Assistant Director, which can be regular, on deputation from the State Government, or contractual, as approved by the Department of AIDS Control.<sup>78</sup>

Initially conceptualised as a States AIDS Cell, under the Department of Health at the state level, SACSs were transformed into decentralised autonomous societies which provided the required level of functional independence to scale up and innovate.<sup>79</sup> The overall responsibility of implementing NACP at the state level lies with the SACS, with technical support from the various divisions at the Department of AIDS Control.<sup>80</sup> SACS also has a governance structure at the state level for programme support and supervision.

The experience so far clearly points to the advantages of having empowered and independent units to push through this programme.<sup>81</sup> Additionally, some states have formed AIDS Control Societies under their Municipal Corporations, such as Mumbai, Surat, Chennai, Bangalore, Ahmedabad, Vizag, to name a few.

### DISTRICT AIDS PREVENTION AND CONTROL UNIT

As a major structural reform, under NACP-III, the management of the HIV prevention and control programme was decentralised to the district level. District AIDS Prevention Control Units (DAPCUs) were set up in high priority (A and B category)<sup>82</sup> districts, spread across 22 states, for the coordination and management of NACP. Functioning under the State Health Department, DAPCUs play a pivotal role in the monitoring and coordination of service delivery from the different facilities in the district. They work in close coordination with the district administration, under the leadership of District Collectors, to take up district specific initiatives by leveraging local resources.

The consistent efforts of DAPCUs have resulted in effective HIV awareness campaigns, strengthening of referral linkages, and the provision of care and treatment to all HIV-positive people in the district. DAPCUs play a key role in the integration of NACP with NRHM and also share the administrative and financial structures of NRHM. They work closely with other line departments in the government setup to mainstream the HIV/AIDS programme.

DAPCUs report to and work through the Chief Medical Officer of the district for medical interventions, and are also responsible for non-health related activities such as the Adolescent Education Programme, supportive supervision of TIs, M&E and mainstreaming. These activities are carried out through the office of the District Collector or Zila Panchayat. The job responsibilities of DAPCU staff are periodically revised in-line with changing programme priorities.

---

78 NACO Annual Report 2013–14.

79 NACO, 2006, Institutional Assessment.

80 NACO Annual Report 2013–14.

81 NACO, 2006, Strategy and Implementation Plan.

82 **Category A:** More than 1% ANC prevalence in district in any of the sites in the last 3 years. **Category B:** Less than 1% ANC prevalence in all the sites during last 3 years with more than 5% prevalence in any HRG site (STD/FSW/MSM/IDU).

### NORTH EAST REGIONAL OFFICE–NACO

The geographical contours, political instability and insurgency, and poor infrastructure in Northeast India have always made it difficult to implement any programme effectively. Besides these, the uniqueness of the AIDS epidemic in this region required focussed and specific interventions, which necessitated a regional structure. Thus, the Northeast Regional Office (NERO), the first regional office of its kind, was set up through a unique partnership between the Australian Agency for International Development Assistance (AusAID), UNAIDS and NACO to strengthen the support for the AIDS response in the Northeastern states. NERO has helped improve the overall implementation rate of the programme, especially TIs and strategic information, in addition to building the capacity of SACs and district level units.

The growing strength of this structure in terms of its performance made NACO delegate greater authority and decision making powers at the local level, by expanding the operational domain of NERO from seven to eight states, with the inclusion of Sikkim. The 'Joint UN Plan for the North East' provides technical assistance to these states towards the scaling-up of the programme and to improve the quality of interventions. The United Nations Office on Drugs and Crime (UNODC) and the United Nations Children Fund (UNICEF) have offices in the Northeast and UNDP and UNAIDS Secretariat have placed staff at NERO, which has assisted in effective implementation and closer monitoring of the activities. Set up in early 2008, NERO's contributions are reflected in the improvements in planning, increased utilisation of funds and programme uptake, and innovative initiatives undertaken by states to meet local challenges through existing mechanisms.

#### 3.8.2.2 ARRANGEMENTS: TECHNICAL SUPPORT STRUCTURES

Technical support was perceived as an important factor to achieve a high level of coverage and maintain the quality of programme implementation. One of the areas where bilateral and multilateral funding played a major role was in ensuring timely availability of technical support on the ground. To achieve a high level of coverage NACO felt the need to identify consultants with strong management and human resource capabilities to setup TSUs to support the development and implementation of HIV/AIDS strategies, especially to support to TIs and care and support linkages in the state, and provide technical support as and when required by SACs.

**The National Technical Support Unit (NTSU)**, which was set up at the national level, was convened and led by NACO, with individual consultants and expert support through development partners/agencies. NTSU focused on rolling out operational guidelines for TIs, building the capacity of project officers at the state level, supporting and facilitating coordination between various technical support structures, and strengthening the programme gaps through various tools and techniques. NTSU also put in place regular reviews of the activities of state level technical support units to ensure maintenance of quality.

Similarly, **Technical Support Units** were also available at the state level to provide management and technical expertise and to ensure the quick roll-out of NACP-III with an emphasis on quality assurance and programme management. TSUs also supported the newly created cadre of Programme Officers, each supervising the work of 10 TIs while engaging in handholding at the field level, ensuring adherence to guidelines as well as addressing gaps at the local level.

NACP-III set ambitious targets for scaling up operations in all of its key implementation areas. In order to achieve the required scale and coverage of services within NACP-III, there was a strong demand for a technical support system to build the capacity of NACO and SACs, as well as provide them with continuous technical assistance. This support was institutionalised through the creation of Technical Support Units at the national and state level.

### TECHNICAL RESOURCE GROUPS

TRGs were formed during NACP-II and continued, during NACP-III, to provide technical support to various themes and components of the national programme. TRGs consisted of representatives from the government, technical experts, NGO and community representatives, who regularly reviewed particular programmatic/ thematic components and provided recommendations for strengthening the programme. Meetings for each of the components were generally held at least once a year.

TRG guidance has helped strengthen the technical quality of the programmes and consequently, the achievements have gone up. At the end of NACP-III, there were close to 18 different TRGs consisting of 200 experts, providing technical advice on all key programmatic components.<sup>83</sup>

### 3.9 LEARNING AND KNOWLEDGE MANAGEMENT

**Issues:** NACP emphasises on Knowledge Translation as an important element of policy making and programme management at all levels.

**Efforts:** The second phase of NACP and more intensely the third phase, focused on building platforms for learning, sharing, and documenting. Several actions were initiated to gather data, process information, publish, and disseminate. Key mechanisms for learning and knowledge management included the following:

#### 3.9.1 LEARNING SITES AND GOOD PRACTICE CENTRES:

With the help of development partners, NACO has been setting up learning sites and good practice centres across the country. Some examples include the Vijayawada model by Care, Bangalore model by Swasti, Avert Society and FHI in Mumbai, KHPT in Mysore, EHA in the Northeast.

#### 3.9.2 DISSEMINATION PLATFORMS:

The National Programme has not only gathered and consolidated learnings but also created various platforms for dissemination and replication of these learnings:

- Publications: NACO has brought out several publications (directly and through its development partners, and civil society research partners) that document case studies, collate stories of change, document models, etc.
- Conferences and Workshops: Several conferences and workshops have been held, such as the International AIDS Conference (International Congress on AIDS in Asia, the Pacific (ICAAP), and National Research Conference with the help of Sexual Health Resource Centre (SHRC), which was set up by DFID. Similar dissemination conferences have been organised by its partners, such as USAID, BMGF, APAC, AVERT Society, etc., to disseminate learnings among stakeholders.
- Summits: Within the country, NACO recently hosted the 'NACP-III Dissemination Summit 2012', which brought together learnings and good practices gathered over five years of the implementation of NACP-III.
- E-Forums: These have been created for exchanging views, experiences, and ideas and to network. E-Forums have become an active platform for learning and sharing, and have resulted in a synergetic network among various stakeholders in the country. Two such forums are AIDS-India and Solution Exchange.

---

83 Report of NACP-IV Technical Working Group: Capacity Building.

Thus, systematic efforts at bringing together learnings from the field have greatly contributed towards improving the overall quality of the national programmes and achieving the desired outcomes and impacts.

### 3.10 GOVERNANCE AND ACCOUNTABILITY

#### 3.10.1 GOVERNANCE

**Issue:** Good governance is critical for strengthening policies and programmes and for fortifying health systems. This is most relevant in the case of the HIV/AIDS programme, given its complexities, which underscore the need for a rigorous, sustained and determined approach to address the most challenging health issue in recent times. Effective governance focuses on the strengthening of systems and infrastructure, along with strong M&E, to increase the effectiveness of the response.

**Efforts:** The governance of HIV programmes in the country has evolved over the years, keeping in mind the emerging necessities as the programme was expanded across the country. The governance structure of NACO consists of the following:

**The National Council on AIDS**, under the chairmanship of the Prime Minister, and with 31 participating ministries and civil society representatives as members, is the highest body overseeing NACP. This body provides the political will and support towards the implementation of the national framework on AIDS control, particularly in the context of mainstreaming HIV prevention within all organs of government as well as the private sector and civil society. Accordingly, all relevant agencies are called upon to develop action plans and provide information on the status of implementation at periodic intervals.

**The National AIDS Control Board**, chaired by the Secretary (Department of AIDS Control), oversees the programme management and implementation of NACP. The Board exercises all the financial and administrative powers that are beyond the powers of the Director General, NACO, and which the Department of Health, GoI, can exercise with the approval of the Department of Expenditure, Ministry of Finance. The Board meets at least once a quarter, approves the annual plans of Department of AIDS Control; reviews quarterly performance reports; approves the re-allocation of funds between programme components; sanctions projects, procurement and awards contracts to private agencies. The Board reviews the reports of the Development Partners' Forum and is empowered to seek clarifications from programmes being implemented by donor partners outside the national budget framework. Minutes of the meetings of the National AIDS Control Board are posted on the NACO website within a month of such meetings.

**The Governing Body of State AIDS Control Society (SACS):** The SACSs, too, are steered by a governing body which is the highest policy making structure of the SACS, and is headed by the Health Minister or the Chief Secretary of the state, and is represented by heads of other key line departments in the state. The appointment of the Chief Secretary as the head of the Governing Body helps to ensure uniformity and results in administrative convenience. The Governing Body meets bi-annually to oversee the implementation of NACP at the state level. This body undertakes key policy level decisions and approves the Programme Implementation Plan (PIP) and annual budget, appoints statutory auditors, and accepts the annual audit report. The Governing Body delegates adequate administrative and financial powers to the Executive Committee and the Programme Director. It also exercises all other statutory powers as ordained under the Societies Registration Act.

**The Executive Committee of SACS** is yet another mechanism to govern the SACS and is headed by the Principal Secretary, Health, of the state. The Executive Committee of SACS exercises powers as delegated to it by the Governing Body. For functional efficiency, this is a small and compact body with limited representation from key departments (finance being mandatory). This committee has representation

from the Director of Health Services; State Mission Director, NRHM; Project Director, SACS; and other key officials of SACS, besides CSO representatives and PLHIV network representatives. The main focus of this committee is to oversee the implementation of the AIDS programme and provide relevant guidance to address challenges.

**The State Council on AIDS (SCA)**, constituted at the state level, ensures political commitment and support at the highest level. SCAs are headed by the Chief Minister, with the Minister, Health, as the Vice Chairperson. The State Council is represented by various departments of the government and civil society. The main mandate of the Council is to set policy guidelines and review the state's performance, including mainstreaming by key departments.

**Technical Advisory Groups** are meant to guide and ensure technical supervision of programmes. NACO has constituted Technical Advisory Groups for various thematic areas, i.e. public health, clinical services, surveillance, M&E, IEC, TIs and research. These groups are expected to meet as per need and also visit states to review the quality of implementation of interventions and provide relevant guidance.

### 3.10.2 ACCOUNTABILITY

**Issues:** A large multi-sectoral undertaking like the HIV response requires several accountability measures to be in place, from the national level down to the district level, from government agencies to multilateral, bilateral, civil society, and private players.

**Efforts:** Given the number of players, quantum of funding, variety of roles, and functions, accountability systems were integrated within the sector from the beginning. These include:

**1) Global Accountability:** Has helped India keep its international commitments and report on them. This was an external push to strengthen and maintain a robust performance management and surveillance system besides fulfilling the intrinsic need for evidence.

**2) The 'Three Ones' principle<sup>84</sup>** has helped push the need for ONE monitoring and evaluation framework. Within all the development sectors, the HIV response led the focus on one strong Monitoring and Evaluation system and quickly established it. This forced all the players to harmonise targets, indicators, and reporting.

**3) The 2001 UNGASS Declaration of Commitment** adopted by India, has outlined the fact that success in the response to AIDS is measured by the achievement of concrete, time-bound targets.

**4) The Country Coordinating Mechanism** is a country-level partnership of stakeholders that is central to the Global Fund's commitment to local ownership and participatory decision making. This consists of various representatives from both the public and private sectors, including governments, multilateral or bilateral agencies, non-governmental organisations, academic institutions, private businesses, and people living with the disease. Among its various functions, the key role of CCM includes oversight of implementation of funded projects as well as ensuring linkages and consistency between Global Fund grants and other national health and development programmes.

**5) The Joint Implementation Review** of the national programme has been seen as another effective accountability initiative of NACO that is scheduled every year. Partners in the JIRM include World Bank, DFID, the Global Fund, Gates Foundation, Clinton Foundation, and the UN agencies.

---

84 Three Ones Principle articulated the need for one agreed HIV/AIDS action framework that provides the basis for coordinating the work of all partners; one national AIDS coordinating authority, with a broad based multi-sector mandate; and one agreed country-level monitoring and evaluation system.

**6) Financial Accountability:** NACO developed and ensured implementation of Guidelines for Financial Management, including clear guidelines on spending. The Department for International Development (DFID) and World Bank, along with some other development partners, pooled their funds and conveyed them to NACO, who then allocated them according to the plan. This helped in ensuring flexibility in allocating funds in the areas of need and in line with the national plan.

## LESSONS

The HIV response went through extraordinary measures of maintaining transparency and accountability. The country's Comptroller and Auditor General, through its audits, uncovers gaps in the performance of the organisation, the results of which are available for public viewing. This helps improve transparency and accountability and, in many ways, propels the programme towards better performance. Management of funds has been one of the areas seen as a challenge and the Achilles heel of the programme. All other sectors that impact developmental outcomes will certainly benefit, though with much pain, from transparency and accountability measures.

**The Global Fund for HIV/AIDS, TB and Malaria (GFATM)**, which funds the HIV/AIDS programme in India, operates through a Country Coordinating Mechanism (CCM) comprising of stakeholders across the spectrum from within the country. CCM is central to the Global Fund's commitment to local ownership and participatory decision making, and consists of representatives from the public and private sectors, governments, multilateral or bilateral agencies, NGOs, academic institutions, private businesses and PLHIV. Among other functions, the key role of CCM includes overseeing funded projects as well as ensuring linkages and consistency between Global Fund grants and other national health and development programmes.

**The Joint Implementation Review (JIRM)** by donors/partners who provide technical and financial support to NACP is yet another mechanism that reviews the progress of the programme and provides recommendations for improving and accelerating the progress. JIRM includes representatives from World Bank, DFID, the Global Fund, Gates Foundation, Clinton Foundation, and UN agencies, and conducts an annual review.

Financial accountability is extremely critical for a programme like HIV/AIDS due to the multiple sources of funding involved. Therefore, NACO has put in place rigorous mechanisms and also developed guidelines for ensuring robust financial management and accountability. Pooled funds by donors including DFID and World Bank have helped in ensuring flexibility in allocating funds where they are most required, and in line with the national plan.

Further, the programme is audited by the country's Comptroller and Auditor General to assess gaps in the performance of the organisation. This information is made available in the public domain, hence improving transparency and accountability, and compelling managers to improve the performance of the programme.

### 3.1 PARTNERSHIPS AND MAINSTREAMING

**Issues:** The emerging complexities of the HIV epidemic across the terrain of the country and the socio-economic impact of HIV/AIDS have made it apparent that the HIV response cannot be limited to one organisation or department. Hence, it was proposed that the mainstreaming of the HIV/AIDS response into the existing responses of various government and non-government bodies and private sector organisations would be a cost-effective and efficient approach. This would help to abate the direct and indirect impact of the epidemic on the social and economic fabric of the country.

**Efforts:** A multi-sectoral response to mitigate the impact of HIV on those infected and affected was initiated by the setting up of NCA by GoI, presided over by the Prime Minister, and represented by Ministers from several departments. In view of this development, NACP-III also adopted mainstreaming and partnerships as part of its core strategy, supported financially and technically by UNDP, at the national and state level. This support helped to provide a direction and framework for initiating the HIV mainstreaming strategy within NACP-III.

UNDP facilitated the setting up of Mainstreaming Resource Units (MRUs) at the national and state level, to equip ministries, state governments and NGOs with the expertise and resources required to disseminate information and services on HIV/AIDS. This helped strengthen the policy environment and resulted in the availability of various welfare schemes and other provisions, such as pension, nutrition, livelihood, shelter and travel concessions, among others, benefitting and improving the life conditions of PLHIV across several regions of India. MRUs, along with SACs, undertake several activities such as training, capacity building, advocacy and sensitisation programmes, provide technical assistance, opportunities for networking with relevant stakeholders, information dissemination and research. NACO has also developed guidelines for mainstreaming, in order to give direction to meaningful collaborations.

Some of the main ministries through which these schemes have been leveraged are Home, Panchayati Raj, Women and Child Development, Rural Development, Labour and Employment, Housing and Poverty Alleviation, Surface Transport and Roadways, Defence, Tourism, Sports and Youth, Social Justice and Empowerment, and Science and Technology. UNDP is currently involved in supporting the Department of AIDS Control in signing MoUs with several ministries. This process had been initiated after the Mainstreaming Conference in December 2012, where close to 23 ministries participated and pledged their commitment.

Mainstreaming and partnerships have also facilitated the engagement of the private sector, CSOs and PLHIV networks, among others. The HIV/AIDS Workplace Policy has motivated a number of private companies to initiate prevention interventions, including raising awareness and provision of condoms within the factory and office premises. Some of the national, multinational and public sector units have begun to provide counselling, testing and ART services to their employees through MoUs with NACO. Efforts are also being undertaken to involve private sector federations such as the Confederation of Indian Industry (CII), the Associated Chambers of Commerce and Industry of India (ASSOCHAM), and the Federation of Indian Chambers of Commerce & Industry (FICCI), under the aegis of SACs.

Civil society partnerships have been another cornerstone of the programme, and have helped in extending outreach to the most vulnerable and marginalised populations, and including them in the ambit of HIV prevention, care and treatment services. Civil society engagement in HIV response in the country includes NGOs, CBOs and other community networks, faith-based organisations (FBOs), service clubs such as Lions Club, Rotary Club, professional organisations such as Indian Medical Association (IMA), private health care facilities, academic institutions, youth clubs affiliated to the Nehru Yuva Kendra, programmes, human right activists, training institutes, etc. These have enhanced the capacity and strength of the AIDS response in a variety of ways.

The primary role of CSOs/NGOs includes: implementation of TIs; mobilisation to improve access to HIV services under the national programmes; enhancing the management capacity of community networks; creating a stigma-free environment for improved access of these services by PLHIV; ensuring the rights of marginalised and vulnerable groups, such as the transgender community, and voicing their concerns at a policy level to effect change; contributing to the programme design of NACP by demonstrating innovative models and sharing experiential knowledge; contributing to the development and dissemination of IEC initiatives.

Partnering with CSOs/NGOs has also helped NACP forge horizontal linkages with other government departments, public and private sectors, thus helping mitigate the impact for those infected and affected. Due to their reach at the grassroots level, NGOs/CSOs in the non-health/HIV sector have also started addressing HIV issues within their programmes. NACO also supports FBOs in prevention, care and support activities in distant and unreachable areas.

## PARTNER SUPPORT TO THE NATIONAL PROGRAMME

NACO works in close coordination with development partners and other international agencies at both the national and state level, through the framework based on the 'Three Ones' principle. Listed below are some of the major initiatives that have contributed towards strengthening the AIDS response through technical and financial support.

- **The Joint UN Support Plan:** This plan is supported by 11 UN agencies and details the technical support provided by the UN system to the AIDS control programme at national, state, and district levels. This includes support to TIs, IEC, ART, including paediatric ART, PPTCT, education, gender, STI, blood safety, and surveillance, and M&E.
- **Global Fund for AIDS, TB, and Malaria:** GFATM supports the following NACP programme areas:
  - **PPTCT, TB/HIV collaboration**
  - **Care and support including ART, drop-in centres, and Community Care Centres.** In addition, GFATM funds are used for capacity building of nursing schools, counsellors, and for the rural Link Worker Scheme in high prevalence districts.
    - Under the Global Fund Round-9 project, the India HIV/AIDS Alliance is supporting the prevention programme by strengthening community institutions and systems for MSMs, hijras and TGs so that the outreach and quality of services can be improved. Under the same project, the principal recipient, Emmanuel Hospital Association, is supporting NACO to strengthen the IDU intervention and Opioid Substitution Therapy services.
- **The World Bank and DFID:** These have pooled funds with GoI to support NACP-III. They have also provided support to the entire range of activities under the programme.
- **The US Government:** The US President's Emergency Plan for AIDS Relief (PEPFAR) has supported GoI in its focus on key priority areas such as health systems strengthening, integration of HIV/AIDS services within general health systems and gender equity. India became part of the PEPFAR initiative in May 2005.
- **USAID:** USAID supports several initiatives, including the AIDS Prevention and Control Project implemented in Tamil Nadu, the AVERT society in Maharashtra to reduce transmission among sex workers and mitigate the impact of STIs, and the Samastha project in Karnataka. It provides assistance for Private Public Partnerships through the Connect project, and technical assistance at the national and state levels through the Samarth project.
- **The Centre for Disease Control and Prevention:** This provides technical assistance at the national level by supporting health systems, strengthening of laboratories, use of strategic information, and building human capacity.
- **The Bill and Melinda Gates Foundation:** Through its 'Avahan' initiative, the Foundation supports prevention interventions among key HRGs. Technical and management support is extended towards coverage of FSWs, MSM, TGs, IDUs and truckers' interventions, as well as for components such as

condom use, STI management, and M&E. BMGF also supports the National Technical Support Unit, State Technical Support Units in Andhra Pradesh and Tamil Nadu, and NERO–NACO.

- **The Clinton Foundation:** This Foundation supports the paediatric ART intervention in India and the rehabilitation of infected and affected children. It also assists NACO in training private sector doctors and nurses for HIV/AIDS care and treatment.
- Other donor agencies that have provided support to the national programme over the years include **GIZ, CIDA, SIDA, AusAID, NORAD, IAVI** and private foundations such as **CIFF, Elton John AIDS Foundation**, etc.

### 3.12 CIVIL SOCIETY AND COMMUNITY ENGAGEMENT

**Issues:** Community mobilisation and empowerment are essential for the successful transition of a programme to its targeted communities. CSOs and NGOs bring with them their experience of community level work in enhancing people's participation. They, therefore, play a crucial role in preparing communities to take ownership of the programme, and thereby enhance the scope of the programme.<sup>85</sup>

Civil society involvement helps to forge linkages with other government departments, public and private sectors, and mitigate the impact on the most at-risk populations living with HIV, PLHIV, people at higher risk of HIV infection, women, and young people.

**Efforts:** CSOs, NGOs, CBOs and FBOs are seen as genuine long-term partners of NACP. They have made significant contributions in disseminating HIV prevention and care services among highly vulnerable population groups. NACP recognises the importance of their participation, particularly in preventive and targeted interventions among HRGs, care and support of people living with HIV/AIDS, and in general awareness campaigns.

The engagement of civil society in the national programme has been in the implementation of TIs, which are part of the comprehensive and integrated approach to HIV prevention among marginalised and vulnerable populations. NACO, in partnership with CSOs/NGOs, provides HIV prevention services to these groups at a place and time where they can be most effectively accessed. Given the efficacy of CBOs and NGOs in implementing TIs, their involvement has steadily expanded over the years.

CBOs/NGOs also support NACO by delivering home-based care, providing CST to PLHIV by running community care centres, facilitating PLHIV network formation, and addressing stigma and discrimination. NACO also engages in building the capacity of these organisations and encourages NGOs in the non-health/HIV sector to expand the scope of their work to include HIV issues, especially stigma and discrimination.

Apart from this, they are also involved in mobilising communities to improve their access to various services under the national programmes; building capacity of community networks and improving their organisational capacity to manage larger programmes; providing social protection for PLHIV; contributing to the programme design of NACP.

FBOs play an important role in prevention, care and support activities in far-flung areas. Several FBOs have already taken up mainstreaming activities, and an inter-faith coalition on HIV/AIDS has been formed to strengthen the activities among their members.<sup>86</sup>

---

85 [http://www.naco.gov.in/NACO/Mainstreaming\\_and\\_Partnerships/Civil\\_Society/](http://www.naco.gov.in/NACO/Mainstreaming_and_Partnerships/Civil_Society/)

86 [http://www.naco.gov.in/NACO/Mainstreaming\\_and\\_Partnerships/Civil\\_Society/](http://www.naco.gov.in/NACO/Mainstreaming_and_Partnerships/Civil_Society/)

### 3.12 FINANCING

**Issues:** HIV is a complex virus and countering HIV/AIDS requires a comprehensive response. This can be achieved only through a scale-up of programmes and interventions to contain the spread of the epidemic as well as provide treatment to those infected. With no cure as yet, new tools are also needed to defeat the pandemic, and investment in research and development for new products remains essential.<sup>87</sup> Thus, HIV is a resource intensive programme.

**Efforts:** It has been noticed that in recent years, financing for HIV/AIDS has taken priority over other diseases such as TB and malaria. In India, too, financing for the HIV programme has seen a steady increase over the various phases of the programme. NACP-III had an assumed budget of Rs 11,585 crore, to implement a wide range of interventions, out of which Rs 8,023 crore was to be provided through the budget, the balance being extra-budgetary funding. The resource envelope identified for NACP-III included external funding from development partners (both budgetary as well as extra-budgetary support), bilateral and multilateral agencies, and UN agencies. These extra-budgetary resources supplemented the domestic contribution by Gol.<sup>88</sup>

The HIV programme has received a larger share of its allocated resources as compared to some other diseases that are prevalent in the country like TB and malaria. For instance, the allocation for NACP in the 2007–08 budget was Rs7.2 billion, as compared to Rs 8.84 billion for all national disease control programmes (including the TB control programme, leprosy, trachoma, blindness, iodine deficiency disorder, and the drug de-addiction control programme).<sup>89</sup>

The higher allocation of funds could be attributed to a few factors such as seeking convergence with global HIV priorities; the urgency to limit the spread of the infection as 88% of the population remain uninfected; advocacy by national and international bodies, especially CSOs; availability of external funding from several sources, including the government and private sector; political leadership and commitment; global attention to the issue;

Significant investments have been made within the country and through several other funding sources such as the World bank, DFID, UN organisations, multilateral and bilateral organisations; international philanthropic organisations such as the BMGF, the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund); the US President's Emergency Plan for AIDS Relief (PEPFAR), to name a few. The global incidence of HIV has declined by 20% since its peak in the mid-1990s, and nearly half of those who could benefit from ART, which suppresses the virus, are receiving treatment.

During Phases I and II, a lot of the funding was being channelled directly through states in line with the government's priorities. However, with the beginning of NACP-III in 2007, funding by these donors as well the World Bank was provided directly into the national budget through a pooled funding mechanism. In 2003, during the budget speech, the Indian Minister of Finance requested smaller bilateral donors to discontinue their support or channel it through the UN or NGOs. This was in line with India's plan of projecting itself as a non-aid-dependent country.

---

87 <http://www.gatesfoundation.org/What-We-Do/Global-Health/HIV>

88 *NACO Annual Report 2013–14.*

89 Expenditure Budget, Volume II (2005–06, 2006–07, 2007–08).

## Lessons from the HIV Programme for an Effective Development Response

Selected heads of expenditure of DoHFW	2004–05	2004–05	2005–06	2005–06	2006–07	2006–07	2007–08	
	Budget	Revised	Budget	Revised	Budget	Revised	Budget	
<b>National AIDS Control Programme</b>	<b>232</b>	<b>422</b>	<b>476.5</b>	<b>476.5</b>	<b>636.7</b>	<b>636.7</b>	<b>719.5</b>	
National Mental Health Programme	30	30	36	36	45	40	58	
Public Health Education	-	-	12.51	12.51	16.46	18.79	19.05	
			<b>NATIONAL RURAL HEALTH MISSION</b>					
National Disease Control Programmes								
National Vector-Borne Disease Control Programme	242.45	265.45	319.16	309.38	345.22	352.95	368.4	
National TB Control Programme	115	129	166.39	166.39	184.17	206.5	249	
National Leprosy Control Programme	53	40.84	38.57	25.82	38.25	35.41	34.65	
National Trachoma and Blindness Control Programme	85	85	86	86	81	98.39	126	
National Iodine Deficiency Disorders Control Programme	7.5	7.5	11	11	14	14.17	24	
National Integrated Disease Surveillance Programme	-	-	80	50	93	33.36	72.01	
National Drug De-addiction Control Programme	-	-	-	-	-	-	10	
<b>Total (National Disease Control Programmes)</b>	-	-	<b>701.12</b>	<b>648.59</b>	<b>755.64</b>	<b>740.78</b>	<b>884.06</b>	
Reproductive and Child Health Project	-	-	267.25	32.85	235.88	5.27	196	
Routine Immunisation	-	-	472.6	155.82	326.5	266	300.5	
Pulse Polio Immunisation	-	-	832	806.83	1,004	1,006.72	1,289.38	
<b>Total (National Rural Health Mission)</b>	-	-	<b>6,508.05</b>	<b>6,075.17</b>	<b>8,141.90</b>	<b>7,190.37</b>	<b>9,839.08</b>	

Table 6: Expenditure Budget, Volume II (2005–06, 2006–07, 2007–08)

India has committed to increasing domestic funding to more than 90% in the next phase of its AIDS response.<sup>90</sup> One of the largest funders of HIV programming in India is GFATM, providing aid worth USD 737 million. This funding has not only been channelled to the government, but also to CSOs to promote innovative models, support the strengthening of institutional and community systems, and advocacy.

Countries like: Brazil, Russia, India, China, and South Africa (BRICS). Together, they contribute to more than half of all domestic spending on AIDS in low- and middle-income countries. Their momentum is unparalleled, having increased domestic public spending by more than 122% between 2006 and 2011.

### 4.0 GAPS AND CHALLENGES IN THE DEVELOPMENT SECTOR

India is witnessing an increase in morbidity and mortality caused by factors other than HIV/AIDS, due to the rising disease burden in other health areas. The lessons from the HIV response could help boost efforts to address the challenges faced by other programmes and also help mount an equally successful response. The table below is an extract from the MDG Report 2012, tracking the progress towards achieving the MDG against these indicators. This section reflects on a few key public health programmes in India, the effective implementation of which could help solidify India's commitment to MDGs.

90 UNAIDS, *World AIDS Day Report 2012*, 21–22.

### 4.1 NON-COMMUNICABLE DISEASES

Non-communicable Diseases (NCDs) now impose the largest health burden in India in terms of lives lost due to ill health, disability and early deaths (DALYs). Sixty percent of the total mortality in India can be attributed to NCDs, while 38% is from communicable diseases, maternal and child health, and nutrition, all combined.<sup>91</sup> The probability of dying between 30 and 70 years of age due to four main NCDs in India is 26%.<sup>92</sup>

Among NCDs, Cardiovascular Diseases (CVD) account for 52% of mortality, followed by Chronic Obstructive Pulmonary Disease (COPD), Cancer, Diabetes and Injuries. Ischemic Heart Disease (IHD) is one of the most common CVDs, accounting for 90–95% of all cases and deaths, followed by stroke, which accounts for 5.8 million fatal cases per year. Projection estimates have shown that unless interventions are made, the burden of NCDs will increase substantially. NCDs account for 43% of DALYs. The potentially productive years of life lost (PPYLL) due to CVDs in the age group of 35–64 was 9.2 million in 2000, and is expected to rise to 17.9 million in 2030. Since the majority of deaths in India are premature, there is a substantial loss of lives during the productive years, as compared to other countries. Heart disease, stroke and diabetes are projected to increase cumulatively, and India stands to lose \$237 billion during the decade 2005–2015.<sup>93</sup> India has also seen considerable growth in the number of cases and deaths due to diabetes and cancer.

Cancer is a major public health concern in India and has become one of the 10 leading causes of death in the country. It is estimated that there are about 28 lakh cases of cancer at any particular point of time, with 10 lakh new cases occurring every year. About 5 lakh deaths occur annually in the country due to cancer. As per WHO Report 2005, the estimated cancer deaths in India are projected to increase to 7 lakh by 2015. The burden of cancer is expected to increase further due to a rise in life expectancy, demographic transitions and the effects of tobacco and other risk factors.<sup>94</sup>

Projection estimates show that the number of people with diabetes in India is 40.9 million, and is expected to rise to 69.9 million by 2025.<sup>95</sup> In 2010, almost 24 million adults over the age of 40 in India had COPD. This number is expected to increase by 34%, to approximately 32 million by 2020. Prevalence rates varying from about 2 to 22% among men and from 1.2 to 19% among women have been mentioned in different reports.<sup>96</sup>

The surge of NCDs within the country could be attributed to the increasing socio-economic status, unhealthy behavioural patterns such as smoking, alcohol consumption, intake of fat enriched foods and beverages, lack of physical activity. Personal behaviours are not merely a matter of personal choice; they are often driven by factors such as higher levels of urbanisation, technological change, market integration and foreign direct investment.<sup>97</sup>

In any given country, the indicators of NCD such as prevalence, number of cases, number of deaths, and number of DALYs of any of the major diseases are used to reflect the status of the ongoing programme interventions.

91 [http://siteresources.worldbank.org/SOUTHASIAEXT/Resources/223546-1296680097256/7707437-1296680114157/NCD\\_IN\\_Policy\\_Feb\\_2011.pdf](http://siteresources.worldbank.org/SOUTHASIAEXT/Resources/223546-1296680097256/7707437-1296680114157/NCD_IN_Policy_Feb_2011.pdf)

92 [http://www.who.int/nmh/countries/ind\\_en.pdf](http://www.who.int/nmh/countries/ind_en.pdf)

93 [http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG\\_3\\_2non\\_communicable.pdf](http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG_3_2non_communicable.pdf)

94 [http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG\\_3\\_2non\\_communicable.pdf](http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG_3_2non_communicable.pdf)

95 International Diabetes Federation, 2006, *Diabetes Atlas*, 3rd ed., Brussels: International Diabetes Federation.

96 [http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG\\_3\\_2non\\_communicable.pdf](http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG_3_2non_communicable.pdf)

97 [http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG\\_3\\_2non\\_communicable.pdf](http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG_3_2non_communicable.pdf)

Table 8: Indicators for NCDs in India

S. No.	Indicators	1998	2004
<b>1</b>	<b>CVD</b>		
	i. No. of cases of IHD	1,86,00,940	2,23,67,840
	ii. No. of deaths due to IHD	4,63,562	5,54,194
	iii. No. of Years of Potential Life Lost (YLLs)	44,61,600	49,52,150
	iv. No. of DALYs	1,43,19,427	1,60,00,808
	v. No. of cases of stroke	7,92,628	9,30,985
	vi. No. of deaths	5,93,362	6,39,455
	vii. No. of YLLs	48,18,740	52,89,357
	viii. No. of DALYs	58,02,295	63,68,970
<b>2</b>	<b>Diabetes</b>		
	i. No. of cases	3,12,57,011	3,77,68,402
	ii. No. of deaths	95,550	1,09,133
	iii. No. of YLLs	10,14,942	11,56,822
	iv. No. of DALYs	19,88,756	22,63,163
<b>3</b>	<b>Cancer</b>		
	i. No. of cases of cancer		8,19,354
	ii. No. of deaths		2,59,814
	iii. No. of YLLs		30,14,295

Source: R.PrakashUpadhyay. An Overview of the Burden of Non-Communicable Diseases in India. *Iranian J Publ Health*, Vol. 41, No.3, 2012, pp.1–8.

Table 9: Overview of Prevalence of NCDs in India

DISEASE	No. of Cases 2005*	Deaths 2005*	Projected no. of cases 2015**	Projected deaths 2015**
<b>Cardiovascular Disease</b>	3,80,41,090 (90% CHD)	2,089,508	6,40,71,981 (95% CHD)	34,20,752
<b>Diabetes</b>	3,10,39,932	n/a	4,58,09,149	n/a
<b>COPD</b>	1,70,20,000	n/a	2,22,10,000	n/a
<b>Cancer</b>	20,16,700	5,38,858	24,96,133	6,66,563

\*CVD/diabetes data from 2005; COPD from 2006; cancer from 2004 \*\*Projected data for CVD/diabetes is for 2015; COPD is 2016; cancer is 2014

Source: D. Wayne Taylor, *The Burden of Non-Communicable Diseases in India*, Hamilton ON: The Cameron Institute, 2010

### 4.1.1 NCD PROGRAMMES IN INDIA

Gol has supported the states in the prevention and control of NCDs through several vertical programmes such as the National Health Programmes for Cancer, Blindness and Mental Health. The Eleventh Plan saw a considerable upsurge in resource allocation towards the prevention and control of NCDs, worth nearly Rs 10,000 crore. However, this was only 28% of the total outlay of health programmes, which is relatively small compared to 72% allocation of resources for Communicable Disease Control Programmes.

New programmes were also initiated on a small scale and in a limited number of districts, and several vertical programmes were sought to be integrated within the framework of NRH during the Eleventh Plan period. These programmes have given insights into problems and experiences in implementation that would be useful in up-scaling and expanding programmes across the country.

### 4.1.2 CHALLENGES

Despite an increase in resource allocation and the expansion of programme interventions to address NCDs, the indicators have not improved significantly in the past decade. Some of the reasons for this are as follows:

- Although the Directorate of Health Services within MoHFW has a dedicated NCD division that acts as the focal point for coordinating NCD control programmes in the country, the absence of an overarching policy and strategy has limited the efforts in this direction.
- The lack of capacity and qualified human resources to tackle the increasing NCD burden poses another restraint. Training to address specific NCDs, particularly diabetes, CVD, and stroke at the primary care level is not included in the 'Human Resources Qualification Standards' established by the Medical Council of India, Pharmacy Council of India, and the India Nursing Council. There is also no clear system for planning the future supply of human resources, particularly for NCDs.
- The paucity of quality data on a timely basis hinders the planning process for addressing NCDs. Despite the rising burden of NCDs, there is no data collected on NCD-related complications, quality of health care, or health expenditure. Reliable and timely consolidation of health information from multiple agencies and multiple health programmes at the national level is seldom achieved.
- The absence of referral linkages and follow-up systems for NCDs is also contributing to the rising fatality. There are no systems for referred care or provisions for linking primary care to other levels of provider services (secondary and tertiary) for diagnosis and follow-up.
- India's focus has been on curative healthcare, due to the burden of communicable diseases such as TB, leprosy, vector borne diseases, HIV/AIDS, with low emphasis on preventive care. The rising NCD burden and the associated mortality, especially amongst the young and productive population in the country, have led to a greater focus in this direction, although the efforts are still very nascent. Investments during the Eleventh Plan and earlier Plans have been more focussed on tackling the inadequate provision of medical services in the public sector.
- The current financing burden for NCD treatment is disproportionately skewed towards the poor. Persons with NCDs in India have incurred significantly higher treatment costs (about double) in terms of out-of-pocket expenses, compared to persons with other conditions and illnesses.
- Lack of flexibility and decentralised focus of programme implementation at the state level needs to be looked into based on their public sector health system, prevalence and distribution of NCDs and socio-cultural context.

### 4.2 WATER, SANITATION, AND HYGIENE

The Water, Sanitation and Hygiene (WASH) programme aims at improving child health and sanitation in India, and has been an area of focus for nearly 50 years; yet it urgently requires improvements in many areas. The sanitation crisis has had a huge impact on health in a country that is home to half of the world's malnourished and underweight children. In India, the Central Rural Sanitation Programme (CRSP) defines sanitation as a broad concept that includes: liquid and solid waste disposal, food hygiene, and personal, domestic and environmental health.<sup>98</sup> Improved sanitation is fundamentally linked to the health of the community. There is ample evidence to show that poor sanitation poses severe health risks, especially in children. Diseases associated with poor sanitation, unclean water, and poor hygiene include dysentery, cholera, typhus fever, typhoid, schistosomiasis and trachoma.<sup>99</sup>

Urban populations may have access to household toilets, but sanitation beyond the home is limited. Many have limited sewerage systems and sewage treatment facilities. Of all the waste water generated in metropolitan cities, the majority is not treated before disposal and is often dumped in rivers, lakes and groundwater, causing high levels of water pollution.<sup>100</sup>

#### 4.2.1 STATISTICS

According to the MDG Annual Report, 2.5 billion people do not have access to improved sanitation and more than half that number belongs to India and China. The World Bank estimates that 21% of the communicable diseases in India are water related. Of these diseases, diarrhoea alone killed over 700,000 Indians in 1999 (estimated)—over 1,600 deaths each day. The highest mortality from diarrhoea is among children under the age of five, highlighting an urgent need for focused interventions to prevent diarrhoeal disease in this age group.<sup>101</sup> Parasitic infections are caused by contamination of water and poor sanitation, leading to stunted growth and debilitation. Skin and eye infections are also caused by contaminated water. High mineral content in water leads to fluorosis, dental decay and weakened bones. This mandates an urgent need for these issues to be addressed by public health professionals, researchers, and policy makers.

### 4.3 SANITATION PROGRAMMES IN INDIA

There are several players working to improve sanitation in India, the most predominant one being the government. Under the 73<sup>rd</sup> and 74<sup>th</sup> Constitutional Amendment, water and sanitation were made state responsibilities. The ministries responsible for sanitation are the Ministry of Housing and Urban Poverty Alleviation and Ministry of Drinking Water and Sanitation (under the Rajiv Gandhi National Drinking Water Mission). Both of these work in conjunction with the Ministry of Finance, Ministry of Environment and Forests, Ministry of Agriculture, and Ministry of Health and Family Welfare. A few central institutions also operate along with the Planning Commission to review the progress of water and sanitation schemes in the country.

Plans for improving sanitation have been included in the Five Year Plans of the Planning Commission since 1951. Several programmes are being implemented by the government to improve sanitation, both in rural and urban areas. Many of these programmes have achieved significant success, and are listed below:

98 Government of India, 2011, Guidelines: Central Rural Sanitation Programme, Total Sanitation Campaign, [http://www.indiawaterportal.org/sites/indiawaterportal.org/files/Guidelines\\_of\\_the\\_Central\\_Rural\\_Sanitation\\_Programme\\_and\\_Total\\_Sanitation\\_Campaign\\_by\\_the\\_Department\\_of\\_Drinking\\_Water\\_and\\_Sanitation\\_2011.pdf](http://www.indiawaterportal.org/sites/indiawaterportal.org/files/Guidelines_of_the_Central_Rural_Sanitation_Programme_and_Total_Sanitation_Campaign_by_the_Department_of_Drinking_Water_and_Sanitation_2011.pdf) (accessed on 7 August 2012) (hereafter cited as 'Total Sanitation Campaign 2011').

99 B. Mason, 2002, 'Report shows impact of poor sanitation on world's health', *International Committee of the Fourth International*, <http://www.wsws.org/articles/2002/apr2002/san-a18.shtml> (accessed on 8 August 2012).

100 Planning Commission Assessment 2002.

101 [http://www.who.int/mediacentre/multimedia/2002/ind\\_sanitation/en/](http://www.who.int/mediacentre/multimedia/2002/ind_sanitation/en/)

- The Total Sanitation Campaign (TSC) programme, launched in 1999, adopted a 'demand-driven' approach which focused on personal hygiene, home sanitation, safe water, garbage disposal, and waste water disposal through health education, human resource development, and capacity awareness activities. This programme was implemented through Panchayati Raj Institutions (PRIs), which were expected to carry out social mobilisation activities for the construction of toilets and the safe disposal of waste. PRIs played an important role in promoting the regular use and maintenance of these facilities, and also partnered with NGOs to emphasise training and implementation. NGOs played an important role in helping change behaviours. As of 2011, TSC had been implemented in 607 rural districts in 30 states.<sup>102</sup>
- The School Sanitation and Hygiene Education (SSHE) Programme, which was launched under the TSC initiative, aimed at providing clean drinking water and hand-washing facilities for school children, besides educating them on clean hygienic practices to reduce the occurrence of diarrhoea and worm infestation.
- The Global Sanitation Fund operates in India in partnership with TSC to promote awareness about sanitation and hygiene in the districts of Jharkhand and Assam. It also focuses on educating the community about behavioural change required for an effective sanitation programme.
- The Nirmal Bharat Abhiyan (NBA), which is being implemented by the Ministry of Drinking Water and Sanitation, is the primary resource for individual household latrines, school sanitation, hygiene education, community sanitary complexes, and anganwadi toilets.
- The Nirmal Gram Puraskar (NGP) is an incentive scheme where PRIs that attain 100% open-defecation-free status receive rewards. With the help of NGP, the annual coverage of sanitation has increased from 3% in 2003 to 7–8% at present.<sup>103</sup> Nirmal Shahar Puraskar is similar to NGP but for urban cities.
- The Village Health and Sanitation Committee (VHSC) is a village panchayat level programme, which was initiated in 2005 as part of the NRHM programme. Under this scheme, a population of 1,500 members from the village form a committee to work with the development committees on matters relating to health, water, and sanitation. VHSC focuses on community mobilisation and involvement in disease-prevention activities.

### 4.3.1 CHALLENGES

The sanitation sector faces many challenges, some of which need long-term planning and design changes led by the government to achieve success.

- Designing interventions as per the diverse cultural expectations, beliefs, and social norms in rural areas not only makes it challenging to implement behavioural change interventions but also makes it difficult to scale-up or replicate successful models. In urban areas, the lack of space and congestion make the poor more vulnerable to health risks, given the inadequate water and sanitation facilities.
- The lack of need assessment at the individual, community and household levels in rural areas prevents the successful design and implementation of interventions. The needs of smaller units and households should be studied to arrive at a robust, practical programme.<sup>104</sup>
- Inadequate emphasis on behaviour change interventions has severely limited the progress in achieving sanitation goals. Thus, sanitation facilities continue to remain under-utilised even if they are available. There is a need to increase resources for behaviour change programmes.

---

102 CSO MDG 2011.

103 CSO MDG 2011.

104 [http://www.who.int/mediacentre/multimedia/2002/ind\\_sanitation/en/index.html](http://www.who.int/mediacentre/multimedia/2002/ind_sanitation/en/index.html)

- Many schemes operate on the basis of monetary incentives, which are detrimental in the long run as they do not encourage behaviour change among the community and are, therefore, not sustainable.
- Stronger and rigorous monitoring of NGOs implementing sanitation programmes is required to achieve better outcomes.
- Inadequate coordination and convergence between the various ministries and departments that control different aspects of water management and WASH is one of the major challenges that has prevented successful programme outcomes. With the Ministry of Water and Sanitation in place, this issue can be addressed to a certain extent.

This sector requires significant financial investment for both building infrastructure as well as for motivating and reinforcing behaviour change to promote the use of these facilities. Therefore, the government alone may not be able to meet the entire financial requirement and secure increased investment and cooperation from donors; the private sector will need to help quicken the pace of the programme.

### 4.4 NUTRITION

India is among the top 50 countries with the highest mortality of children under five years (The State of World's Children 2012, UNICEF). Malnutrition is one of the major causes (attributable to one-third) for this category of deaths. India has an Infant Mortality Rate (IMR) of 44 per 1,000 live births. There is a stark rural–urban divide, the rural IMR being 48 and the urban IMR being 29 (RGI SRS October 2012). This also indicates the severity of malnutrition in rural areas as opposed to urban areas.

#### 4.4.1 STATISTICS

- 22% of the children born in India are underweight; nearly half of the children under five years of age are stunted (48%); 43% are underweight and 70% of them are anaemic (NFHS-III).
- One out of every five children under five years of age (20%) suffered from moderate or severe wasting; nearly one-third of children in the age group of 12–23 months did not ever receive Vitamin A supplementation (CES 2009).
- The median duration of breastfeeding in India is 3.8 months; only slightly greater than half (56%) of the infants born are exclusively breastfed during the first six months of life (Coverage Evaluation Survey 2009, UNICEF).
- More than one-third of Indian women (36%) and men (34%) suffered from chronic nutritional deficiency, and 55% women and 24% men were found to be anaemic (NFHS-III).

#### 4.4.2 CHALLENGES IN THE NUTRITION SECTOR

- The problem of malnutrition is being addressed only at the national and state levels, which may not be inadequate; thus there is a need to focus on the household and community levels to reduce malnutrition.
- The current approach to reducing under-nutrition fails to take into account the complex and multifaceted nature of the issue, which is dependent on a host of economic, environmental, agricultural, health, cultural, political, and administrative determinants.

## Lessons from the HIV Programme for an Effective Development Response

---

- The existing programmes are not sufficiently reaching the most vulnerable groups such as infants and young children, women, or the most needy and vulnerable.
- Nuanced approaches are required for reaching specific hard-to-reach target groups, as well as mothers and young infants.
- There is a lack of nutrition rehabilitation programmes for cases of acute malnutrition and wasting.
- The programme design does not take into consideration differential approaches for rural and urban areas, among different economic levels, as well as social and cultural differences within Indian society.
- The absence of a comprehensive national programme or approach specifically aimed at improving nutrition prevents convergence and synergy between existing programmes. This has resulted in the negligence of a number of important areas in the existing governmental programmes. There are also no programmes for nutrition education and monitoring.
- There is a lack of coordination between various central, state, and local departments and bodies, leading to the absence of links across the health, education, water, sanitation, and agriculture sectors.
- The national systems responsible for the collection and analysis of data on nutrition outcomes are insufficient. This leads to poor monitoring and decision making.
- The public sector has to promote the involvement of the private sector in addressing nutrition challenges. The private sector brings certain strengths which should be leveraged by the public sector to improve on efficiency and scale.
- There is a shortage of viable business models that enable the poorest people to access fortified products at an affordable price. Though attempts have been made by several players, a self-sustaining, scalable model is still not available.
- India has not developed a cadre of public health nutritionists (although there is a cadre of academic and clinical research nutritionists) that can analyse the core technical issues within the system and provide suitable solutions. Several programmes still rely on doctors or other medical professionals for solutions, while the problem of under-nutrition is cross-sectoral, requiring a broader understanding of the issues in question. There is no specialised post pertaining to nutrition at the central ministry level.
- There is inadequate understanding of both systemic issues and issues affecting nutrition.
- The lack of political support and commitment towards addressing the challenge of malnutrition is reflected in the inadequate budgetary allocations, especially in the case of child nutrition.
- Corruption, misappropriation and under-utilisation of financial assistance across the country results in poor quality of food supplements being supplied by the government, irregularities in supplies to the inequitable access to services, combined with discriminatory social and cultural practices are some of the reasons for the slow progress in this sector.

## Lessons from the HIV Programme for an Effective Development Response

The table below summarises the gaps and challenges that are common across HIV as well as other development sectors:

Table 10: Gaps and Challenges

Gaps & Challenges	HIV & AIDS	Diabetes	Cardiovascular diseases	Chronic lung disease	Mental Health	Maternal Health	Child Health	Nutrition	Sanitation	Livelihoods
1 Demand-side barriers (enhancing demand and uptake of services)	√	√	√	√	√	√	√		√	
2 Inequitable access to services	√	√	√	√	√	√	√		√	√
3 Human resources management (adequate trained staff, staff motivation, ongoing training & performance management)	√	√	√	√	√	√	√	√	√	
4 Lack of adherence support and continuum of services	√	√	√	√	√					
5 Lack of adequate infrastructure and equipment	√	√	√	√	√	√	√			
6 Inadequate financial management systems	√	√	√	√	√	√	√	√	√	√
7 Poor access to social entitlements						√	√		√	
8 Poor supply due to weak procurement systems	√	√	√	√	√	√				
9 Poor referrals and linkages	√	√	√	√	√					
10 Community involvement	√	√	√	√	√		√	√	√	
11 Insufficient coverage of target population	√			√			√	√		√
12 Inadequate supervision, quality of care protocols	√	√	√	√	√	√	√	√	√	√
13 Poor strategic information & evidence						√	√	√	√	√
14 Gender Disparities	√						√		√	√
15 Coordination between various departments	√							√	√	√

Initiatives to address the gaps and challenges listed within each of the above-mentioned programmes could benefit from the manner in which India's successful response to HIV/AIDS. Some of the common issues that emerge—such as the lack of political commitment, inadequate resource allocation, lack of evidence based planning, building the capacity of programme implementers—are a few issues that differentiates them from the manner in which the HIV response was designed and implemented. The next section details some of the lessons from the HIV response that lend themselves to be replicated in these sectors.

## SECTION 3 - SUMMARY OF LESSONS/ FINDINGS

### 5.0 WHAT WE CAN LEARN FROM THE HIV EXPERIENCE

The HIV/AIDS epidemic is unique and unlike any other public health issue that has been encountered in a long time. Besides health, HIV impacts several other dimensions such as legal, social, economic, and psychological. This is evident from the impact it has on the lives of those infected and affected. Poverty, economic deprivation, social marginalisation and denial of rights are some of the issues that PLHIV come across because of their status. These issues then heighten PLHIV's risks and vulnerability. Further, as noted in the document, the populations most at risk of HIV, who are also considered the main drivers of the epidemic in India, have faced the threat of punitive laws because of their behaviours, which are considered as beyond accepted norms. The vulnerability of women and the high rate of infection have been further compounded by the lack or denial of their rights.

Given these situations, it was acknowledged that a comprehensive response to HIV would necessarily need to move beyond the traditional approach of a health programme, to address the other dimensions mentioned above. This departure from all earlier approaches to health programmes in the country required dynamic action and leadership. The response mounted by India, with its guiding principles, strategies and approaches, is unmatched in how it has managed to address an epidemic of such complexity within a short span of 26 years.

India's successful response to the HIV epidemic holds lessons for many other development sectors in the country, such as nutrition, sanitation, and maternal and child health, which have been unable to demonstrate comparable results, and are, in fact, experiencing diminishing returns on investments made. This section looks at some of the different strategies and approaches adopted by the HIV sector, which can be adapted to generate similar results in other sectors. Captured below are some of the core lessons:

#### LESSON 1: GARNERING POLITICAL COMMITMENT

Advocacy to garner support and mandate, and to engage the top political offices in the country both at the national and state levels, can help to push the agenda, giving it the importance required to design a dynamic programme. Efforts to involve policy makers at the national and state levels helped the HIV programme garner the response it needed. Further, the support of legislators and policy makers who have the mandate to design policies helped to push the envelope further as the relevant issues could be voiced within the folds of the Parliament and the legislative assemblies, and thus had the opportunity to be translated at a policy and programme level. The acknowledgement that HIV was not only a health issue and that it needed to be integrated into the agenda of other ministries and departments was pushed through with the setting up of the NCA and SCA.

#### LESSON 2: STRUCTURAL ARRANGEMENTS

The establishment of autonomous structures within the folds of the health programme at all levels, with senior administrative officers helming the initiative, can help in making headway. This provides the space and scope required to tailor a response as per requirements. NACO is an autonomous body located

within MoHFW, while SACs and DAPCUs fall under the state and district administration, respectively. The decentralisation of institutional structures, coupled with the presence of dynamic leadership at all levels, helped in ensuring the independence and flexibility to circumvent challenges and increase programme effectiveness.

This was a departure from the functioning of some of the other health programmes, such as nutrition, women and tribal health, to name a few, which require the coordinated efforts of various government departments for implementation. The WASH programme also faced the same predicament till recently. Similar importance and centralised authority and responsibility need to be accorded to these other sectors to mandate a similar response.

### LESSON 3: ENSURING A COORDINATED RESPONSE

The adoption of the Three Ones Approach marked the first effort at developing a unified national HIV/AIDS strategic plan—a potentially hydra-headed programme—in the form of a reasonably well-coordinated, M&E framework so that all players could subscribe to a single vision, mission, and plan with clear authority. This not only enabled maximise resource utilisation but also helped to avoid duplication and overlapping of efforts on the ground. In a country like India, with limited resources, the adoption of a similar response across sectors such as maternal and child health and NCDs could be very beneficial.

### LESSON 4: WORKING WITH COMMUNITIES

The extent of the partnerships formed with civil society and communities for the HIV programme was unprecedented. Civil society and HIV-affected people led efforts to expand access to HIV programmes and were involved in design, implementation, service delivery, addressing issues of stigma and discrimination, etc. Communities and PLHIV also got an opportunity to voice their needs and concerns, thereby aiding the tailoring of appropriate responses.

One of the hallmarks of HIV care and support has been community- and home-based care. NGOs/CBOs implement a continuum of prevention, care and support programmes. CBOs and PLHIV networks have been engaged in providing counselling and care services; they have also been trained to support adherence, outreach and patient involvement, leading to sustained health seeking behaviour and outcomes. This approach can be easily adapted for programmes addressing nutrition, sanitation, diabetic, mental health and cancer care.

### LESSON 5: MULTI-SECTORAL APPROACH AND MAINSTREAMING

The recognition of the involvement and coordination of various stakeholders helped in building momentum and getting support from all quarters—government, non-government, public and private sector. This helped mitigate the impact on the health of infected and affected communities by addressing the underlying issues of HIV and AIDS. The strong involvement of multiple government agencies, and civil society, including NGOs, FBOs, technical agencies, private employers and businesses, affected communities, academia, and institutes has the potential to mitigate the impact and also ensure appropriate local and national responses.

Programmes such as malnutrition, sanitation, non-communicable diseases, and climate change could take several lessons from this.

### LESSON 6: DESIGNING AN EVIDENCE-BASED RESPONSE

The programme has been designed on the basis of strong and multiple sources of evidence. This has helped to revise estimates, provide data for programme design and also undertake mid-course correction as and when required. Right from the beginning, regular and systematic sentinel surveillance, behavioural and biological surveys, etc., have been instrumental in designing the right programme at the right time for the right people. Besides surveillance and research based data, IT-enabled monitoring systems such as SIMU have also aided planning, implementation, and monitoring of such a large programme with varied components and hard-to-reach populations. The programme has, as a result of this information, been able to optimise its resources and reach the key populations that have to bear the maximum impact of the epidemic. Evidence-based approaches have, therefore, led to maximising the reach and scale of operations through optimised resources and targeted efforts. This is vital for other programmes if they seek a similar response.

### LESSON 7: COMPREHENSIVE PROGRAMME DESIGN

NACP exemplifies how an effective programme can be evolved by improving, consolidating and scaling-up need-based, successful and innovative models in response to HIV/AIDS. Each stage of the programme has gathered evidence on emerging lessons and tried to leverage these to consolidate and strengthen the next phase. NACP includes the comprehensive provision of prevention, care and treatment services, and through the use of IEC, emphasises awareness and behaviour change communication to effect change; builds capacity at all levels to enhance programme performance; and ensures systematic collection of data through the nationwide SIMS to revise the programme design.

The district level decentralisation of the programme, which aims at saturating the coverage by classifying districts on the basis of prevalence and incidence, has paid dividends. This has helped to maximise resources in areas where they are needed, and to expand coverage of populations. This all-round approach, which involves plugging all aspects, followed by strict M&E, has been key to the programme's success. Moreover, the state and district level decentralisation has also helped design and implement locally relevant models.

Initiatives such as WASH have a lot to learn from the HIV programme, particularly the manner in which it has adapted and scaled up successful models like the TI or how it has utilised BCC. The mere provision of services and infrastructure may not be effective without persistent efforts at behaviour change. For example, in the WASH programme, the mere availability of toilets may not make any difference unless it is followed-up with exercises to actualise behaviour change. Similarly, there may exist health services and facilities for tribal communities, but without a strategy on positive health-seeking behaviours, such a programme will lack uptake.

Comprehensive programme design also underscores the need for a multi-disciplinary team approach. The HIV programme has established multi-disciplinary teams and added new health worker cadres, enhancing counselling, adherence support, patient education, and community outreach. This approach has transformed professional hierarchies, strengthened patient-provider relationships, and facilitated task-shifting and task-sharing.<sup>105</sup> Other programmes, too, need to adopt this kind of team approach so as to ensure optimal results. For example, the prevention of diarrheal diseases among children needs a team approach involving schools, doctors, nurses, behavioural scientists, media, etc. Similarly with tribal health services—besides doctors and nurses, there is also a need for behavioural scientists, researchers, public health experts, public health engineers, advocates, etc.

---

105 [file:///C:/Users/Glow/Downloads/Scale\\_up\\_of\\_HIV\\_care\\_and\\_treatment\\_can\\_it.10.pdf](file:///C:/Users/Glow/Downloads/Scale_up_of_HIV_care_and_treatment_can_it.10.pdf)

Besides the provision of services and dedicated manpower, the development of operational guidelines and standard operating procedures were a crucial component, which helped to bring about uniformity across programmes. Supply chain mechanisms were put in place to minimise stock-outs.

### LESSON 8: EFFECTING APPROPRIATE LEGAL AND POLICY ACTION

NACP, initiated in 2002, articulated the Government of India's commitment to the HIV response by developing a multi-sectoral response, large-scale involvement of NGOs from policy level to the grassroots, and the review and reform of criminal laws to ensure that they are in tandem with international human rights obligations. In addition, the policy highlights the government's commitment to strengthen anti-discrimination laws and ensure that legislative measures protecting the vulnerable will be undertaken.<sup>106</sup> Some states have devised their own policies. Manipur was probably the first state to launch an HIV/AIDS Policy in 1996, which preceded the national policy.<sup>107</sup>

Besides these, the endorsement of international treaties, global commitments, and political declarations have also shaped the country's response by providing direction, better clarity, and exerting a certain amount of pressure on the government. In the absence of a comprehensive legislation in the country, the HIV programme adopted and adapted several laws drafted across the globe to focus on specific areas. This has helped to reinstate the rights of the PLHIV community, especially its women members.

Political advocacy at the national and state levels, too, has helped to gather momentum and effect policy changes as is required to facilitate policy changes for the HIV programme.

The above-mentioned strategies would also be useful for all other development sectors as any developmental challenge in India—be it sanitation, nutrition or livelihoods—will have repercussions on the relevant indicators in the region, which, in turn, affect global performance. Hence, influencing the international policy scenario through advocacy alliances and other relevant platforms can catalyse and shape India's policies and actions towards addressing a particular cause.

### LESSON 9: FINANCING

HIV is probably the only programme where a large chunk of resources have been contributed directly or indirectly by external agencies, donors and funders, apart from Gol's contribution. World Bank, DFID, USAID and BMGF are some of the donors that have supported the programme response. This funding has given the programme the flexibility to take appropriate decisions to respond to immediate programme exigencies.

The programme has adopted a performance-based financing mechanism, managed to eliminate user fees (which are usually small and keep the poor away) and used innovative insurance schemes. Performance-based financing has also been used in TB and malaria programmes, and although it has its pros and cons, it has largely pushed forward the urgency of programming.

### LESSON 10: CONSISTENT CAPACITY BUILDING TO STRENGTHEN SYSTEMS

In HIV, unlike other sectors, equal, if not more emphasis was given to the strengthening of systems. This has resulted in improving programme delivery and uptake, building the capacity of manpower and strengthening infrastructure. Besides this, SIMS and other data collection mechanisms continue to

---

106 Government of India, 2003, *National Aids Prevention and Control Policy*, 15 April, para 6.1.

107 Manipur State AIDS Control Society, 2012, Home: Welcome to Manipur State AIDS Control Society, <http://manipursacs.nic.in/> (accessed on 19 December 2012).

provide information on strategic information, programme performance, and monitor the progress of the programme. This has supported the rapid scale-up and replication of programmes throughout the country. In other sectors, programming is often prioritised over the strengthening of systems, which then hinders any rapid scale-up. Proper review and planning for the strengthening of systems is essential for the rapid scale-up of any programme, be it nutrition, climate change, chronic disease programme, or sanitation.

### LESSON 11: FACILITATING AN ENABLING ENVIRONMENT

The HIV programme has moved beyond the confines of providing services to adopting a framework to mitigate the negative impact on those infected and affected. Efforts such as the collectivisation of vulnerable communities such as FSWs, MSM, etc., have helped to create an environment that supports communities to seek help with confidence and voice their concerns to effect policy change to better address their issues. For example, the gender option of 'other' and the creation of the TG Welfare Board are outcomes that have helped these populations to be mainstreamed within the society.

The adoption of GIPA and the involvement of PLHIV networks has been another step towards creating an enabling environment. By adopting a rights-based approach, the HIV programme aims at ensuring a life without stigma and discrimination. Provision of legal services through CSOs working on legal issues has led to reforms.

Mainstreaming is another strategy which continues to help infected and affected communities avail of social protection schemes made available by the other ministries and departments.

Stigma was, and perhaps still is, the most critical structural barrier to HIV programming. Similar is the case with other programmes, such as nutrition, sanitation and mental illness, where the most affected parties also tend to experience gender, caste, and economic stigma. HIV-related stigma has required sensitive demand generation for the most at-risk and affected populations, as well as for care providers. The focus on stigma reduction has been one of the key ingredients in improving services for the most at-risk populations, which would otherwise be unable to access any service.

### LESSON 12: EMPOWERMENT APPROACH

Last but not the least of the core lessons is the empowerment approach. While most programmes begin by delivering services to those who may need them, HIV programming made a bold choice by emphasising the need to empower communities so that the communities generate the demand themselves, and the resultant behaviour change is sustained and not thrust on them by the programmes. HIV Program has seen many networks and advocates voicing their needs, and despite the heavy stigma and discrimination, several community-based organisations emerged to fight for their rights. This greatly helped increase ownership – the fact that affected communities were visible and vocal in advocating their issues at national and international platforms.

This document suggests the leveraging of lessons from India's HIV response and applying them to other programmes, keeping in mind contextual realities, practicalities, resources and feasibility. We acknowledge that this process of learning from India's response to HIV is an ongoing one, and we encourage debates about and additions to the points highlighted in this document. The next steps forward would include a national consultation of experts from various sectors to examine the specific applicability of lessons from the HIV sector. We are humbled by the vast body of work achieved in such a short time and take cognisance of the fact that there may be other examples and lessons from HIV, which do not find mention in this document.

### ANNEXURE: LIST OF PERSONS CONSULTED AFTER CONCLUSION

1. Dr. T. Ilanchezhian
2. Dr. Prasanna Kumar
3. Dr. L. Ramakrishnan
4. Gunaseelan Jaya
5. Joson Meloot
6. Dr. A. Sathish Kumar
7. Vinita Siddhartha
8. Dr. Sai Subhasree Raghavan
9. Dean Lewis
10. P. Kousalya
11. Anandi Yuvaraj
12. Dr. T.L.N. Prasad
13. Ms.Alka Narang
14. Dr.Rajeeb Kumar Sharma
15. Deepak K.
16. Pankaj Kumar Sharma
17. Dr. Rebecca Sinate
18. Ritu Kumar Mishra
19. K. Ezemy
20. Anamika N. Saikia
21. Jyoti Prasad Sarmah
22. DhritiBania
23. Nayandhiju Sharma
24. W.C. Humtsoe
25. Arpana Barman
26. Dr. B. Langkham
27. Dr.Pramod Kumar Singh
28. Akshay Kumar Das
29. RajuTamang
30. L. Pachuman
31. H. Rosenara
32. Pankaj Kumar Choudhuri
33. F. Hussain
34. Sanjib Chakraborty
35. Lincoln
36. Parag Goswami
37. Anand Grover
38. Vandana Mahajan
39. Suneeta Dhar
40. Dr. Reynold Washington
41. Dr. Suniti Solomon
42. J.V.R. Prasada Rao
43. Ashok Rau

# CONCLUSION

Targeted Intervention Programme of NACO is one of flagship programmes under NACP for prevention of HIV among the High Risk Groups. The TI programme has evolved over time to address the needs of specific categories of High Risk Groups. TGs, who till recently were a part of the MSM intervention, have a separate intervention for them that takes into account their uniqueness while designing the intervention. Another step in this direction is the Sunrise Project for the IDUs, including the female IDUs in the North East part of the country. This project also has prison intervention for the IDUs. However the intervention needs to expand beyond its primary target population. Spouses and children need to be brought under the ambit of the prevention programme of the HRGs to be addressed more comprehensively. Prevention programmes need to be adapted to suit local needs. The diverse geographies play a key role in designing an intervention. There is a need to have geo- prioritization to come up with customization of the interventions.

Dissemination of correct and consistent information is a significant component of prevention strategies. IEC and BCC have been an integral part of the various phases of NACP. There is a need to secure funding commitment by leveraging funds from NRHM and other line departments for a sustained impact. There is a need for a paradigm shift in the way IEC is perceived. Content heavy, static approach needs to give way to innovative and interactive methods to enhance the retention of key takeaways messages.

Community involvement plays crucial role in the NACP. It is at the centre of the national response. The NACP has made efforts to create an enabling environment by engaging community in the decision making processes in every phase. The TI programme is implemented by the Community Based Organizations and there exist Technical Resource Groups to that have representation from the community. Capacity building of the community has been a priority under the NACP. The challenge to strengthen community partnerships by addressing capacity building needs that take into account the heterogeneity of the epidemic. This can be done by customizing the various training modules under NACP and make provision for regular refresher. In addition to this, effective community participation can be secured by ensuring their meaningful participation in key process of programme planning and implementation including in key decision making bodies. These steps are essential to maintain the continued support and collaboration of the community for an effective response to combating the epidemic.

The legal system of any country plays a critical role in defining the environment for the communities affected by HIV. India, in the last few years, has made significant strides in addressing the legal framework and making community friendly policies and laws. The establishment of Transgender Welfare Boards and the landmark judgement by the Supreme Court regarding the gender identity of the Transgender population and Transgender policy in Kerala are few such examples that reflect India's commitment towards making the legal system more responsive towards the unique needs of the HIV affected communities. The Court has also referred the curative petition filed against the apex court's 11 December 2013 judgement upholding the validity of section in the Indian Penal Code and the January 2014 order by which it had dismissed many review petitions to a five bench judge. The long pending approval of the HIV Bill by the Parliament would only go on to reinforce the commitment of the government.

Evidence based programming is one of the corner stones of NACP. Since the inception of the programme , NACO has realized the significance of scientific data gathering. There exists a robust mechanism for the annual HIV Sentinel Surveillance. HSS along with IBBS has been conducted in the year 2015 shedding light on the National and state pattern , prevalence and incidence. The evidence generated from these exercises is then used to develop and design context specific interventions. To achieve optimum results from such evidence gathering exercises, focus needs to be given to coordination between the Strategic Information and the programme component. Apart from the HSS and the IBBS, the data collection system of NACO, SIMS , needs to be strengthened to generate uniform data across geographies. One of the areas that need to be looked into with urgency is the Integration of all IT applications under NACO wit SIMS for stronger linkages. There is also a need for enhanced use of system generated data for programme effectiveness. Empathise needs to be paid to efficient and officious data management at state / sub state level and regular programme monitoring .

NACO has adopted multi-sectoral convergence I as one of the key approaches to address the issue of mainstreaming of HIV. Continuous endeavours have resulted in signing of MoU between NACO and 14 non- heath ministries. Department of Telecommunications, Department of Youth Affairs, Ministry of Youth Affairs & Sports and Department of Higher Education, Ministry of Human Resource Development are few of the Ministries with whom MoUs are signed. Momentum needs to be maintained in this direction so that Ministries can be brought within the ambit of mainstreaming. NACO, through its social protection initiatives provided over a million social assistance benefits to HIV affected people. With the relevance of social protection firmly established, the concept needs to evolve and design a basic minimum social protection package for PLHIV. Financial assistance, nutrition, education, travel, shelter are suggested components of the Minimum Package. The Minimum Package is proposed as a way forward for amplifying the reach of Social Protection to the most marginalized.

Decentralization and devaluation of power are critical contributors to the success of the national programme. SACS sphere heads the response at the state level. In the recent years structural challenges have been highlighted that impede the efficacious implementation. Strengthening the HR systems for large scale workforce management and devising a method for timely recruitment would ensure Institutional Strengthening. Clarity about the roles of NTSU and TSU is important so that these two arms of capacity building can exploit their potential to the optimum.

Built on the foundation of the Mellinium Development Goals, the Sustainable Development Goals are one of the most comprehensive blue print for eliminating extreme poverty . SDGs are designed to fast track the Agenda 2030 - "Leave No One Behind and target inequality in its varied forms. A set of 17 Goals SDG Goal 3 talks about ensuring healthy lives and promote well-being for all at all ages. SDG Goal 3.3 specifically talks about ending the epidemic by 2030. The lessons from the success of the HIV response will serve as a platform for the NCDs to make the peogramme more comprehensive, participatory and sustainable .



