

Chapter 8

HIV/AIDS and Children in the Sangli District of Maharashtra (India)* (preliminary version)

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Summary: In order to assess the impact of an adult HIV/AIDS-related death on the household in general and children in particular, a comparative study of the three types of households was undertaken in Sangli district of Maharashtra. A total of 118 households with an HIV/AIDS death, 100 households with a non-HIV/AIDS related death and 100 households with no deaths were included in the survey. A significant negative impact on the economy of households where an active adult has died due to HIV/AIDS was clearly evident from the responses. Households with HIV/AIDS deaths have reported reduced savings during the period of observation, reduced expenditures on consumer durable items, and disposal of assets in order to raise or supplement income. On social front they have reportedly experienced discriminations and few of them have had to send their children away to distant relatives, and withdraw children from school. Adult deaths due to HIV/AIDS also impacted negatively upon children's ability to access both health and education. While the members of the extended family provide orphans with the shelter, it is obvious that several of these children do not receive continued education and health care when needed. The impact on both households and children is much more negative in case of those which are socially and economically disadvantaged. The negative attitude towards people with HIV/AIDS was found to be quite widespread. People living with HIV/AIDS spent huge amount of money to get cure. This study clearly points out towards a need of a comprehensive response to HIV/AIDS which includes efforts to reduce stigma and discrimination at all levels; developing supportive network system for the women and the orphans; and more specifically preparing families to provide for children in the eventuality of death of both the parents or one of the parents.

JEL: D13, I12, I18, J11, J13

*** This study presents the views of its authors and not the official UNICEF position in this field.**

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AIDS, PUBLIC POLICY AND CHILD WELL-BEING *

edited by Giovanni Andrea Cornia

Table of contents

Introduction - *Giovanni Andrea Cornia*

Part I: Overview of the HIV/AIDS Impact and Policy-Programme Responses

1. Overview of the Impact and Best Practice Responses in Favour of Children in a World Affected by HIV/AIDS - *Giovanni Andrea Cornia*

Part II. The Social and Economic Impact of HIV-AIDS on Children:
Evidence from Eight Country Case Studies

2. The Impact of HIV/AIDS on Children: Lights and Shadows in the “Successful Case” of Uganda - *Robert Basaza and Darlison Kaija*

3. The Impact of a Growing HIV/AIDS Epidemic on the Kenyan Children – *Boniface O.K’Oyugi and Jane Muita*

4. The Socio-economic Impact of HIV/AIDS on Children in a Low Prevalence Context: the Case of Senegal - *Cheikh Ibrahima Niang and Paul Quarles van Ufford*

5. HIV/AIDS, Lagging Policy Response and Impact on Children: the Case of Côte d’Ivoire - *Jacques Pégatiéan and Didier Bilibolo*

6. The Current and Future Impact of the HIV/AIDS Epidemic on South Africa’s Children - *Chris Desmond and Jeff Gow*

7. Perinatal AIDS Mortality and Orphanhood in the Aftermath of the Successful Control of the HIV Epidemics: The Case of Thailand - *Wattana S. Janjaroen and Suwanee Khamman*

8. HIV/AIDS and Children in the Sangli District of Maharashtra (India) - *Ravi K. Verma, S. Salil, Vera Mendonca, S.K. Singh, R. Prasad and R.B. Upadhyaya*

9. Limiting the Future Impact of HIV/AIDS on Children in Yunnan (China)
China HIV/AIDS Socio-Economic Impact Study Team

Part III: The Sectoral Impact of HIV-AIDS on Child Wellbeing and Policy Responses

10. The HIV/AIDS Impact on the Rural and Urban Economy - *Giovanni Andrea Cornia and Fabio Zagonari*

11. Poverty and HIV/AIDS : Impact, Coping and Mitigation Policy - *Tony Barnett and Alan Whiteside*

12. Mitigating the Impact of HIV/AIDS on Education Supply, Demand and Quality - *Carol Coombe*

13. The Impact of HIV/AIDS on the Health System and Child Health - *Giovanni Andrea Cornia, Mahesh Patel and Fabio Zagonari*

14. Increasing the Access to Antiretroviral Drugs to Moderate the Impact of AIDS: an Exploration of Alternative Options - *Pierre Chirac*

15. The Impact of HIV/AIDS on Orphans and Program and Policy Responses - *Stanley Phiri and Douglas Webb*

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1. HIV/AIDS and Children in INDIA and Maharashtra

1.1 HIV/AIDS scenario in India

According to the National AIDS Control Organization (NACO) the total number of registered AIDS cases in India since 1986, is 28215, out of which 21482 are males and 6733 are females. The total HIV infections are estimated to be 3.86 million in the country by June 2001. The high prevalent states are Tamil Nadu, Maharashtra, Manipur, Karnataka and Andhra Pradesh. The fastest spread of HIV/AIDS is noticed among sexually active who are also the most productive people in the prime age of 15-44 years. Data from various sentinel sites in the country are showing that the HIV infections had increased sharply among Commercial Sex Workers, rapidly progressing among STD attendees and is rapidly spreading among the low risk behaviour group, as the infection is spreading from Commercial Sex Workers to their clients which are acting as bridge population and then to the wives of these clients. Prevalence of HIV/AIDS has also been recorded even among the low risk population in rural areas. Nearly 84 percent of the infections is through the heterosexual transmission route and the remaining is through the route of blood transfusion and perinatal transmission. Among the total registered cases 89 percent cases are adult members and 3.6 percent children were infected (NACO, 2000).

The state Maharashtra (population of 96.7 million people, 77% literate) is situated in the west-southern side of India. It is the most industrialised state of the India. At the same time it is also the second state of the India for population size. Another important feature of Maharashtra is that it is the highest migrants recipient state.

Maharashtra is also one of the highest HIV prevalence states and has also experienced a rapid increase in the number of cases since 1986. The total number of AIDS cases registered in various sentinel sites in Maharashtra reached to 9504 by September 2001 (7154 males and 2350 females). The districts like Mumbai, Sangli, Kolhapur, Pune, Satara, Latur, Raigad, Akola, Chandrapur etc. are experiencing a relatively higher prevalence of HIV/AIDS in the state. Out of the total number of cases registered in Maharashtra nearly one-third are registered in Mumbai and almost one-fourth cases are in Sangli district. These two districts account nearly two-third of the total AIDS cases registered in Maharashtra. It is evident from the distribution of the AIDS cases that the epidemic has already spread to the rural areas in the state as the least urbanized districts like Sangli, Satara are also experiencing high prevalence of HIV/AIDS. Out of the total number of the registered cases, the male female ratio is almost 3:1. In Sangli district such ratio is nearly 4:1. The perinatal transmission is also one of the major modes of transmission. The observed difference in the sex ratio in the AIDS cases is mainly due to higher concentration of HIV/AIDS among male migrants from Sangli, who have returned back to their place of origin after diagnosis of the disease. Though the prevalence of

CHAPTER 8: HIV/AIDS AND CHILDREN IN THE SANGLI DISTRICT OF MAHARASHTRA
(INDIA)

HIV/AIDS was initially concentrated among high-risk population in urban areas but the existing figures of AIDS cases in some districts like Satara, Kolhapur, Latur, Chandrapur, Raigad etc. are showing the strong presence of the epidemic among the low risk population in the rural areas of the state. The HIV positive cases among the high-risk group population were 13.9 percent in 1998 and it has gradually increased over time, which is 14.1. (Table 1.1).

The death toll due to HIV/AIDS in the state is 915 in which 677 were males and 238 were females. More than half of the total deaths occurred in the state were reported in Mumbai district (313) followed by Sangli (296). Among the total female deaths occurred due to AIDS in the state, Sangli experienced more female HIV/AIDS deaths compared to other districts in the state. This shows that the process of HIV transmission from infected males to their wives in the Sangli district has a history of more than a decade.

Table 1.1. Seropositive Cases in Maharashtra among High Risk Group population.

S.No	YEAR	SCREENED	HIV+	%
1	1986-1998	415506	57890	13.9
2	1999	99641	13644	13.7
3	2000	94257	12997	13.8
4	2001	46323	6537	14.1

Source: Maharashtra State AIDS Control society, 2001

1.2 Basic Health Indicators for children and people

Table 1.2 Some basic indicators related to child health Status in India over different time periods.

	1985	1990	1995	2000
1.LEB (e_0^0) ¹	56.4	59.1	61.7	64.2
2.IMR ²	97	80	74	74(1999)
3.IMR AIDS ³	93(85-90)	78(90-95)	72(95-2000)	72 (2000-2005)
4.U5MR ⁴	38	26.3	24.2	10.8
5.DPT3 ⁵	15.18	22.50	22.56	
6.MEASLES ⁶	-	20.29	20.54	
7.ORT ⁷		25.9 (92-93)		26.8(98-99)
8.15-49 ⁸		61.9 (92-93)		65.1(98-99)
9. BIRTHS ⁹		34.2 (92-93)		42.3(98-99)

Sources: 1 and 2 RGI, SRS Bulletins; 3 Demographic Impact of HIV/AIDS United Nations Population Division; 4 RGI, SRS Bulletins; 5 and 6 UIP DIVISION, Dept. of Family and Family Welfare, Ministry of Family and Welfare, India; 7,8 and 9 National Family Health Survey, Phase I & II, 1992-93 & 1998-1999

If we look at the tables keenly, we find, over the last two decades India achieved demarcated gain in its life expectancy at birth (table 1.2).

Similarly if we look at the infant mortality rate we find it is reducing over the time period. In the year 1985 the infant mortality rate was 97 and reduced to 80 in the year 1990 and subsequently reduced 74 in the year 1999. The gradual declining of IMR may be attributed to the effective immunization and vaccination programme of the country,

like; Pulse Polio Programme, DPT vaccination programme, Free distribution of Oral Rehydration Solution packets (ORS), Effective IEC activities adopted by the health personals, popularised breast feeding among the mothers etc. The infant mortality rate in India “with AIDS” had been estimated by the United Nations Population Division has also showing the decline trend of the infant mortality rate with AIDS over the periods. The infant mortality rate “with AIDS” was 93 in the period 1985-90, 78 in the period 1990 – 1995, and gradually decline to 72 in the period 1995 – 2000.. The under five-child mortality rate also follows a similar pattern. It was 38 in 1985, 26.3 in 1995 and 10.8 in the year 2000. The cause may be attributable to the effective immunization, vaccination and IEC programme of the government. The overall social development and improvement in health care facilities are also the major determinants of the reduction in under five-child mortality in India.

The universal immunization coverage like DPT3, measles and the free distribution of ORS packets are also some of the ongoing health programmes improving child well being in India. The proportion of one-year-old children immunized against diphtheria, pertusis and tetanus with 3 doses, is also increasing slowly over the period of time. The DPT3 immunization coverage had been increased from 15.2 in 1985 to 22.5 in 1990 and 22.6 in 1995. The measles coverage in the country is also showing positive trend. In 1990, 20.29 percent of the children were covered by this vaccination, where as, in 1995 the coverage was of 20.5 percent. A slow increase in ORT usage is also been found in the country over the period of time. The utilization of antenatal services is also found to be rising slowly. The proportion of the women in the age group 15-49, who have attended at least one pregnancy check up by skilled medical personnel has also increased from 61.9 percent in 1992-93 to 65.1 percent in 1998-99. It has also been observed from the past trend that the utilisation and rendering of services of health care particularly in the aspect of birth attended by the skilled health professional has increased over the period. Over the period, there is also the increasing trend of birth attended by the trained health professionals. It has increased from 34 percent in 1992-93 to 42 percent in 1998-99.

1.3 Purpose of the study

Given these trends, this section aims at assessing whether the recent explosion of AIDS epidemic poses a health problem with serious personal, socio-economic and other consequences. A number of recent studies in India have documented the increasing pace of HIV infection and it’s impact on individuals, families and society as a whole. This complex epidemic that has primarily emerged due to heterosexual transmission fuelled by less studied patterns of bisexual or injecting behaviour. Data from sentinel surveillance system shows a rapid evolution of the epidemic mainly in the southern and western parts of India. Andhra Pradesh and Karnataka have now overtaken Tamil Nadu to join Maharashtra as the states with the highest prevalence of HIV. The major northern states still report very low levels of HIV. Their vulnerability to the epidemic, however, in terms of male migration, adverse gender norms and weak infrastructure makes action in these states critical for the future path of the epidemic. Given its large population base and increasing population, India is expected to have the largest concentration of AIDS affected individuals in the world if the current rate of transmission continues.

In view of the above, it is highly desirable to have a comprehensive knowledge about transmission of the epidemic and its community level impacts through morbidity and deaths. This is within this context, the present study on “Socio-economic Impact of HIV/AIDS Morbidity and Deaths on the Households and Their Coping Strategies” will be useful for formulating policies and programmes for long term preventing measures as well as short term relieves and rehabilitation for those who are in crisis especially orphan children and elderly.

1.4 Basic characteristics of Sangli district

Sangli is one of the fast developing districts of Maharashtra and the 21st district in terms of size with total land area of 87,572sq.km. It is one of the southern districts of Maharashtra and forms a part of Deccan plateau. It is bounded with Satara and Solapur districts to the north, state of Karnataka to the east and south, Kolhapur district to the southwest, while; it has a small boundary with Ratnagiri District in the west.

As per the 1991 census, the total population of Sangli district was 2,209,488. The district ranks 15th in terms of size of population accounting for about 2.8 percent of the state population. Decadal percent growth in the population during 1981-91 for the district (20.4 per cent) is slightly lower than the state as a whole. Sangli is one of the less urbanised districts of the state having about only one fifth of its population in urban areas. According to 1991 census, 39 per cent of the population in the state lives in urban areas, which was 22.7 percent in case of Sangli.

In 1991, the scheduled caste population of the district was 12.6 percent as against 11 percent for the state as a whole. The corresponding proportions of scheduled tribe population were 0.49 and 9 percent respectively. Population Density of the district was 258 persons per sq. km., which is slightly higher than the state population density of 256 persons per sq. km. It is the seventh densely populated district in the state. The decadal growth rate of population of the district has decreased by 3.16 percent during the past one decade.

The total population in the age groups 0-6 is 324,178 in which male children accounts for 54.1 percent. Sex ratio of the population, i.e., number of females per 1000males, is, 958, which is higher than the overall state average of 934 and the district holds eighth rank in the state in terms of its sex ratio. The declining sex ratio over two decades can be observed in the district. The rapid increase of literacy rate in the district over a decade can be noticed very easily. There is 17 percent increase in case of female literacy rate where as male literacy rate has increased by 11.4 percent from 1991 census to 2001 census. Further, the infant mortality rate of Sangli district is gradually decreasing from 1989-90 to 1994-95. The urban areas are experiencing relatively higher infant mortality rate than the rural areas.

Demographic Profile of Sangli district

Table 1.3. Demographic situation over Sangli district

Density	301
Area	2.79% of Maharashtra
Sex Ratio	957 (10th rank)
Literacy	76.70(15th rank)
Range of Female Literacy	60% and above
Literate Female Per 100 Literate Males	75
Total Population	2581835
Males Population	1319267
Female Population	1262568
Percentage Decadal Growth Rate	16.85
Male Literacy	86.25
Female Literacy	66.88

1.5 Evolution of HIV/AIDS in Sangli district

Sangli is one of the most vulnerable districts of Maharashtra state with respect to the HIV/AIDS pandemic. As mentioned earlier, out of the total cases in Maharashtra, nearly one third are reported in Sangli district alone. The main factors responsible for the rapid spread of the epidemic can be attributed to the following reasons:

(i) Migrant population Because of wide range of road and rail network communications from different states, mainly from Karnataka and Andhra Pradesh and particularly from the bigger cities like Mumbai and Hyderabad, the place (Sangli) has become a centre of trade and commerce for the nearby rural areas. The poor people from the rural areas of the district and also from the neighbouring states have been migrating to the twin cities of Sangli and Miraj due to the existence of different industries and other employment opportunities.

(ii) Good economic condition: Sangli is one of the highest productive districts in agricultural production because of its good irrigational facility and irrigated lands. As a result, even the rural population of this district are socio-economically better off. In addition, a substantial proportion of Sangli population is involved in the business related to gold and jewellery and hence linked with Mumbai and Surat. Thus, business network of Sangli with cities like Mumbai and Surat, which are considered as the centres for trade and commerce, is responsible for the economic prosperity of this district. Thus, the economic prosperity of the people coupled with their mobility pattern and lack of proper knowledge regarding the mode of transmissions of HIV/AIDS creates a vulnerable environment for the spread of HIV/AIDS.

(iii) Commercial Sex Workers: The practice of commercial sex is quite common and well known in the district of Sangli. The urban areas of the district have an easy access for these kinds of practices. Most of the Commercial Sex Workers (CSWs) who are practising their profession in the red light areas of these towns are the migrants from different districts of Maharashtra and the neighbouring states like Karnataka and Andhra

CHAPTER 8: HIV/AIDS AND CHILDREN IN THE SANGLI DISTRICT OF MAHARASHTRA
(INDIA)

Pradesh. These urban areas are also having different types of industries, which accelerate the process of migration and mobility of population in the district. The Commercial Sex Workers (CSWs) are also visited by the youths from different parts of the district. The existence of commercial sex workers also found in even along the high traffic flow areas.

(iv) Devadasis: The practice of Devadasi tradition (temple prostitutes) is still prevalent in the district of Sangli. The Devadasis are the migrants from the neighbouring state especially from Karnataka. The majority of the Commercial Sex Workers (CSWs) of Miraj town are the Devadasis, who are the migrants from the neighbouring districts of Karnataka.

Table 1.4. Number of AIDS Cases in different Years according to the Age and Sex of the patient at Sangli General Hospital, Sangli.

AGE GROUP	0-6		6-14		15-19		20-29		30-39		40-49		50-59		60+		TOTAL
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F	
1992	-	-	-	-	-	-	4	3	-	-	-	-	-	-	-	-	7
1993	-	-	-	-	-	-	6	-	2	1	1	-	1	-	-	-	11
1994	-	-	-	-	-	-	3	6	3	1	1	-	-	-	-	-	14
1995	1	1	-	-	1	1	30	14	30	12	9	1	4	4	-	1	109
1996	1	-	-	3	-	4	77	32	70	16	32	7	5	1	11	1	260
1997	8	3	2	1	5	-	94	46	133	26	54	11	13	3	9	3	411
1998	14	15	7	3	1	1	61	34	118	63	53	20	19	13	8	2	432
1999	19	15	6	3	4	2	72	25	112	38	53	11	19	1	7	3	390
2000	22	18	2	5	-	9	56	45	99	53	36	12	18	2	7	3	387
TOTAL	65	52	17	15	11	17	403	205	567	210	239	62	79	24	42	13	2021

Source: General Hospital, Sangli, 2001 (Abbreviation : M = Male, F = Female)

Table 1.5. No. of AIDS deaths in different years according to their Age and Sex of the patients at Sangli General Hospital, Sangli.

AGE GROUP		0-6		6-14		15-19		20-29		30-39		40-49		50-59		60+		TOTAL
YEAR↓	SEX→	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F	
1992		-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	1
1993		-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	1
1994		-	-	-	-	-	-	1	1	1	1	-	-	-	-	-	-	4
1995		-	1	-	-	-	-	6	1	5	1	-	-	2	-	-	-	16
1996		-	-	-	1	-	-	13	7	16	2	5	2	2	-	2	-	50
1997		-	-	-	1	-	-	19	5	19	3	12	2	2	1	1	1	66
1998		-	-	-	-	-	-	15	4	13	4	2	2	-	1	-	-	41
1999		5	1	1	1	-	1	8	3	12	2	8	5	-	-	1	-	48
2000		4	4	-	1	-	-	3	5	10	4	5	2	2	-	-	-	40
TOTAL		9	6	1	4	-	1	67	26	76	17	32	13	8	2	4	1	267

Source: General hospital, Sangli, 2001. (Abbreviation : M = Male, F = Female)

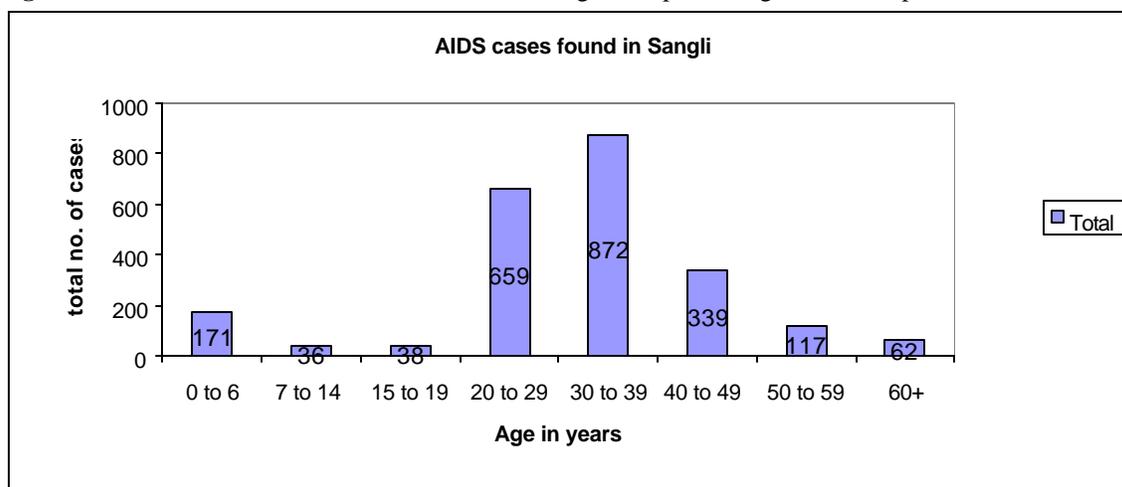
AIDS, PUBLIC POLICY AND CHILD WELL-BEING

Table 1.6. HIV/AIDS Profile Of Sangli District

REPORTS FROM Z.B.T.C. SANGLI										
Showing the No. of and percentage of HIV Positive cases found from the screening of the blood Bottles collected since Feb. 92 upto Oct.2001.										
Year	Feb 92 to Dec 92	1993	1994	1995	1996	1997	1998	1999	2000	Oct-01
Total No. of blood units screened	10476	12828	15192	16368	15716	18085	19051	20960	29006	26295
HIV reactive	200	346	657	528	486	723	592	548	572	422
Reactive percentage	1.9	2.8	4.32	3	3	3.8	3.1	2.6	2	1.6

Source: Zilla Blood Testing Centre, Sangli

Figure 1.1. Total No. AIDS cases found in different Age Groups in Sangli District, up to Oct. 2001



The younger Age group specially 20 to 39 years is more affected.

Table 1.7. Year wise No. of Ante-Natal cases Screened, HIV positive found and there percentage of positivity in Sangli.

Years	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
No. of ANC's Screened	228	27	45	1317	1668	1811	2176	3154	3024	2268
No. of ANC's positive	9	7	1	57	85	96	132	166	142	91
Percentage found positive	3.9	25.9	2.2	4.3	5	7.2	6	5.3	4.7	4

Source: General hospital, Sangli, 2001.

Table 1.8. Year wise prevalence of HIV positive cases in STD Clinic Attainers

Year	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
No. of Attainers	200	74	191	600	986	632	766	609	726	598
No. of HIV positive	13	23	76	224	426	542	361	268	302	236
Percentage	6.5	31.8	37.8	37	50.36	85.75	47.43	44.6	41.6	39.45

Source: General hospital, Sangli, 2001

Figure 1.2 Percentage of HIV positive cases in STD clinic attendees

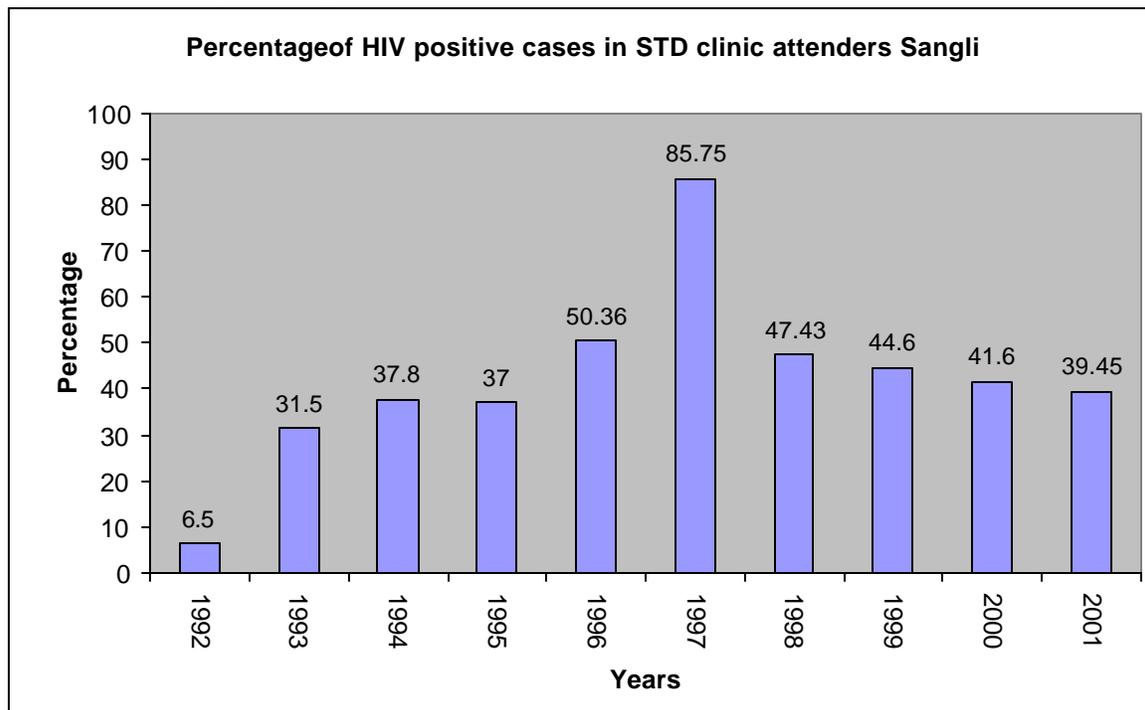


Table 1.9. No. of AIDS cases in Sangli district according to sex up to October 2001

No of AIDS cases upto oct. 2001		
Males	1621	70%
Female	689	30%

1.6 Mortality situation in Sangli district

The proportion of adult deaths has been continuously increasing after 1991 in urban as well as rural areas of Sangli except 1993 in rural Sangli. However, these proportions for the deaths in the age group 15 to 64 do not reflect any definite trend. Though the likelihood of indulging into higher risk behaviour was reported among young adults in Sangli, the existing trend may be resulted due to the incubation period associated with convergence of HIV infection into AIDS. The proportion of urban male deaths is gradually increasing over a period 6 years. However, the pattern in the proportion of male deaths in rural areas does not reflect the same pattern. Increasing trend in male deaths in urban areas of Sangli needs to be examined thoroughly and it should be responded programmatically without any further delay.

It is expected that increasing proportion of adult deaths may result in increasing number of orphans, which in turn may affect the schooling of children on one hand and changing composition of labour force on the other. If this process began, females/girls are likely to be the first victim of dropping from schools.

2. Basic indicators of maternal and child wellbeing in Sangli district

2.1 Maternal and Child Health

Looking at the status of maternal and child health services and their utilisation in Sangli district, it is found that about 96 percent of women had access to ANC care services, out of these 60 percent had availed full ANC consisting of two tetanus toxoid injections, iron and folic acid tablets and at least three antenatal check ups. This implies that although the general awareness about ANC was high among women, compliance was relatively lower. There is a need to motivate women to ensure the complete ANC. About 41 percent of women had one or more complications during pregnancy and for the majority of the women, the private doctors had been the primary source of treatment. Although home deliveries were relatively more in rural areas (37 percent) than the urban areas (11 percent), 76 percent of the deliveries were conducted by using disposable kit. This shows that the safe motherhood concept of aseptic delivery has been effectively propagated. About the 26 percent of women developed post delivery complications and almost three-fourth of them had sought treatment for their complications. Immunization coverage among the children was very high (87 percent).

2.2 Family Planning

The contraceptive prevalence rate was found to be 63 percent, with not much of urban-rural discrepancy. Permanent method (59 percent) was more widely accepted than spacing method (4 percent). This calls a serious promotion of spacing methods. Promotion of family planning methods by health workers was significantly low (4 percent) thus urging the need to address the situation through the training programs for health workers, especially in terms of strengthening their counselling and motivational skills.

2.3 Utilization of government health services

The health programs are almost oblivious to the health needs of adolescent girls. Barely 13 percent of the adolescent girls were catered by the health workers, who provided the girls with IFA tablets. Only 13 percent of the women had approached government health facilities, hinting the preference for private health services.

2.4 Knowledge and prevalence of RTI/STI and HIV/AIDS

The awareness of RTI was very low (28 percent among males and 12 percent among females). More males (45 percent) were aware of STI compared women (12 percent). Although awareness of HIV/AIDS was high among both males and females, the percent of respondents having misconceptions about HIV/AIDS was 29 percent and 35 percent amongst males and females respectively. Most of the people had sought treatment for RTI from private doctors.

CHAPTER 8: HIV/AIDS AND CHILDREN IN THE SANGLI DISTRICT OF MAHARASHTRA
(INDIA)

Table 2.1. Percent of Eligible Women who have the knowledge of RTI, STI and HIV/AIDS.

Percentage of eligible women who were aware of			
Reproductive Track Infections	11.5	11.1	12.7
Sexually Transmitted Infection	12.0	10.8	15.8
HIV/AIDS	85.5	83.7	91.2
Percentage of males age 20-54 having knowledge of			
Reproductive Track Infections	27.8	28.6	25.0
Sexually Transmitted Infection	44.9	44.1	47.5
HIV/AIDS	95.6	95.4	96.2

Source: RCH-RHS survey, 1998.

2.5 Educational achievement

Figure 2.1. Enrolment pattern of primary school students in Sangli district.

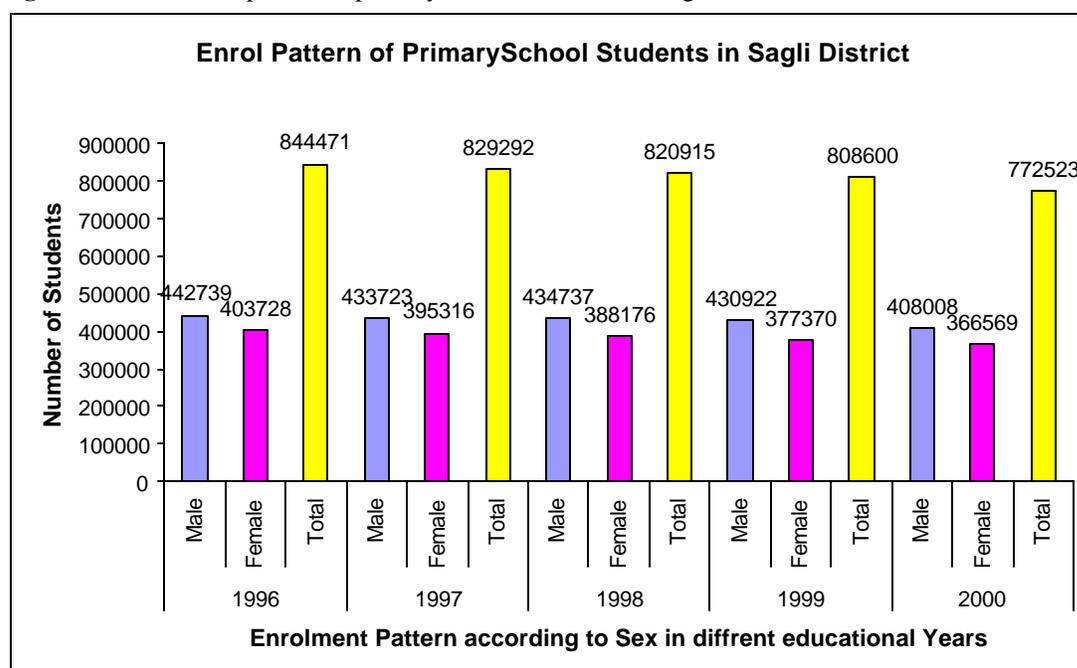


Table 2.2. Enrolment pattern of Secondary School students in different years according to their sex in Sangli district.

Year	1989	1990	1991	1992	1993	1994
Males	96029	98213	101422	101829	104808	109278
Females	57412	61485	65749	69640	75075	80175
	1995	1996	1997	1998	1999	
Males	112661	116541	119345	121418	128423	
Females	85695	90545	94508	97901	108925	

The enrolment of primary students in Sangli district points to a declining trend for both boys and girls over the period 1996-2000. In contrast the secondary school's enrolment has increased over the period of time irrespective of sex. How much of the decline is the result of adult deaths, impoverishment or other AIDS related factors is a matter of further investigation.

2.6 Child health indicators

(i) Weight of newborn

Weight is an important indicator of child health. Normally a newborn should have a weight of 2.5 kgs. It was reported that 82 percent of babies in urban areas were weighed at the time of their birth, while nearly 63 percent of the babies were weighed in rural areas as reported by their mothers. Of these babies, around 37 percent (34 percent in rural areas and 38 percent in urban areas) were below normal weight (less than 2.5 kgs), indicating that existing child welfare programme in both rural as well as urban areas require proper attention as it has a definite link with the existing levels of infant and child mortality.

(ii) Immunization

The universal immunization programme (UIP) continues to provide vaccination against six preventable child diseases viz., polio, TB, Diphtheria, Pertussis, TT and Measles. The outlined objective of the ninth five-year plan was to achieve 100 percent coverage of all these vaccines for all the infants in India by the year 2000. In order to understand the immunization coverage among the children, all the children born between Jan 95 to Jun 97 were covered under the RHS survey. The data shows that the immunization coverage was almost universal in SANGLI district as there were very few children who were not immunized.

Table 2.3. Immunization status of children:

PARTIALLY IMMUNIZED	49
FULLY IMMUNIZED	40
NOT AT ALL IMMUNIZED	11

Source : RHS-RCH survey 1998-99.

Immediately after birth the baby is given one drop of the polio oral vaccine, which is known as Zero polio. In this district more than 80 percent of babies had received zero polio vaccine. The proportion of babies who received all doses of BCG, three doses of DPT and Polio each and protected against Measles was 97 percent, 96 percent, 96 percent and 92 percent respectively. Percentage of children protected by all vaccines was 87 percent. This shows that even in rural Sangli coverage of immunization is on the better side. The data suggest that Polio “0” was given more to newborn babies of urban areas and to the children of relatively better-educated mothers. Immunization coverage did not vary much by different socio economic characteristics, of the mother like residence, caste, education or type of house but it was found to be nearly 100 percent for the babies of higher educated mothers.

Survey findings of multi indicator cluster survey 97 also recorded an average of more than 95 percent of babies for full immunization in the rural areas of Sangli. Immunization coverage by sex of the child shows that percentage was slightly higher among males than

female babies. However the difference was not significant. The education of the mother was found to be an important variable in determining.

To reduce the risk of night blindness, babies are supposed to receive doses of vitamin A, every six months starting from the ninth month. Data shows that still less than 15 percent of babies were given two or more doses of vitamin A. new born are given a course of iron and folic acid tablets to reduce the risk of anaemia. How ever, it was found that very few proportion of babies of the district of Sangli were given full course of IFA tablets or liquids.

(iii) Breastfeeding and weaning practices

Table 2.4. Percent of women initiating breast-feeding in Sangli district.

1-3 Days	27
After 3 Days	33
Within 2 Hours	36
After 2 Hours but same day	5

Source: RHS-RCH Survey 1998-99.

Early initiation of breast-feeding and nutritious food has significant impact on child survival and maternal/child morbidity. WHO recommends that baby should be given breast milk immediately after the birth and the baby should be given breast milk exclusively upto 4-6 months. Afterwards, supplementary foods should be initiated.

The RCH-RHS survey results are revealing that the education is playing a key role regarding early initiation of breast-feeding, as comparatively higher proportion of educated mother had started breastfeeding immediately after birth. Fifty-three percent of the women have provided breast milk exclusively and around three fourth of them have fed the child exclusively on breast milk for four months. WHO suggests that after four months of exclusive breast milk, a child requires supplementary foods from the fifth month. At least between the 5-6 months, the baby should be given semisolid food and between the 7-12 months, the baby should receive solid food along with breast milk.

3. Impact of HIV/AIDS on families and children: evidence from the Sangli survey

The impact of HIV/AIDS adult deaths on various indicators of child well-being is presented in tables 3.1 to 3.9. Such tables present the results of a sample survey investigation carried out in Sangli in late 2001. The description of the sample and sampling procedure followed are illustrated in Annex 1. These tables provide a comprehensive comparison on various child well being indicators across three different types of households, some affected by a HIV/AIDS death, some affected by a death for other causes and some (the control group) unaffected by any death. In most cases the percentages are self-explanatory. How ever in cases, where 'N' is too small, we have given the numbers rather than percentages.

AIDS, PUBLIC POLICY AND CHILD WELL-BEING

The average *per capita income* is Rs.10705/-, which is slightly more in case of the HIV/AIDS death households than the non-HIV/AIDS deaths i.e., Rs.8638/- and with no deaths i.e., Rs.10255/-. The *percentage of the wages from the low skilled workers and high skilled workers over the total income* is less among the HIV/AIDS death households than the other households. The percent of *wages from the medium skilled workers* is slightly more in case of the HIV/AIDS household than the non-HIV/AIDS deaths and the same less compared to the households with no deaths. The *percentage of income from self-employment* is found 31 percent among the HIV/AIDS households, which is found more than other households, the non-HIV/AIDS households (30 percent) and the household with no deaths (29 percent). The *income from self-employment* is more in the HIV/AIDS households may be due to the lack of skilled persons more among the household members as the skilled person have perhaps died. The *transfers over the total income* is more in case of the death households than the households with no deaths. The income from transfers may be private gifts and public transfers, and this may be due to the loans from the community, civil society as well as from credit institutions.

Table 3.1. Main characteristics of the HH interviewed (different shades indicate different blocks of similar type indicators)

	HIV/AIDS death	Non-HIV/AIDS death	No deaths
Rural HH Interviewed (if applicable)	84	70	69
Urban HH Interviewed (if applicable)	34	30	31
Total number of HH Interviewed	118	100	100
Total number of HH members	619	499	567
% adult members over total members	40.4(250)	43.1 (215)	49.7 (282)
% elderly members over total members	18.3 (113)	14.0 (70)	9.7 (55)
% male HH members over total HH members	15.3 (259)	13.4 (226)	17.2 (290)
Average income per capita	Rs. 10705	Rs. 8638	Rs. 10255
% wages from low skilled workers over total income	17.8	22.61	18.6
% wages from medium skilled workers over total income	7.4	6.9	14.9
% wages from high skilled workers over total income	1.5	2.45	5.6
% incomes from self-employment over total income	31.0	30.2	29.2
% transfers over total income	11.2	11.7	4.5
% adult members and elderly members illiterate	12.4 (77)	11.2 (56)	11.1 (63)
% adult members and elderly members with primary education level	11.9 (74)	8.8 (44)	10.8 (61)
% adult members and elderly members with secondary education level	18.9 (117)	19.63 (98)	24.33 (138)
% adult members and elderly members with higher education level	9.04 (56)	7.61 (38)	7.93 (45)
% HH with no land *	45.8	41.0	49.0
% HH with no animals *	47.5	41.0	25.0
% HH not owning the house where they live	16.9 (20)	15.0 (15)	46.0 (46)
% HH living in a house made of non-durable material	11.0 (13)	9.0 (9)	10.0 (10)
% HH without sanitation in the house	74.5 (88)	70.0 (70)	67.0 (67)
% HH with no vehicles	63.5 (75)	40.0 (40)	19.0 (19)
% HH with no production tools	95.8 (113)	57.0 (57)	51.0 (51)
% HH with no consumer durable	39.0 (46)	26.0 (26)	11.0 (11)
% HH playing no social, community, or economic roles			
% HH playing no political or religious roles			

CHAPTER 8: HIV/AIDS AND CHILDREN IN THE SANGLI DISTRICT OF MAHARASHTRA
(INDIA)

The *percentage of illiterates* (12.4 percent) is more among the HIV/AIDS deaths households than the non-HIV/AIDS households (11.2 percent) and the households without deaths (11.11 percent). Majority of the adult and elderly members are found with *secondary level education* in all the three types of households. The percent of the *adult and elderly members with primary education* is ranging from 11 to 12 percent and for *with higher education level* it ranges from 8 to 9 percent.

Table 3.2. Summary statistics of the HH sampled

	HIV/AIDS death	Non-HIV/AIDS death	No deaths
1. N. HH with the head being illiterate	17	13	13
2. N. HH with the head having a primary or secondary education level	88	75	75
3. N. HH with the head having a higher education level	13	12	12
4. N. HH with land *	19	36	29
5. N. HH with low income level	34	34	12
6. N. HH with medium income level	67	58	75
7. N. HH with high income level	17	8	13
8. N. HH having allocated a small Average Daily Time to child care	45	56	60
9. N. HH having allocated a medium Average Daily Time to child care	33	19	23
10. N. HH having allocated a large Average Daily Time to child care	40	5	17
11. N. HH having not received any type of help	19	17	26
12. N. HH having received help from the government	27	29	27
13. N. HH having received help from the civil society (NGO or religious organisations)	23	20	14
14. N. HH having received help from the community (extended family, neighbourhoods or CBO)	88	72	57
15. N. HH having received old age pensions from the government	6	6	4
16. N. HH having received unemployment compensations from the government	0	1	0
17. N. HH having received orphan/child allowances from the government	0	3	1
18. N. HH having received disability allowances from the government	1	1	0
19. N. HH having received other transfers from the government	5	3	1
20. N. HH having received credits from the government	14	14	18
21. N. HH having received transfers from the government	3	3	4
22. N. HH having received food from the government	3	1	4
23. N. HH having received other help in kind from the government	4	2	0
24. N. HH having received jobs from the government	1	0	0
25. N. HH having received other forms of help from the government	1	5	0

Forty-six percent of the households have *no land* and 47.5 percent households have *no animals* among the HIV/AIDS deaths households. Nearby about 17 percent of the HIV/AIDS deaths households, 15 percent of non-HIV/AIDS deaths households and 46 percent of no death households do not *own the house where they are living*. Eleven percent of the HIV/AIDS death households are living in the *houses made by non-durable material*, which is slightly more than the non-HIV/AIDS households (9 percent) and the households with no deaths (10 percent). Seventy-five percent of the HIV/AIDS death households *have no sanitation facilities in their houses*, which slightly higher than the other households as 70 percent of the non-HIV/AIDS death households and 67

percent among the no death households. Nearly 64 percent of the HIV/AIDS death households do *not have any vehicles* as against 40 percent of non-HIV/AIDS death households, and 19 percent in case of no death households. Approximately 96 percent of the HIV/AIDS death households *have no production tools* where as the same is around 50 percent in other type of households. Nearly 39 percent of the HIV/AIDS death households *have no consumer durables* is also higher as compared to the other two types of households as (26 percent in case of non-HIV/AIDS death households and 11.0 percent in case of no death households). The reason for *not having the production tools and consumer durables* may be due to the sale of those assets to reduce the economic burden of the households due to the high treatment costs of HIV/AIDS. The percent of the households with *no land and animals* are more among the HIV/AIDS death households than the non-HIV/AIDS death households, may be again due to the high treatment cost of HIV/AIDS than the other illnesses and specially when the incubation period is quite long.

Table 3.3. Indicators of child well-being by HH with a HIV/AIDS-related death, HH with a non HIV/AIDS disease-related death and HH with no deaths (apart from the orphan rate, all total figures could be meaningfully split into male and female figures in case of perceived gender discrimination)

	HIV/AIDS death	Non-HIV/AIDS Death	No deaths
N. children (CM) in the HH (1)	256	214	230
N. male children (CM) in the HH (2)	126	116	124
% orphan CM (over total CM in the HH) (orphan rate)	55.85 (143)	56.54 (121)	1.30 (3)
% CM (over total CM in the HH) who died due to any cause during the period of observation (death rate) (3)	0.78 (2)	0	0
% CM (over total CM in the HH) being sick due to any disease during the period of observation (diseases prevalence rate) (4)	57.8 (148)	63.04 (135)	59.6 (137)
% CM (over total CM in the HH) being unable to visit an health care centre when in need of essential health care services	25.39 (65)	17.75 (38)	8.69 (20)
% CM (over total CM in the HH) withdrawn from school	4.3 (11)	4.7 (10)	2.61 (6)
% CM (over total CM in the HH) being discriminated against for any reason (6)	20.1 (53)	2.80 (6)	3.50 (8)

Table 3.3 reveals some important indicators of child well being by households with a HIV/AIDS related death, non-HIV/AIDS related death and households with no death.

It is evident from the table that out of total *number of 700 children*, 256 children were in the HIV/AIDS deaths household, 214 children in the non-HIV/AIDS deaths households and 230 children in the no deaths households. The sex differentials in the number of children does not vary significantly in the three categories of the households. It is important to observe that 143, 121 and 3 among them in three categories of the households respectively were the orphans, (the children who lost their mother or both parents of age up to fifteen years) and hence as expected the proportion of the orphan children was extremely high in HIV/AIDS deaths households. The orphan rate is around 56 percent in both HIV/AIDS and non-HIV/AIDS deaths household. *Percentage of the*

child members (over the total child members) who died due to any cause during the period of observation was almost negligible. However, the *Percentage of the child members (over the total child members in the household) being sick due to any disease during the period of observation (disease prevalence rate)* was vary high with 57.8 percent (143 children) in HIV/AIDS deaths households, 63 percent (135 children) in non-HIV/AIDS deaths household and 59.6 percent in the households with no deaths. The disease prevalence rate is almost similar in all three types of households and hence there is a no reason to expect excess morbidity among the children due to HIV/AIDS. However *the percentage of the child members (over the total child members in the household) being unable to visit an health care centre when in need of essential health care services* is 25 percent in HIV/AIDS deaths households a considerably higher proportion than the non-HIV/AIDS households (17.8 percent) and the third category of households (8.7 percent). This may be due to the lack of money or lack of time among the adult members as they might have engaged in other activities or may be due to the existing discrimination by the health providers. Irrespective of the possible reasons for the lack of access to health facility, there is an urgent need to initiate the programmatic responses to minimise the morbidity impact. *The percentage of the child members (over the total child members in the household) with drawn from the school* is more than four percent in the HIV/AIDS deaths households and only 2.6 percent in households of non-HIV/AIDS deaths. It was amply evident in our qualitative assessment that schools were not responsible for these dropouts but the parents themselves asked a substantial proportion of such children to discontinue their studies. *The percentage of the child members (over the total child members in the household) being discriminated against for any reason* is 20.1 percent in case of HIV/AIDS deaths households, which is many fold higher than the same among children in the other households.

AIDS, PUBLIC POLICY AND CHILD WELL-BEING

Table 3.4. Indicators of child wellbeing by HH with a HIV/AIDS-related death, HH with a non HIV/AIDS disease-related death and HH with no deaths and by the education levels of the head of the HH (apart from the orphan rate, all total figures could be meaningfully split into male and female figures in case of perceived gender discrimination)

	HIV/AIDS death			Non-HIV/AIDS death			No deaths		
	Illiterate	Primary Secondary	Higher	Illiterate	Primary Secondary	Higher	Illiterate	Primary Secondary	Higher
N. children (CM) in the HH (1)	47	177	32	26	169	19	30	183	17
N. male children (CM) in the HH (2)	21	90	15	14	88	10	15	95	14
% orphan CM (over total CM in the HH) (orphan rate)	48.9 (23)	63.8(113)	21.99 (7)	42.3 (11)	56.2 (95)	79.0 (15)	6.7 (2)	0.05 (1)	0
% CM (over total CM in the HH) who died due to any cause during the period of observation (death rate) (3)	0	1.1 (2)	0	0	0	0	0	0	0
% CM (over total CM in the HH) being sick due to any disease during the period of observation (diseases prevalence rate) (4)	36.2 (17)	63.3 (112)	59.4 (19)	80.8 (21)	65.1 (110)	63.2 (12)	56.7 (17)	60.11 (110)	58.8 (10)
% CM (over total CM in the HH) having worked during the period of observation	19.2 (9)	9.6 (17)	3.1 (1)	15.4 (4)	16.0 (27)	10.5 (2)	20.0 (6)	15.85 (29)	5.9 (1)
% CM (over total CM in the HH) being unable to visit an health care centre when in need of essential health care services	42.6 (20)	39.6 (70)	15.6 (5)	26.92 (7)	32.5 (55)	36.8 (7)	40.0 (12)	7.10 (13)	0
% CM (over total CM in the HH) withdrawn from school	2.1 (1)	5.7 (10)	0	7.7 (2)	4.7 (8)	0	3.3 (1)	2.73 (5)	0
% CM (over total CM in the HH) being discriminated against for any reason (6)	0	20.3 (36)	40.6 (13)	3.8 (1)	3.0 (5)	0	6.7 (2)	3.28 (6)	0

Table 3.4 presents the distribution of some selected indicators of child well being among HIV/AIDS death households, non-HIV/AIDS deaths households and no death households, by the education levels of the head of the households.

The education of head of the household is an important factor influencing the overall development of children in terms of providing them with better education as well as health care. It is clearly evident from the table that *Percentage of child being sick due to any disease during the period of observation* is higher, primary and secondary education levels of the head of the households in case of HIV/AIDS deaths households than the other type of households, whereas the disease prevalence rate is very low among HIV/AIDS death households whose head is illiterate. It is difficult to explain the appropriate causes for such a variation on the basis of the existing analysis. *Percentage of child members having worked during the period of observation* is more in case of the HIV/AIDS households whose head is illiterate than those households whose head is having the education level of primary and secondary and higher. In other categories of households the difference is not very sharp. *Percentage of child members being unable to visit the health care centre when in need of essential health care services* high among the HIV/AIDS households whose head is illiterate and having the education level of primary and secondary than the non-HIV/AIDS households. *Percentage of child members withdrawn from the school* is again more in the case of the HIV/AIDS households whose head is having the education level of primary and secondary than the non-HIV/AIDS households. *Percentage of child members being discriminated against for any reason* is too high among the households of HIV/AIDS whose head of the household is having the higher level of education than the households whose head is having the education level of primary and secondary education level. *Percentage of child members (over the total child members in the household) being discriminated against for any reason* can be observed even in the households of non-HIV/AIDS but it is quite less compared to the HIV/AIDS households. Overall, it appears that the impact of HIV/AIDS is more severe in case of illiterate households, particularly in terms of seeking health care services. In higher educational categories, HIV/AIDS seems to have more negatively impacted upon the continuity of children in to schools, and perceived discrimination.

AIDS, PUBLIC POLICY AND CHILD WELL-BEING

Table 3.5. Indicators of child wellbeing by HH with a HIV/AIDS-related death, HH with a non HIV/AIDS disease-related death and HH with no deaths and by income levels of the HH (apart from the orphan rate, all total figures could be meaningfully split into male and female figures in case of perceived gender discrimination)

	HIV/AIDS death			Non-HIV/AIDS death			No deaths		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
N. children (CM) in the HH (1)	70	138	48	60	127	27	21	177	24
N. male children (CM) in the HH (2)	33	73	20	31	69	16	11	95	18
% orphan CM (over total CM in the HH) (orphan rate)	82.9 (58)	48.6 (67)	37.5 (18)	68.3 (41)	56.7 (72)	29.4 (8)	0	1.13 (2)	4.2 (1)
% CM (over total CM in the HH) who died due to any cause during the period of observation (death rate) (3)	0	1.5 (2)	0	0	0	0	0	0	0
% CM (over total CM in the HH) being sick due to any disease during the period of observation (diseases prevalence rate) (4)	45.7 (32)	56.5 (78)	79.2 (38)	41.7 (25)	71.7 (91)	70.4 (19)	57.1 (12)	58.2 (103)	91.7 (22)
% CM (over total CM in the HH) having worked during the period of observation	15.7 (11)	10.8 (15)	2.1 (1)	26.7 (16)	12.6 (16)	3.7 (1)	9.5 (2)	16.4 (29)	20.8 (5)
% CM (over total CM in the HH) being unable to visit an health care centre when in need of essential health care services	51.4 (36)	31.2 (43)	33.3 (16)	35.0 (21)	32.3 (41)	25.9 (7)	47.6 (10)	7.9 (14)	4.2 (1)
% CM (over total CM in the HH) withdrawn from school	7.1 (5)	2.9 (4)	4.2 (2)	4.2 (4)	4.7 (6)	0	0	2.8 (5)	4.2 (1)
% CM (over total CM in the HH) being discriminated against for any reason (6)	24.3 (17)	13.0 (18)	29.2 (14)	0	4.7 (6)	0	0	4.5 (8)	0

Table 3.5 presents the distribution of some selected indicators of child well being in three types of households by income levels of the households

It is evident from the table that the orphan rate among the HIV/AIDS death households in all income levels is higher than the non-HIV/AIDS households except in the case of middle-income level where the orphan rate is more in non-HIV/AIDS households. The *orphan rate* is nearly 83 percent in low-income group of HIV/AIDS households, where as, it is around 57 percent in the non-HIV/AIDS household.

The gradual decrease in the *orphan rate* can be observed as the income level increases. One can comprehend from the above that the HIV/AIDS mortality is indirectly proportional to the income level of the household. The high *disease prevalence rate* among children in all three types of households observed is irrespective of income levels. *Percentage of child members being unable to visit the health care centre when in need of essential health care services* is more than 50 percent in low income level of HIV/AIDS death households, where as, it is around 35 percent in non-HIV/AIDS and 47 percent in the households of no deaths. The *Percentage of child members being unable to visit the health care centre when in need of essential health care services* is more than 30 percent in the middle income level households of both HIV/AIDS and non-HIV/AIDS households. The same is the case of HIV/AIDS households of high-income level in the deaths households. The existence of high *disease prevalence rate* and the *percentage of the child members being unable to visit the health care centres* are alarming and the need point for enhancing accessibility of the healthcare facilities for the children in Sangli district. Percentage of child members having worked during the period of observation shows a declining trend as the income level of the households increases both in the case of HIV/AIDS deaths and non-HIV/AIDS deaths households. *Percentage of the child members with drawn from the school* is also more in the case of HIV/AIDS deaths households in all income levels compared to the non-HIV/AIDS deaths and households with no deaths. It is important to mention that the proportion of such children is high among the households of low-income level than the medium and high in case of HIV/AIDS deaths households. The *percentage of the child members being discriminated against for any reason* is higher at the both ends of income level. This shows that income level of households does not have any impact on the social discrimination in case of households experienced HIV/AIDS deaths during the specified reference period.

In sum, 4 indicators of child wellbeing out of 6 covariate with the level of income, indicating that low-income is -*ceteris paribus* – a factor that compound the impact of HIV/AIDS on children. Only stigmatisation and child morbidity seem to be invariant in relation to income.

Table 3.6. Type of coping strategies adopted by HH with an HIV/AIDS-related death, HH with a non-HIV/AIDS disease-related death and HH with no deaths.

	HIV/AIDS death	Non-HIV/AIDS death	No deaths
Sustainable coping strategies			
% HH having reduced savings	63.0 (74)	51.0 (51)	36.0 (36)
% HH having reduced needed investments (1)			
% HH having reduced expenditures on consumer durables	12.7 (15)	10.0 (10)	8.0 (8)
% HH having sold non-productive assets (jewellery, other non-essential items)	14.4 (17)	10.0 (10)	4.0 (4)
% HH having increased the Average Daily Time for productive activities (2)	73.7 (87)	81.0 (81)	67.0 (67)
% HH having reduced the Average Daily Time for family and other activities (3)	72.0 (85)	81.0 (81)	63.0 (63)
Partially sustainable coping strategies			
% HH with members having out-migrated in search of distant work opportunities	10.2 (12)	9.0 (9)	11.0 (11)
% HH having placed children with distant families	5.1 (6)	0	3.0 (3)
% HH with a member having left his/her job to care for sick HH members	3.38 (4)	0	0
Unsustainable coping strategies			
% HH having increased incomes from sale of assets (1)	22.0 (26)	21.0 (21)	23.0 (23)
% HH having reduced expenditures on essential food	54.2 (64)	44.0 (44)	5.0 (5)
% HH with children withdrawn from school	7.6 (9)	8.0 (8)	4.0 (4)
% HH with members having foregone visits to health care centres when in need of essential health care services	64.4 (76)	55.0 (55)	28.0 (28)
Total number of households	118	100	100

3.1 Coping strategies

A measure of the impact of HIV/AIDS on the wellbeing of children and of the households is also given by the survival strategies they adopt to smooth the shock of AIDS. While some of these policies are sustainable over the long term and do not induce any negative change in child wellbeing, other strategies can entail considerable costs for the children of the household affected. Table 3.6 hereafter presents the types of coping strategies adopted by the households with a HIV/AIDS-related death, households with a non-HIV/AIDS disease-related death and households with no deaths.

Households with an HIV/AIDS deaths adopted more frequently sustainable coping strategies than the non-HIV/AIDS households and the households with no deaths (reduced household savings, reduced households *expenditures*, on consumer durables and sold non-productive assets (jewellery, other non-essential items)). No perceptible difference is evident in the case of changes in time use patterns.

Greater HIV/AIDS death household also experienced out migration in search of distant work opportunities, placed their children with distant families and allocated time to care for a sick household member compared to the control group.

AIDS affected families also appear to have adopted more frequently than the control group strategies such as reducing expenditures on essential food and – to a lesser extent – withdrawing children from school.

AIDS, PUBLIC POLICY AND CHILD WELL-BEING

Table 3.7. Type of coping strategies adopted by HH with a HIV/AIDS-related death, HH with a non HIV/AIDS disease-related death and HH with no deaths according to the education level of the head of the HH

	HIV/AIDS death			Non-HIV/AIDS death			No deaths		
	Illiterate	Primary Second ary	Higher	Illiterate	Primary Second ary	Higher	Illiterate	Primary Secondary	Higher
Sustainable coping strategies									
% HH having reduced savings	76.5 (13)	60.2 (53)	61.5 (8)	38.5 (5)	56.0 (42)	33.3 (4)	30.8 (4)	37.8 (28)	30.8 (4)
% HH having reduced needed investments (1)	47.1 (8)	56.8 (50)	69.2 (9)	53.9 (7)	57.3 (43)	58.3 (7)	0	35.1 (26)	38.5 (5)
% HH having reduced expenditures on consumer durables	17.7 (3)	16.4 (10)	15.4 (2)	7.7 (1)	9.3 (7)	16.7 (2)	0	9.5 (7)	7.7 (1)
% HH having increased the Average Daily Time for productive activities (2)	58.8 (10)	77.3 (68)	69.2 (9)	76.9 (10)	82.7 (62)	75.0 (9)	69.2 (9)	67.6 (50)	61.5 (8)
% HH having reduced the Average Daily Time for family and other activities (3)	76.5 (13)	69.3 (61)	46.2 (6)	61.5 (8)	77.3 (58)	66.7 (8)	61.5 (8)	63.5 (47)	69.2 (9)
% HH with members having out-migrated in search of distant work opportunities	23.5 (4)	8.0 (7)	7.7 (1)	0	10.7 (8)	8.3 (1)	38.5 (5)	6.8 (5)	7.7 (1)
% HH having placed children with distant families	5.9 (1)	5.7 (5)	0	0	0	0	23.1 (3)	0	0
% HH with a member having left his/her job to care for sick HH members	17.7 (3)	1.1 (1)	0	0	0	0	0	0	0
Unsustainable coping strategies									
% HH having increased incomes from sale of assets (1)	11.8 (2)	22.7 (20)	30.7 (4)	15.4 (2)	20.0 (15)	33.3 (4)	23.1 (3)	21.6 (16)	30.8 (4)
% HH having reduced expenditures on essential food	58.8 (10)	52.3 (46)	61.5 (8)	46.2 (6)	44.0 (33)	41.7 (5)	23.1 (3)	2.7 (2)	0
% HH with children withdrawn from school	5.9 (1)	10.2 (9)	0	15.4 (2)	9.3 (7)	0	7.7 (1)	5.4 (4)	0
% HH with members having foregone visits to health care centres when in need of essential health care services	58.8 (10)	68.2 (60)	46.2 (6)	61.5 (8)	54.7 (41)	50.0 (6)	76.9 (10)	24.3 (18)	0

The coping strategies adopted by households with a HIV/AIDS-related death, a non-HIV/AIDS related death and no deaths seem to vary little according to the education level of the head of the household (this may be due to the fact that when we divide the households according to different levels education for different coping strategies, the number of households becomes too small to provide the meaningful comparison). In any case, it appears (evidence not shown) that the household headed by an illiterate person revert somewhat more frequently to measure such as the reduction of savings, reducing time allocated to family activities placed children with distant relatives and caring for sick relatives.

In contrast the households with higher education level seem to have adopted different strategies for coping which are of both sustainable and partially sustainable nature, compared to the illiterate category. A larger proportion of them has reduced savings, increased time in productive work, reduced expenditure and reduced investment. Altogether the differences are not, however, very pronounced.

AIDS, PUBLIC POLICY AND CHILD WELL-BEING

Table 3.8. Type of coping strategies adopted by HH with a HIV/AIDS-related death, HH with a non HIV/AIDS disease-related death and HH with no deaths according to the asset position of the HH. In case of urban households, please measure their asset position by using appropriate asset categories (housing, productive assets, urban land, other assets)

	HIV/AIDS deaths		Non-HIV/AIDS deaths		No deaths	
	No Assets (18)	Land (64)	No Assets (15)	Land (58)	No Assets (5)	Land (50)
Sustainable coping strategies						
% HH having reduced savings	55.6 (10)	67.2 (43)	60.0 (9)	54.0 (31)	60.0 (3)	42.0 (21)
% HH having reduced needed investments (1)	44.4 (8)	64.1 (41)	60.0 (9)	77.5 (45)	0.0 (0)	36.0 (18)
% HH having reduced expenditures on consumer durables	11.1 (2)	12.5 (8)	13.3 (2)	12.1 (7)	0.0 (0)	8.0 (4)
% HH having increased the Average Daily Time for productive activities (2)	83.3 (15)	75.0 (48)	86.7 (13)	82.7 (48)	60.0 (3)	70.0 (35)
% HH having reduced the Average Daily Time for family and other activities (3)	77.8 (14)	68.8 (44)	86.7 (13)	82.7 (48)	60.0 (3)	66.0 (33)
Partially sustainable coping strategies						
% HH with members having out-migrated in search of distant work opportunities		11.0 (7)	6.7 (1)	12.1 (7)	40.0 (2)	8.0 (4)
% HH having placed children with distant families	5.6 (1)	6.3 (4)	0.0 (0)	0.0 (0)	0.0 (0)	2.0 (1)
% HH with a member having left his/her job to care for sick HH members	0.00 (0)	3.1 (2)	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)
Unsustainable coping strategies						
% HH having increased incomes from sale of assets (1)	(0)	18.8 (12)	6.7 (1)	31.0 (18)	20.0 (1)	30.0 (15)
% HH having reduced expenditures on essential food	72.2 (13)	45.3 (29)	40.0 (6)	46.6 (27)	0.0 (0)	4.0 (2)
% HH with children withdrawn from school	0.00 (0)	9.3(6)	6.7 (1)	12.1 (7)	0.0 (0)	4.0 (2)
% HH with members having foregone visits to health care centres when in need of essential health care services	72.2 (13)	51.6 (33)	60.0 (9)	53.5 (31)	40.0 (2)	22.0 (11)

Table 3.8 presents the *type of coping strategies adopted by HH with a HIV/AIDS-related death, HH with a non-HIV/AIDS disease-related death and HH with no deaths according to the asset position of the HH*. In case of urban households, please measure their asset position by using appropriate asset categories (housing, productive assets, urban land, other assets):

It is clearly evident from the table that the HIV/AIDS households and the households with no deaths, which are having land, reduced savings as well as needed investments along with reduced expenditures on consumer durables than the households, which have no assets. Among the HIV/AIDS households, the *percentage of the households having increased average daily time for productive activities* is more in the households, which have no assets than the households, which are having land. The percentage of the households having reduced the average daily time for family and other activities is high among the households of which have no assets than the households, which are having the land both in the household of HIV/AIDS death and non-HIV/AIDS death, and the same is reverse in households with no deaths.

Among the partial coping strategies, more than 10 percent of the HIV/AIDS deaths households, which are having land experienced out-migration and in the households of no deaths 40 percent of the households, which have no assets, experienced the out migration. The *percentage of the households having placed children with distant families* can be noticed only among HIV/AIDS households and the households, which are having land (6.25 percent), which is higher than the households, which have no assets (5.56 percent). The *percentage of the households with a member having left their job to care for sick household members* can be observed only in the households which are having land among HIV/AIDS households.

As would be expected, in all three categories, an higher proportion of households that have land have sold out assets to increase the income. However the fact that a high proportion of no death households have also sold out assets implies that at this stage of epidemic the impact is not visible on selling of lands. The percentage of the households which reduced the expenditures on essential food is 72 percent among the households with no land which is higher than the households which are having land. The percentage of the households that have withdrawn children from the school is also more among the households, which are having land than the households, which have no assets in all types of households, but it is more among the deaths households than the no deaths households. The percentage of the households *with members having fore gone visits to health care centres when in need of essential health care services* is 72 among no land HIV/AIDS death households. *The households with no assets have high percentage of the households with members having fore gone visits to health care centres when in need of essential health care services in case of non-HIV/AIDS and the households with no death also.* Overall, asset (land or no land) does not seem to have clear relation ship with the coping strategy at this stage of epidemic. One visible impact however is on the withdrawal of the children from school, the incidence of which is more among households with no assets.

Similar conclusions apply to the analysis of the survival strategies adopted by families hit by an AIDS death in relation to the control group, when each of the three sub-samples is further stratified in relation to the level of income and the access to financial assistance from the community, the NGOs or the government. In particular, AIDS affected families with low income appear – as expected – to reduce more frequently than middle and high income families

AIDS, PUBLIC POLICY AND CHILD WELL-BEING

Table 3.9. Type of coping strategies adopted by HH with a HIV/AIDS-related death, HH with a non HIV/AIDS disease-related death and HH with no deaths according to the income level of the HH

	HIV/AIDS death			Non-HIV/AIDS death			No deaths		
	Low (34)	Medium (67)	High (17)	Low (34)	Medium (38)	High (8)	Low (2)	Medium (75)	High (13)
Sustainable coping strategies									
% HH having reduced savings	67.7 (23)	55.2 (37)	82.4 (14)	55.9(19)	48.3 (28)	50.0(4)	33.3 (4)	37.3 (28)	30.8 (4)
% HH having reduced needed investments (1)	41.2 (14)	56.7 (38)	88.2 (15)	55.9(19)	63.8 (37)	12.5 (1)	33.3 (4)	32.0 (24)	23.1 (3)
% HH having reduced expenditures on consumer durables	20.6 (7)	9.0 (6)	11.8 (2)	17.7 (6)	6.9 (4)	0.0 (0)	8.3 (1)	9.3 (7)	0.0 (0)
% HH having sold non-productive assets (jewellery, other non-essential items)	6	7	4	0	10	0	0	4	0
% HH having increased the Average Daily Time for productive activities (2)	73.5 (25)	74.6 (50)	70.6 (12)	88.2 (30)	77.6 (45)	75.0 (6)	50.0 (6)	65.3 (49)	84.6 (11)
% HH having reduced the Average Daily Time for family and other activities (3)	70.6 (24)	73.1 (49)	70.6 (12)	88.2 (30)	77.6 (45)	75.0 (6)	50.0 (6)	62.7 (47)	76.9 (10)
Partially sustainable coping strategies									
% HH with members having out-migrated in search of distant work opportunities	5.9 (2)	11.9 (8)	11.8 (2)	2.9 (1)	12.1 (7)	12.5 (1)	8.3 (1)	10.7 (8)	15.4 (2)
% HH having placed children with distant families	8.8 (3)	4.5 (3)	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)	8.3 (1)	2.7 (2)	0.0 (0)
% HH with a member having left his/her job to care for sick HH members	5.9 (2)	1.5 (1)	5.9 (1)	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)
Unsustainable coping strategies									
% HH having increased incomes from sale of assets (1)	11.7 (4)	22.4 (15)	41.2 (7)	5.9 (2)	25.9 (15)	50.0 (4)	0.0 (0)	29.3 (23)	7.7 (1)
% HH having reduced expenditures on essential food	67.7 (23)	50.8 (34)	41.2 (7)	58.8 (20)	39.7 (23)	12.5 (1)	16.7 (2)	2.7 (2)	7.7 (1)
% HH with children withdrawn from school	11.8 (4)	6.0 (4)	11.8 (2)	11.8 (4)	8.6 (5)	0.0 (0)	0.0 (0)	5.3 (4)	7.7 (1)
% HH with members having foregone visits to health care centres when in need of essential health care services	76.5 (26)	61.2 (41)	52.9 (9)	64.7 (22)	50.0 (29)	50.0 (4)	50.0 (6)	26.7 (20)	15.4 (2)

the consumption of consumer durables, health services and even essential food, or to have placed their children with relatives (table 3.9). In contrast, there is no perceptible difference of survival strategies adopted depending on the availability of financial help from the local community, NGOs or the government, most likely because of the limited value of such assistance

4. Community and district interventions to prevent HIV/AIDS in Sangli district

4.1 Programmatic Response

The rapid spread of HIV/AIDS epidemic in Sangli district during the last decade has reached an alarming stage for targeted intervention to restrict the further spread of this epidemic in the general population. In early 1990s the disease was prevalent among the high-risk population like the *Commercial Sex Workers (CSWs), Devadasis and Truck drivers*. But within a short time span it has changed its course to the rural housewives through their husbands and also among their children. As the HIV is alarming, its distribution to all blocks in the district are raising the programmatic interventions to restrict the further spread. The intervention programmes like the HIV/AIDS awareness campaign and strong IEC activities by the health department and the active involvement of NGOs in the field of controlling this epidemic is an emerging need to the public. The ongoing activities in the Sangli district can be divided in to seven categories. Theses programmes are;

- Preventive educational approaches to the general public
- Condom distribution to reduce the possible transmission from high-risk group population to the low risk population,
- Reduction of transmission from mother to child
- Treatment of STDs
- Psychological support to the infected patients and to their family members
Through counselling centres
- Control of risky behaviours.
- Anti stigma campaign

(i) Preventive educational approaches to the general public

The Maharashtra State AIDS Control Society (MSACS) is doing wide publicity to improve the awareness about HIV/AIDS among the public, but still it is far away from the target of giving complete knowledge on the exact modes of transmission of this epidemic. The superstitions and misconceptions regarding the mode of transmission of this epidemic are still prevalent among the public. Though the awareness rallies, street plays and poster display are going on in the district but hardly it is reaching to all segments of the population. The ignored segments of the population covers the migrants who are working in the sugar cane fields, industrial labourer and the general public in the rural areas. These populations do not have any access to the ongoing IEC activities carried out either by the government or by the non-governmental organizations. The street plays by the local artists through some NGOs are also restricted to the high-risk population of this area. The awareness programmes are also restricted to the students of rural

area and the out reach of the audio 'n' video display propaganda by some of the voluntary organisations is limited to few villages.

(ii) Control of risk behaviours

The wide spread practice of *Devadasis and Commercial Sex Workers* in Miraj and Sangli towns of the district and its network of rail and road transport facility accelerate the mobility of the people from rural to urban areas. This creates a vulnerable environment of indulgence of people in high-risk behaviour and spreading of HIV/AIDS in this district. The red-light areas are also attracting the youths from different parts of the district mainly from the business class and labour class (who are working in the local industries). It was reported of different levels of interaction that presence of bars/liquor shops in Sangli district as well as other nearby areas has as the main catalyst behind enhanced risk for potential infection of HIV/AIDS among young adults in the district. The practice of prostitution along the highways also attracts the truck drivers and the mobile population from different areas. The awareness activities by the Maharashtra State AIDS Control Society (MSACS) and the local nongovernmental organizations are not able to restrict the risky behaviour of these population segments.

(iii) Condom distribution to reduce the possible transmission from high-risk group population to the low risk population

Definitely there is increased concentration on condom distribution programme so that even the couples who have adopted sterilization may also adopt condom use as a part of HIV preventive measure. As a result, Sangli is a unique district where grass root workers have been trained for universal promotion of condom use as a HIV prevention method rather than a contraceptive. However, the ground level reality is not different than any other district of the stat; of course urban people were reported to have better access to free available condoms being distributed by different NGOs working for HIV prevention programme. The quality of condom available under free distribution system is another barrier in promotion of condom use. There fore a good quality social marketing programme for condom promotion is highly desirable with focus on product positioning and good quality services. It is important to mention that *Commercial Sex Workers (CSWs), Devadasis and Truck drivers* were not reported to utilize the facilities available at the civil hospital. The need of condom vendors for the clients in red-light areas and to the truck drivers along the highway were mentioned by most of the stakeholders but neither government nor the any NGO has started any intervention for the entire urban area till the date in the district.

(iv) Anti stigma Campaign

The government is trying to stimulate an anti stigma campaign related to HIV/AIDS morbidity with the help of Maharashtra State AIDS Control Society (MSACS). The local NGOs and CBOs are also actively involve in this programme and helping MSACS to achieve its goal. But still the existance of different types of misconceptions and superstitions are clearly visible irrespective of socio-cultural backgrounds of the people. Though the MSACS and local NGOs and CBOs are putting their level best to reduce the misconceptions and superstitions related to the HIV/AIDS morbidity and death, but still it is prevalent among the general public. The clear evidences of the

discriminations like; divorce, separation, and change in the family structure are found in this highly stigmatized society. Discrimination on the basis of gender and discrimination against the children and other family members are clearly visible in Sangli district. Even the discrimination by the health providers for the HIV/AIDS patients is showing a need for strengthen the anti-stigma campaign throughout the district starting from the service provider to general population.

4.2 Community-level Interventions for HIV/AIDS and Related Illnesses in Sangli District

(i) Reducing Transmission from Mother to Child

The mother to child transmission in India, which is existing in many parts of the country including in rural areas is highly under reported due to lack of clinical testing facilities. The vertical transmission is really deep rooted and the ongoing programmes are still in pilot-based in India. The AZT programme is going in Sangli district, but it is limited to only one major hospital, which cannot serve the whole population of the district particularly in rural areas. According to the NACO based pilot programme, AZT is an ongoing programme and is being provided for all the ANC attendees in the Civil Hospital, Sangli.

(ii) Voluntary testing

The voluntary testing for HIV is an ongoing service provided by the Civil hospital, Sangli. In order to make it accessible to more peoples of the district particularly to the rural population one more test centre has been established in the primary health centre, Mahisal. A very nominal charge of Rs.10/- is being charged for the voluntary test. Because of the wider publicity and the nominal examination fee the attendees for voluntary testing are increasing day by day. The counselling sessions including both pre-test counselling and post-test counselling are the plus points to attract more people for the voluntary test of HIV/AIDS.

(iii) Treatment of STDs

The availability of medical officers for treating the sexually transmitted diseases is limited only to the urban areas. The patients from the rural areas are mainly approaching the indigenous health providers rather than the government medical officers. The HIV/AIDS testing facilities are available for the attendees of STD clinics at free of cost in the Civil Hospital at Sangli. However, such facilities are not available in other hospitals/clinics in the district. As a result, the number of patients attending STD clinic at the Sangli civil hospital is continuously increasing and posing severe burden on the available infrastructure. Ofcourse one NGO is providing the treatment for the STDs in three clinics established in rural areas of the district, but the treatment for sexually transmitted diseases needs to be decentralised by developing such facilities atleast at rural hospitals in the district. Therefore the good quality integration of government and local NGOs should be promoted in order to provide condoms in the red light areas and the sites stop over of truck drivers in the near by areas. However, in order to strengthen the use of condom in general population of the district with special focus on agricultural and/or industrial labourers, a good social marketing programme should be promoted. In view of the poor outreach of the free distribution of condoms and lack of proper use even the district level family welfare officials

were of the opinion that social marketing of different brands of condom will be the best alternative for ensuring the condom promotion in this district.

4.3 Psychological support to the infected patients and to their family members through counselling centres

With the existing social discrimination to HIV/AIDS infections, the persons living with HIV/AIDS are being forced to face the isolation resulting in psychological depression. Due to this depression, it has been commonly observed in almost all areas of Sangli district that there is a change in the lifestyles of the infected persons with HIV/AIDS, leading to the massive impact on their economic as well as societal life. The counselling centres, which are providing the psychological support and precautions for the proper diet and medicines, are limited only to urban areas of Sangli district, even in spite of higher or similar level of prevalence of HIV/AIDS in rural areas. As a result, lack of counselling and medical facilities in rural areas are making them more vulnerable of facing the discrimination more than their urban counterparts. All the three counselling centres, which are providing the required counselling for the infected patients are located in the urban areas only. As a result the infected persons in the rural areas has ought to depend on the indigenous health providers who are not much aware about HIV/AIDS and even do not know art of proper counselling to the patients. Some NGOs and private medical practitioners, who are extending the counselling facilities to the patients also restricted to the urban areas only.

The heartfelt need of public demand in Sangli district

1. Sex Education in Schools (in School curricula)
2. Provision of Government Financial Assistance to the HIV Patients and the relief and rehabilitation for those who are in crisis specially orphan children and elderly.
3. Demonstration of Condom use and make easy accessible to it and Condom Distribution for the HIV Patients to strengthen the condom promotion preferably by suitably developed social marketing scheme.
4. Day Care Centres with Free Treatment and Medicine
5. Existing health care system should be strengthen to bear the burden of increased communicable diseases and proper care of HIV/AIDS patients.
6. Massive Social Awareness to HIV/AIDS at community level and to create awareness among public through strengthening the inter sectoral coordination.
7. Compulsory HIV test before marriage and among all the indoor patients and this facility should provide the test of HIV/AIDS at free of cost.

5. Perception of stakeholders' of Sangli district on different measures taken and implemented by the government

The stake holders, who were interviewed in this area are the (i) Families infected/affected by HIV-AIDS, (ii) representatives of NGOs working in that area and involved in the field of education, health and family welfare services, (iii) representatives of community based organizations and (iv) social actors involved in different social welfare activities of Sangli district.

The families, which are having at least one adult active member is being infected with HIV/AIDS, and/or the families experienced the death of an adult active member due to HIV/AIDS had been interviewed on their perception regarding different aspects of policy and programmes relating to HIV/AIDS in the district. Three families each from rural and urban areas were interviewed for this purpose. All the families included in the analysis were from the low/middle income group and the households had the dependents like school going children and elderly. It was amply evident from such interactions that the discrimination for the HIV/AIDS infected and other household members is a common phenomenon in their locality. The undulating disease prevalence is leading to the severe economic burden on the households especially on the women and children. The children and the women who had lived happily prior to the infection of the adult active member in the household, bound to go for income generating activities as to meet the household expenses because of the bedridden stage of the infected adult member. The women even though they were not infected with HIV/AIDS were also found to be discriminated by the neighbours as they are providing the physical assistance to the infected family members.

At the time of playing also children are facing the problem of avoidance by their playmates especially in the rural areas. Soon after the economic crisis faced by the household the women mostly adopt at least some income generating activity to meet their household expenses. Two families in the rural area are also getting help from an NGO, which is now providing minimum needs for the children especially books and other reading materials to continue their education.

5.1 The type of activity and organizational characteristics of the NGOs

The NGOs are involved at community level with different developmental programmes like; education for the children, providing income generating assets to the women and elderly, sex education for the youth, health education, providing socio economic support to the families with HIV/AIDS, medical assistance for the women and HIV/AIDS infected persons and regular counseling activities. All the NGOs interviewed are located in the urban areas but having an organized structure up to the grass root level to render their services and having with more than three to ten branches located in rural areas. The effective promotion of condoms to the *Commercial Sex Workers* and the selling of condoms at a subsidized rate through vendors for the clients of CSWs are the main activities taking by the NGOs. The awareness programmes on substantial abuse like; prohibition of drug abuse, smoking and alcohol consumption are also the other key activities taking by the local NGOs along with the HIV/AIDS preventive education. The arrangement of public meetings and delivery of regular lectures by the different people mainly the doctors and the social workers to provide health and Sex Education for the *Commercial Sex Workers* and for the youths of the rural areas are other important work taking by these NGOs. Extension of the knowledge on different health aspects of women especially on the Reproductive Track Infections (RTIs), Sexually Transmitted Diseases (STDs) by the trained staff (ANMs) for adolescent girls and women in rural areas are form the other component in the domain of work taken by the local NGOs. They are also actively involved in awareness programmes by making the awareness rallies, organizing street plays and display of posters is in progress. The other women oriented activities are like; construction of working women hostel in the Sangli town, hostel accommodation for Devadasis' daughters are some of the initiatives taken

by the local NGOs. At par with this, the AIDS counselling and rehabilitation center for the infected persons in Sangli town is also supplying the nutritious food to the children who are the victims of malnutrition and ill health in the Sangli district.

5.2 The Role and Organizational Characteristics of the Community Based Organizations

The community level organizations are mainly focusing themselves in developing the self-confidence among the HIV/AIDS patients and providing the psychological support to their families through proper counselling sessions. They are trying to give a hope and the positive side of the life of the infected persons and trying to motivate them for fighting against the HIV/AIDS epidemic. They are also involved in providing the legal support to the infected person and their family through the proper counseling. These organizations are also providing both the individuals and family counseling. The members of the CBOs are providing the recreational facilities and medical assistance to the persons living with HIV/AIDS. The awareness activities like awareness on drug abuse and self-help activities are the ongoing programmes of these organizations. These organizations are also helping people for different income generating activities especially to the women for the home based income-generating activities in rural areas.

5.3 Social actors and their activities

The social actors interviewed in order to have insights in to the problem under study were the doctors by their profession and basically involved in the field of HIV/AIDS for more than a decade in this area. They are mainly involved in creating awareness of HIV/AIDS among the students and teachers and imparting the sex education for both the teachers as well as the college students of this area. The other major area of service of these social actors is to counsel the infected persons and their family members.

They are providing the health education to the general public with the help of some local voluntary organizations and to the adolescent students with the help of teachers in different schools and colleges. They are also delivering lectures on the reproductive health and sexual transmitted diseases (STDs) to the commercial sex workers (CSWs) and to the migrants, who are involved in different industries of Sangli district. They are advising and insisting the truck drivers for using condom before having sex with the CSWs. They are also imparting the Sex education to the teachers of the rural areas and to the volunteers in high-risk areas like red-light areas and highways. They are also providing the medical assistance and free counseling to the persons who are living with HIV/AIDS.

The Stakeholders' perceptions were primarily centred at the involvement of different government departments in activities related to HIV/AIDS prevention, control and management of crisis arising out of it. These discussions also included the reasons on the success of various activities and accessibility of different programmes at the grass root level. Further, they also suggested some intervening programmes, which should be taken immediately by different departments of governments in order to reduce the impact of HIV/AIDS in the society.

5.4 Perception of the stake holders on some of the Policy & Programmes of the ministries of Education, Health and Social Welfare in Maharashtra state

Though the government of Maharashtra has been implementing different programmes as long term preventive measures to reduce the potential spread of HIV/AIDS and short term relief and rehabilitation for those who are immediately in crisis due to HIV/AIDS morbidity and/or deaths. Still there is some heartfelt need of necessary intervention programmes. It was observed during our interactions with the stakeholders in Sangli that different department of state governments are required to put up their point efforts in order to reduce the impact of HIV/AIDS on the society. The non government organizations (NGOs), which are involved at the grass root level and actively participating and extending the mass awareness programme are claiming and criticizing the failure of government as all these programmes are not reaching to the grass root level properly.

Given below are some important areas for minimising the impact of HIV/AIDS and receiving less attention both in terms of policies and programmes, by different government departments.

5.5 The main areas neglected by the Department of Education

- Health education including sex education should be compulsory both for boys and girls in their school as well as in the college curricula.
- Inadequate training to teachers regarding how to impart sex education to the students, so alternative forms of teaching should be developed by the ministry to impart sex education to the students at different levels.
- Preparation of reading materials for the children related to HIV/AIDS to gain the knowledge on its different aspects.
- Fee concessions for the children of HIV/AIDS infected and affected families.
- Involvement of teachers at community level to create awareness among the general public with due government circular.

The ongoing IEC activities in the field of HIV/AIDS did not reach to its optimum level as in case of the awareness on Pulse Polio immunization. Therefore majority of the stakeholders were also opined that the existing IEC programme should be reorganized in the context of HIV/AIDS. The health education should be a subject for the children in the schools and the ministry of education has to take further necessary steps to implement it. The stakeholders are also opined that the government is unable to implement these programmes mainly due to the availability of limited information base related to HIV/AIDS and also due to the existence of different cultural traditions. The culture of silence is playing a major barrier to impart the sex education at the school and college level. As the teachers can not be able to teach the sex education in the class room because of existing cultural traditions and customs, the ministry of education should develop the alternative methods to impart sex education through the regular lecturers by the doctors and the medical staff in the schools and colleges. So in order to impart the sex education for the students, the ministry of education should widen the domain of population education related activities among the students especially among the adolescents.

5.6 The most neglected areas by the Department of Health

- Lack of Preventive materials to rural staff in terms of adequacy, continuity and time
- Diagnosis and treatment of STDs at rural hospitals
- Lacking of training to health service providers specially in dealing with HIV/AIDS.
- Lack of commitment among medical personnel
- Existing discrimination in treatment of HIV infected persons and to their families.
- Lack of medical support for HIV/AIDS infected persons.
- Limited facilities for blood testing.
- Lack of culture sensitive IEC materials
- Lack of facilities of free ANC care and free HIV/AIDS Counselling

Though the ministry of health in Maharashtra has been making concerted efforts in implementing different programmes in the state through MSACS to overcome with the problem of HIV/AIDS, but still there are many neglected areas emerged during the stakeholders interview in the Sangli district. The ministry of health should go adopt an effective IEC programme and the target-oriented approach should capture the existing diversity in the awareness of this epidemic. The preventive and symptomatic treatment for HIV/AIDS should be decentralized and make available at least at the level of rural hospitals.

The ministry should also take some necessary steps to reduce the discrimination by the service providers towards the HIV/AIDS infected persons and to their family members. It has also been reported the negligence and irresponsibility of the medical practitioners at the time of discharging the service to the HIV/AIDS patients. Blood testing facility should also extend to the local hospitals especially for the inpatients. Government should adopt the provision of free ANC care to the infected women. Though the ministry of health tried and had developed a wide range of information on HIV/AIDS, but due to lack of commitment among the providers it could not reach to the general populations. In order to reduce the psychological burden among the patients, counselling centres in the rural area should also be opened. The stakeholder were of the opinion that though the ministry has accessibility of staff members up to grass root level, but it hardly reach in its goal to provide effective IEC programme. So some modified steps should be taken by the govt. like discharge of the IEC activities at work places viz; Sugarcane industries, agricultural fields, Dhabas on the highways should be enhanced. The main area of neglected is the treatment of the infected persons, which suggest the reorganization of existing health care system in view of the increasing disease load with diverse nature.

5.7 The most neglected areas by the department of Social Welfare

- Provision of food items for the dependent family members of HIV.
- Rehabilitation for AIDS orphans.
- Minimum Rs.150/- from Sanjay Gandhi Niradhar Yojana to elderly of infected families.
- Lack of information on the AIDS orphans

Though the ministry of social welfare is carrying out many programmes to minimise the discrimination in the society, it is the right time to take some bold step to react against the HIV/AIDS in the state. As the society is highly stigmatised, the infected persons and their family

members are highly discriminated in the society. As a following consequence on the enormous expenditure on treatment of HIV/AIDS, the families underwent with the tremendous economic crisis and sometimes it has been found that the treatment cost became unbearable for the family. So, there is an utmost urgency has been felt by the stakeholders that the ministry should made provision for some financial assistance through various welfare programmes to reduce this impact. The priority should be given in some of the existing schemes like Sanjay Gandhi Niradhar Yojana in providing the house for the infected persons especially to the females, who were facing more discrimination as compared to their male counterparts. The social ministry should also stimulate the awareness activities on HIV/AIDS and its consequences. The children mainly the AIDS orphans in the district should be identified and should be provided with all facilities including education; shelter home and the government should develop the suitable mechanism to take care of these children. Social welfare programme for migrants at their place of work distinction, which may reduce their potential indulgence in to different levels of risky behaviour for HIV/AIDS infection. Poverty elevation programme should give due importance to blue collar migrants at the place of origin as a substantial proportion them are forced to migrate in search of their livelihood. They have also opined that govt. should involve the local voluntary organizations in operating these steps so that it can be materialised in a proper way.

5.8 Steps should be taken by the different departments of government to overcome the problem of HIV/AIDS: Views of Stakeholders

5.8.1 Ministry of education

As the Society is highly stigmatised, the associated discrimination and high expenditure for the treatment is resulting in the direct impact on the education of the children of HIV/AIDS families. So the ministry of education in order to reduce the dropouts should provide free education. The school uniforms, termination of the school fees and supply of the reading and writing materials for the children to be done. The AIDS orphans should entitled for free education with every facility; if possible the government should open a residential school for the AIDS orphans like Ashram shala. To reduce the further possible spread of HIV/AIDS, the sex education should be taught and lesson on AIDS should incorporate, at all standards at least from secondary education. Government should give emphasis on girl's education also.

5.8.2 Ministry of Health

The various awareness programme adopted by the ministry of health is not reaching to the target population. The medical facilities for the treatment of HIV/AIDS should be decentralized and should extended to the rural hospitals also, as a substantial proportion of the persons with HIV/AIDS are residing in the rural areas and there is no immediate accessibility of the health care facility in rural areas. Primary Health Centres should take care of the proper distribution of the medicines (including the tablets, injections and tonics) that are provided by the department at free of cost to the general public. The test facilities in government hospitals should be increased and the free treatment of the infected persons including the supply of necessary drugs, medicines and counselling should decentralized to all the rural hospitals. The preventive cum curative measures of the health services should be promoted properly to the population, especially to the rural population where these services are relatively poor than the urban areas. The health staff

should also not make any discrimination while providing the services to the people on the basis of the caste, religion, economic class and the disease. Some action should also be taken by the health ministry to identify the indigenous health provider who actually misleads the rural ignorant people regarding this epidemic. Sometimes these indigenous health providers also treat the people with HIV/AIDS and counsel them in a wrong manner.

5.8.3 Ministry of Social Welfare

Though the ministry of social welfare is implementing a number of plans and programmes for the welfare of the people but it hardly give special consideration to the HIV/AIDS infected persons and their families. Due to the limited information and high administrative cost, the government is unable to take any noticeable step for HIV/AIDS patients and their families. The ministry should establish a rehabilitation centre for the infected persons. The social welfare department should also help the infected people and their families by providing some income generative assets. Govt. can also establish some rehabilitation centres in the district for infected persons and make available some home based income-generating assets to the infected persons in the rehabilitation centre. The welfare ministry should also provide the food security for the dependents particularly the elderly people and the children of the HIV/AIDS infected persons in order to avoid the malnourishment among the families.

6. Some qualitative insights on the discrimination pattern against HIV/AIDS patients and their families in Sangli district

This section aims to explore some important dimensions of the existing discrimination against HIV/AIDS in Sangli district of Maharashtra. The Sangli district is one of the least urbanized districts in the state and majority of its population is depending on the agricultural economy. With the increase in number of HIV infections in the district, people's attitude and behaviour towards the infected persons have been changing over a period of time resulting in to increased social discrimination against the infected persons as well as the other family members of the households. The existing discriminations are multi-dimensional in nature and resulting in to severe impact on the persons living with HIV/AIDS as well as other members in their households. The mode of such discriminations are varying from individual to individual and hence the intensity of the impact are also diverse in nature. This qualitative study had been focused on the households in which the death occurred due to HIV/AIDS in between the June 1999 and June 2000. The major findings of these through in-depth interviews are revealing the existence of a wide range of discrimination in the society. The observed discriminations against HIV/AIDS are briefly discussed under the following heads.

6.1 Discrimination at family level

The persons infected or died due to HIV/AIDS were the active adult members and most of them were the head of the households. The entire responsibilities of the households were undertaken by them before the incidence of infection and in some cases even up to two to three years after infection. As the health condition of the diseased was deteriorating over the period of time, both medical and physical assistance had been required. The physical assistance from the household

members for a longer period lead to fear of possible infection among other family members and hence resulted in the discrimination against the persons living with HIV/AIDS even by their spouses and other family members. It had been observed that in some households the separate room, bed and eating utensils had been arranged for the persons living with HIV/AIDS. It was also observed that in few households, the women proposed for divorce from their husbands, infected with HIV/AIDS and in some cases they get separated from their husband also. In some cases, it has also been found that some women have shifted their place of residence along with their children within the village, however a few such women were shifted to their parents. The HIV/AIDS infected persons were also facing the ill languages of the villagers and some of them even at work places also as they mostly comprehend that it is transmitted through multiple heterosexual relations only. The HIV/AIDS infected persons who were working in the agricultural sectors mostly faced the discrimination at their place of work.

6.2 Discrimination at societal level

The HIV/AIDS infected persons were reported to often face the adverse comments of the villagers. A substantial proportion of the infected persons had to face the social boycott by their co-workers at their work places due to the perception prevailing in the society that HIV/AIDS occurred only because of multiple heterosexual relationship. As most of the infected persons were the cultivators and had to work along with other workers, their co-workers used to pass comment in ill languages and through singing some focal songs at the agricultural fields. In some cases it has also found that the employer had forced the infected person to leave the job. Neighbours used to discriminate these persons and their families by passing some bad comments, murmuring and whispering which sometimes results into the shifting of the residence of these families to other locality. In some cases, it has also been reported that the villagers did not allow the infected persons and their family members to participate in social activities at village and community level viz; marriages, other ritual and cultural programmes. Most of the persons living with HIV/AIDS and their household members were depending on their friends for the necessary and timely help. Though, they were getting help from their friends but they perceiving it in a discriminated manner. Some of the households were having very limited contacts with the friends. It is commonly observed in almost all villages that the friends also used to comment and ignore the person living with HIV/AIDS. In some villages the friends had also insulted the person living with HIV/AIDS.

It has also been observed that the modes of discriminations were differing from one household to other. The members of the household who were involving in political activities for longer time were not facing any discrimination as the villagers were afraid of the political power and richness of those households for which they usually do not discriminate them. How ever in the same village, it was also found in a reverse way in case of ordinary family, where all the household members were facing such discrimination almost every aspect of social life.

Though the discrimination against the children was less both within and outside the family, children were facing discrimination at schools, playing ground etc. It is worth mentioning that the children of HIV/AIDS deaths households often became the victims of stone throwing, beating, beating and sometimes boycotted by other children. Very rarely the children faced the same discrimination in the village like the adult members.

The discrimination at the health care centres was often reported by other patients both to the infected persons and to their family members. Some of the other patients at the health care centres in the villages used to request the medical practitioners not to provide the treatment for the infected persons and to their family members. Mostly the women who were the wives of infected persons faced the discrimination by the villagers at the health care centres. It is nowhere observed during the period of study on the discrimination against the person living with HIV/AIDS and their family members by the health care providers. The children were sometimes discriminated by the other patients at the health care centres. The interaction with some health care providers has clearly indicated the need of a day care centre at Sangli for the infected persons from almost all areas of the sangli district.

6.3 Discrimination in Marriage

It had been observed that the impact of HIV/AIDS on marriage for girls was profound and significant. No one is coming forward to marry the girls of the HIV/AIDS households including close relatives and friends of those particular households, due to fear of infection. However, in case of gents there is no problem of marriage. It is evident in an interaction with one of head of the HIV/AIDS household that after the death of his wife, due to AIDS he married another girl to look after his two kids. But where as in other households the marriage of a girl had been cancelled as her father had expired due to the AIDS.

6.4 Discrimination against the community leaders and social activists

It has also observed in one village that there is no discrimination found against the household in which one death of a female member occurred due to HIV/AIDS and the infection was through blood transmission.

One household, which is actively involved in social developmental activities, is also not facing any discrimination. The villagers in that village believe that the transmission of the HIV/AIDS is mainly through the sexual contact only and that person living with HIV/AIDS had never been observed by the villagers involving in such a risky behaviour and that person living with HIV/AIDS was also having good reputation among the different sections of population due to his good helping nature. So the villagers never discriminated the family members of that household in any respect.

6.5 Discrimination at the place of work

The discrimination of HIV/AIDS exists both at the place of work place as well as at the residence. One of the respondents had explained how he and his family members were faced discrimination due to HIV/AIDS as *“I was working in a petrol pump and my colleagues were used to insult me very often, so I left the job. I was also a committee member in the village, after they come to know that I have been infected with HIV/AIDS, the other members of the committee started to discriminate me every ground. My wife left me with my children immediately after knowing the infection to her parents’ village. None of mine including friends and my relatives*

come forward to help me and villagers also started to comment in ill languages to me and my other family members”.

Another died person-faced discrimination as quoted by his wife as *“he was suffering from HIV due to illness and he could not go for work. So all his colleagues always advising him to leave the service as he was working in the bank. He was also a member of community level organization and soon after they come to know that he was infected with HIV/AIDS, the other members of the organizations were forcing him to withdraw himself from that organization. So he can not bear all these things and started taking alcohol to forget the hatredness of the other family members, neighbours and villagers.”*

6.6 Discrimination at community organizations in rural areas

The discrimination towards HIV/AIDS even exists at community level in the rural areas. One of the respondent quoted the discrimination against her brother in-law as: *“He was a participant of community organization, where other members always pressured him to leave the organization because of HIV infection. “As you are an HIV infected person don’t come to this committee”. He was also working as an agricultural worker in others land on yearly contract and he had been forced to leave that job due to the infection of HIV/AIDS”.*

6.7 Discrimination against the family members

In many households it has observed that the infection of one of the household member led to the discrimination against all the household members even if they were not infected with HIV. One of the rural women explained how her family members were discriminated by the villagers. Some of the villagers used to blame her brother-in-law to leave the community organization and they also often used to blame them as they are also the members of the community organization. *“Not only they forced to remove my brother- in-law from the community organization but even us also”. “Due to the comments from some people, his wife left him and went to her mothers place along with her children. Neighbours are also rumouring and suspecting the infection in his wife but in reality she has not”.*

The discrimination against the elderly persons also exists in the society due to HIV/AIDS. A 70 years old man share his experience as *“that his son was died because of HIV/AIDS and after his death his mother got shocked and died with in fifteen days of her son’s death and now he is alone and nobody is there to take care of him. The neighbours are also started to pass comments on him”.*

The discrimination due to HIV/AIDS death to a woman both in the family and in the community is revealing the extent of discrimination how it led to a lower status of the dependents in the family. One of the widow respondent narrates her experience as *“my in-laws are commenting me daily in the house and they are treating me as a sweeper after my husbands death” and the attitudes of the neighbours and other villagers changed towards me and now I am feeling mentally disturbed due to this and planning to go to my mother’s place. Sometimes my in-laws are accusing me physically also”.*

6.8 Discrimination by family members

The discrimination by the family members towards the HIV/AIDS infected person and their dependents in most of the joint families exist in the society. An eighty years old man told about the death of his son, daughter in law and grandson and about how his son faced discrimination in his house by other family members as *“My daughter in law died one year prior to the death of my son and after six months my grand son also died, all these three died due to AIDS. As my son was suffering from HIV/AIDS he had been provided by separate room, bed and eating utensils by other family members in order to avoid the infection. They used to discriminate my son by using harsh language and scolding all the time. They never communicate properly with my son. Friends and relatives were also reluctant to willing to come here when he was ill”*.

The family members discriminate against another women was revealing the extent of stigma attached with of HIV/AIDS in the rural society. After the death of the male adult active member, the household experienced one more death of his child who was also infected with HIV/AIDS. As his wife was also infected with HIV, the household members started discriminating her. This resulted up to the expulsion of that lady from the house and she went to her parents' home as a widow. Even there also she faced the discrimination by her parents after few days and led her to be isolated from them. Though she had been provided with the all facilities but none of them were willing to talk with her. This situation reveals the impact of HIV/AIDS on rural innocent women.

6.9 Discrimination against Devadasies

The discrimination against a woman who belongs to the Devadasi, (traditional system in Indian society) a lower cadre in the society is highlighting the extent of discrimination of HIV/AIDS in the society. The Devadasies once praised in the Indian societies though they were meant for only to satisfy the sexual desires for higher cadre people in olden days in the society now constitutes the high-risk population. The sister-in-law of a Devadasi, who died of due to HIV/AIDS infection revealed her helplessness situation due to discrimination *“When my in-law was ill, nobody had come to see her. Most of the time she used to go to the temple and was praying god and I think even god was also angry on her and No body had helped her at the time of treatment The children were already sent to other place and as we are the Devadasies our settlements are always away from the village and now we do not have not much contacts with the village and villagers. Now the children as being illiterates are became the garbage collectors and there is no scope left for their education now and nobody is helping them in any respect. The perception of other people towards us is differing now.*

6.10 Discrimination out of hostility

The discrimination due to HIV/AIDS is leading to unfriendliness among some families. The close friendly ties are became slacken and disappearing over the period of time and the future of the children are become question. The death of a couple due to HIV/AIDS is resulted into the insecurity among the elderly members in both houses. The sixty years old women after the death of her son and daughter in-laws due to HIV/AIDS explained the present situation of the household as *“both my son an daughter in-law were died due to HIV/AIDS and the children were*

taken by in-laws. After my son's death we got some money from the government and our in-laws are not returning the money and they are also not sending the children. All the time they blaming my son as he is the responsible for their daughter's death and suspecting the children may also be infected with HIV/AIDS if they kept them in this house, so they are not sending them. At present the children are with us for few days but they will be taken back after some days. They are also blaming my son's character as they consider AIDS is a dirty disease, so they don't want to send the children back to our house".

6.11 Discrimination by parents

The discrimination made by the parents towards the died persons is also visible in some areas. As the investigator went to an household the parents of the died persons denied to give the interview in first visit. In that household only two elderly members mother and father of the died person are there and they were not at all interested to give the information about their son. The aged man said *"Though my son died we are not feeling bad because he died due to AIDS, the dirty disease, because of that fellow we lost our prestige and reputation among our relatives and society. Let that fellow died no need to talk about him now. It is good that he died and now we are peaceful and we are feeling shame as his parents".* This old man is also thinking that AIDS is the infection occurred only through the multiple heterosexual relations in which risk behaviour his son was involved.

6.12 Discrimination against the children

Another women of aged 55 years narrated her experience as *"my son married a prostitute, all the people used to pass comments and treated him as worthless. Because of his deed, we did not allow him to stay in the house and we felt that our prestige and social status of the house has gone down and we forced them to stay in other house. He was a driver and died two years before and after that other people started commenting our grandson and questioning in regards to his birth. But now we the aged people are not getting any support from any body in the village. Now the child is with us and we are providing him the education and other support, because no body is helping forward to help that poor boy as he born to a prostitute and his father died due to HIV/AIDS. We are treating the boy as our grandson. Some neighbours and other children are commenting the boy unnecessarily.*

6.13 Discrimination in High-educated Households

It is clearly visible that the discrimination is also exists even in the high educated families. One respondent, mother of a HIV/AIDS died person revealed the discrimination against the family by their daughter in-law. *"We all took TT injections from an indigenous health provider soon after knowing the status of my son is infected with HIV/AIDS, in order to prevent from HIV/AIDS infection. Our daughter in-law was undergoing the teachers training and she was working in a convent school for her experience. Soon after knowing the status of her husband she left the house along with her children to her parents' place and do not come back to stay with us. Now she is fearing to stay here".* She also continued *"None of our household members had said anything to any body that our son had died of HIV/AIDS as we belongs to the higher caste*

(Brahmin), because we wanted to keep our reputation and social status as usual". She also asked to maintain confidentiality to this matter for her social respect.

6.14 Discrimination against females

The discrimination against a woman in rural area leads the women into a state of psychological depression. The unnecessary verbal abuse from the relatives, friends and from villagers was found common to her. But some of the neighbours used to pass comment her by linking the sexual relations with other people and also used to blame her that she could not satisfied her husband in sex so that he had developed a tendency to visit other women for sex his sexual satisfaction and that lead to the infection. After all she blamed for the whole thing, as she was the core for both infection and even to the death also.. The neighbours are used to comment their in-laws and even to the children of the household. The children had been discriminated by other children in the school in all aspects even at the time of playing. By facing all these type of verbal abuses sometimes leads a strong psychological depression of the women and sometimes it results into commit suicide.

Immediately after knowing the status of one died person, his wife left him and went to her mother's place along with her children. Though she studied up to class ten, she is suspecting that her children also may infect with HIV/AIDS as their father was infected with HIV/AIDS.

6.15 Findings from the interaction with the Indigenous Health Providers

It has been found from the interactions of the indigenous health providers that there is no much discrimination faced by the children, but only children of non-HIV households makes discrimination of HIV/AIDS household children. Though the discrimination is highly prevalent for adult family members but towards the children is too less, almost negligible. The sympathy is also exists in the society for the children of HIV/AIDS households as they are innocent in this matter, sometimes giving moral and social support to the children. The existing discrimination in rural areas towards adult family members is really horrible. Avoiding the members of HIV/AIDS household is a common factor. Even in the family itself the discrimination exists like; not touching the clothes of HIV/AIDS infected person, providing separate room, bed, eating utensils for HIV/AIDS infected person are quite common by the other family members.

As the health provider, we noticed the discrimination by other patients both towards the infected persons and their family members. Even sometimes the Non-HIV patients requests us not to treat the HIV patients and their family members. The infection of HIV/AIDS of any household member decreases the social status of both individual and household level.

Though we take precautions to avoid infection among both other patients and ourselves, still the public doubts on us.

The refusal by private practitioners in urban areas is the main reason for increasing the patients for indigenous health providers for treating HIV/AIDS in rural areas.

One of the medical practitioners who refused to disclose the name of a HIV/AIDS infected died person is showing the extent of discrimination prevailing in the villages. As he told *“I don’t want to spoil their lives who are living peaceful by disclosing their name, I cant believe you (the researchers) and the moment the researchers enters the household, the villagers who already suspecting as HIV/AIDS household will start discriminating them”*.

The other indigenous health provider, who is a government employee (non-medical staff), said as *“though the infected persons are economically poor, they are not hesitating to pay up to Rs.5000/- for one bottle of tonic with a hope to get complete cure from HIV/AIDS. The patients’ main aim is to get rid from HIV/AIDS otherwise the discrimination by the relatives and friends, which are really unbearable for them. Though there is no curable medicine for HIV/AIDS, the infected persons are going to Kerala for their treatment in order to lead their life peacefully and without any discrimination”*.

6.16 Discrimination at Community Level

It is also evident from the interactions with the political and community leaders in Sangli district that these HIV/AIDS patients and their family members are being discriminated in the society by the community level officials and political leaders. The discrimination by political leaders like, village president and some political leaders at block level had been observed. One of the village president who is highly educated and having long-term political background quoted that “ there is a change in the morbidity pattern in his village since a decade and the number of HIV infections are increasing day by day. The infected persons should be kept away from the village at least 1000 feet from the residential area of the village and there should be separate school and hospital for HIV/AIDS households and for their family members as they are also sometimes developed the symptoms of HIV/AIDS. There should be provision of separate school for the children of both infected children and the children of HIV infected families. There is no discrimination found by the schoolteachers and the medical personnel for the children. But it is very common in the villages that the adults who are infected with HIV/AIDS are facing discrimination by other adult members of the village. Most of the infected persons used to take alcohol every day and this may be the one of the main reason to be discriminating them. Another thing is that the people who were infected with HIV/AIDS were mainly involved with the risk behaviours like; sexual relations with prostitutes in urban areas and this led to devaluating the name of their village in the district. The HIV/AIDS infected persons are increasing everyday. One of the community leader has told that less discrimination has been faced by the people who were infected through other modes of transmission like; blood transfusion than the people who were infected due to their risk behaviour. Due to their risky behaviour the village name and social prestige of the village is going down we are loosing our values in the village meetings. The head of the other villages are also directly blaming us by the village name and the social impact of HIV/AIDS had already passed through the individual and household levels to village level also. Now around 30 villages of this district are blamed as AIDS villages.

6.17 Evidences from the interaction with the –social activists

One of the social activist and professor quoted about the discrimination of HIV/AIDS as *“children discrimination is not much but at considerable level mainly in the schools. The non-*

HIV/AIDS children discriminate the children of HIV/AIDS household and shopkeepers also sometimes discriminate these children. Though there is no discrimination by the health providers but it is commonly observed the discrimination made by other patients at health the care centres. Even some of the health practitioners are discriminated the women of HIV/AIDS households. There are some evidences of some private practitioners, who are discriminating the pregnant women of HIV/AIDS infected person at the time of her antenatal care. The discrimination among elderly people in the HIV/AIDS household is also common. But the intensity may be less as compared to the adult members. Change in the family composition and marital disharmony and migration are the three main outcomes of the discrimination of this area.

6.18 Discrimination in the View of Social Workers (AIDS Counsellors)

The interactions with the social workers, the AIDS counsellors in some of the hospitals of Sangli are revealing the existing pattern of discrimination by the health care providers, especially by the private doctors in the urban areas and indigenous health providers of the rural areas. The infected persons at the time of treatment are discriminating by the doctors and by the other health staffs. One of the counsellors in Miraj explained about the discrimination as “ most of the AIDS patients are coming from rural areas where they were highly discriminated by their family members, community members and others which mostly leads them for further risk behaviour like smoking and consumption of alcohol. The family members especially spouses and in-laws are discriminating the infected persons. The discrimination for the infected returned migrants is found mainly by the villagers, who are not allowing these people to do work in the village.

ANNEX 1 Sampling procedure

To fulfil the specified objectives of the study as stated in Section I the following surveying procedure had been adopted.

1. The overall sample included 300 households. For the comparability of results, all households were extracted from rural and urban areas as per the actual distribution of cases.

2. Dividing the overall sample into three sub samples of 100 households each drawn from populations with broadly similar socio-economic characteristics, but differing in terms of the presence/absence of HIV/AIDS or deaths related to HIV/AIDS. Concretely:

- The first sub sample of 100 households had adult member(s) and this sub sample of households had experienced an AIDS death among an active adult member,
- The second sub sample of 100 households had adult member(s) had experienced a non-AIDS death (due to an illness, not an accident) among an active adult member,
- The third sub sample of 100 households without an experience of death among an active adult member.

3. Each of the three sub samples of 100 households was derived by the following method:

The 100 households with adult(s) known to be diagnosed HIV/AIDS-related death were extracted from the related lists kept by the local health institutions and by other local institution. In these households there should had been the AID-related death of an active adult member aged from 20 to 50 years between the 24th and the 12th month before the date of the survey.

From the compiled list of identified households where an adult died during the reference period, 100 households were selected randomly proportionate to the size of the broad educational categories. If the number of households is very few in certain categories, then most HH were selected from the categories to which the majority affected HH belonged.

The addresses of finally selected households were used to prepare list of their villages/urban blocks. The other two categories of households were selected from these villages or urban blocks. This would allow a control of broad socio-cultural and economic factors.

The 100 households with one non-HIV/AIDS disease-related death (due to illness, not due to an accident), were selected from the local list of households living in the same villages/urban blocks as that of HIV/AIDS household and belonging to the same broad educational categories. From the list of all the households where adult deaths or chronic non-AIDS morbidity is identified, 100 households were systematically selected representing four broad educational categories of HIV/AIDS affected households. In this case, the selected households should have experienced a non-HIV/AIDS-related death 24th and the 12th month before the date of the survey. Given very low adult mortality in some villages, it is possible that few 'matched' households of non-HIV/AIDS deaths did not come from the same village.

The 100 households with no deaths were selected from the house list specially prepared of households living in the same area and belonging to the same broad educational categories during the preceding 24 months. Care had been taken that these households are spread over the entire study area rather than coming from few pockets.

4. Each of the three sub samples were further stratified by four levels of education

- 13 households purposively chosen from the universe of households where the died adult member was illiterate
- 19 households were purposively chosen from the group of households where the died adult member achieved a primary education level
- 56 households were purposively chosen from the group of households where the died adult member achieved a secondary education level
- 12 households were purposively chosen from the group of households where the died adult member achieved a higher education level

5. Time frame of the survey

All questions included in the questionnaire aimed at obtaining information about household conditions or events occurred during the last 12 months from the date of the interview. The only exceptions are questions n. 45, 46, 47, 48, 53, 54, 55, 58, 62 in section G: these questions aimed at comparing behaviours over the last 12 months from the moment of the interview with behaviours in the preceding 12 months.

Collection of the Household Addresses of sub samples

Collection of the households with HIV/AIDS and non-HIV/AIDS deaths during the specified reference period.

The required sample target was 100 households with HIV/AIDS adult deaths, hundred households of non-HIV/AIDS adult deaths and another hundred households without any type of adult deaths with in the reference period. The households with HIV/AIDS deaths had been collected from different sources like, General Hospital in Sangli, Municipal Corporations of Sangli and Miraj Urban Blocks and Nagar Parishads from the tehsil head quarters like, Tasgaon, Atpadi, Islampur and Vita Nagarparishads and village level Gram Panchayaths, which are the main sources for the birth and death registration. In order to have a comprehensive list of the household addresses of both HIV/AIDS and non-HIV/AIDS types the other sources like Primary Health Centres, Sub-Centres were also contacted. Overall, from these different sources the 192 households addresses of HIV/AIDS deaths were collected. Of course among these 192 some of the households were found where cause of death was not mentioned as HIV/AIDS with certainty. That was why, we contacted the local medical practitioners and included in the list only after conformed by them that the death had been occurred due to only HIV/AIDS.

It is worth mentioning that the collection of details about the died persons due to HIV/AIDS became extremely difficult in the context of ethical issues related to HIV/AIDS. When the research team approached the different sources like civil hospital, blood banks, NGOs faced a lot of problems in obtaining the addresses due to the reason of confidentiality. Almost all these sources refused to give the information on the addresses of the HH with HIV/AIDS deaths. Necessary permissions were obtained to secure the addresses from these sources and precautions were taken that the confidentiality is maintained. Care was taken that the list of addresses does not have mention of HIV/AIDS.

Once the detailed addresses of 192 HIV/AIDS related deaths were compiled, the distribution of the HIV/AIDS deaths were plotted on the geographical map of the district. Subsequently, 45 villages and four urban centres were included in our study design based on concentration of such deaths with required target of urban and rural proportion. At the next stage, the research team collected information on non-HIV/AIDS deaths occurred with in the reference period from the rural as well as urban areas included in the study. The two types of households that is HIV/AIDS and non-HIV/AIDS deaths were matched according to their broad socio economic conditions. In case matching was possible with in same village, the matched households were searched from the near by villages giving due care to their socio economic conditions. At the end, the same number of households which experienced no deaths with in the specified reference period were selected from the similar socio-economic strata. The operational details are briefly explained in the following sections.

Selection of non-HIV/AIDS households

The detail household addresses of non-HIV/AIDS deaths had been collected from the sub-centres, primary health centres and gram Panchayats, municipalities and corporations. In general the non-HIV/AIDS deaths are more registered, only the household addresses in which the education level of the died person is same as the education level of the died person in HIV/AIDS house hold had been collected. Over all hundred households were included for the purpose. The selection of the household had been matched by taking the education of the died person with the HIV/AIDS household. In matching the both types of households, the maximum distance had been maintained not exceeding the 10 km for more than 90 percent of the surveyed households. Nearly ten percent of the households had been matched within a distance of 10 to 20 km.

Selection of the households without deaths

The households of no deaths had been collected mostly from the same village and urban block in which the both the HIV and non-HIV/AIDS deaths households were interviewed. Near by fifteen households of no deaths had been interviewed within a distance of fifteen kilometres. In the case of both higher educated and illiterate households the matching was not possible with in the same village or urban block. Overall, hundred households were included. In the selection of the households the help from local ANMs, MSWs and the village president (Sarpanch) was sought. Several cases the households had been selected and identified with the help of the members of the HH of both HIV/AIDS and non-HIV/AIDS households.

References

- AIDS Prevention and Control Project (1997) *Tamil Nadu HIV Risk Behaviour Surveillance Survey, Baseline Wave-1996*, Findings Dissemination Seminar April 15, 1997, Chennai
- Bharat S. (1999) *HIV/AIDS Related Discrimination, Stigmatisation and Denial in India – A study in Mumbai and Bangalore*, Unit for Family Studies, Tata Institute of Social Sciences (TISS) and UNAIDS, Mumbai
- Gangakhedkar, R.R. et al (1997) “Spread of HIV Infection in Married Monogamous Women in India” in *Journal of the American Medical Association*, vol. 278, pp. 2090-2092
- George, A. (1998) *Sexual Behaviour and Sexual Negotiation Among Poor Women and Men in Mumbai. An Exploratory Study*, SAHAJ Society for Health Alternatives, Baroda
- Hira, S. et al (1997) “HIV Infection in the Workforce and Its Perceived Impact on Industry” in Godwin, P. (ed) *The Looming epidemic*, Mosaic Books, New Delhi, pp. 139-149
- India, Ministry of Health, National AIDS Control Organisation (1998) *Prevention Indicators Survey of Five States in India, 1996-97*, Ministry of Health, New Delhi
- Institute of Social Diseases (1995) *HIV/AIDS Intervention Amongst Injecting Drug Users and their Sexual Partners*, The Helpline Centre, Singjamei Parking, Manipur
- Lahiri, S., Balk, D., and Pathak, K.B. (1995) “Women in 13 States have Little Knowledge of AIDS” in *National Family Health Survey Bulletin* No. 2 (October)
- Mane, P., and Maitra, A.S. (1992) *AIDS Prevention: The Socio-Cultural Context in India*, Tata Institute of Social Sciences, Mumbai
- Mastro, T.D et al. (1998) “HIV Infection and AIDS in Asia” in Pizzo, P.A., and Wilfert, C.M. (eds.) *Paediatric Aids: The Challenge of HIV Infection in Infants, Children and Adolescents*, 3rd edition, Williams & Wilkins, Baltimore, pp. 47-63.
- Mehendale S. (1998) “HIV Infection Amongst Persons with High Risk Behaviour in Pune City: Update on Findings from a Prospective Cohort Study” in *AIDS Research and Review*, vol. 1, pp. 2-9
- NACO, *Country Scenario, 1998 –1999*. MFHW.GOI.India, New Delhi
- NACO, Ministry of Health and Family Welfare, Govt of India (1997) *A Summary of the Findings of the High Risk Behaviour Study from 18 Cities*, NACO, New Delhi
- NACO (1998) *National Aids Control Project Phase II 1999-2004, Technical Annexe*, NACO, New Delhi

NACO (1998) *Project Implementation Plan. NACO Ph II(1999-2004)*, MFHW.GOI.India, New Delhi

Nadakarni, V. et al. (1994) *Monitoring and Evaluation Study of the AIDS Prevention Programme*, Tata Institute of Social Sciences (TISS), Mumbai

Nag, Moni (1996) *Sexual Behaviour and AIDS in India*, Vikas Publishing House, New Delhi

NGO Mamta (1998) *Sexual behaviour- STDs-AIDS: Knowledge/Attitude/Practice and Treatment Seeking Behaviour – An Urban Slum Study*, NGO Mamta

NGO Sharan (1998); *Report on the five-city survey of IDUs*; NGO Sharan

Pelto Pertti (1999) “Sexuality and Sexual Behaviour: The Current Discourse” in Saroj Pachauri (ed.) *Implementing a Reproductive Health Agenda In India: The Beginning*. Population Council, New Delhi

Priya, R. (Undated) “Contextualising AIDS: An Indian Perspective” in: Dadian, M., and O’Grady, M. (eds) *Cairo and Beijing: Defining the Women and AIDS Agenda*, Family Health International, AIDSCAP Project, Arlington

Ramasubban R. (1999) *HIV/AIDS in India: Gulf between Rhetoric and Reality*, in Saroj Pachauri (ed.) *Implementing a Reproductive Health Agenda In India: The Beginning*. Population Council, New Delhi

Rao, A., Nag, M., Mishra, K., and Dey, A. (1994) “Sexual Behaviour Pattern of Truck Drivers and Their Helpers in Relation to Female Sex Workers” in *The India Journal of Social Work*, (Special Issue : Sexual Behaviour and AIDS in India) vol. 55(4), pp. 603-17.

Rodrigues, Jeanette J et al (1995) “Risk factors for HIV Prevention in People Attending Clinics for Sexually Transmitted Diseases in India” in *British Medical Journal*, vol. 311, pp. 283-286

Salunke, S.R, Shaukat, M., Hira S.K., Jagtap M.R.(1998) “HIV/AIDS in India: a Country Responds to a Challenge” in *AIDS*, vol. 12 (suppl B), pp. S27-S31.

Savara, M., and Sridhar, C.R. (1994) “Sexual Behaviour Amongst Different Occupational Groups in Maharashtra, India and the Implications for AIDS Education” in *The Indian Journal of Social Work* (Special Issue : Sexual Behaviour and AIDS in India) vol. 55(4), pp. 617-32.

Sethi Geetha (1999) “Government Response to HIV/AIDS” in Saroj Pachauri (ed.) *Implementing a Reproductive Health Agenda In India: The Beginning*. Population Council, New Delhi

Singh, R. (1999). *HIV/AIDS, Workers and Labour Rights: A study of Vulnerability of the Workers in Wazirpur Industrial Areaa, Delhi*, Centre for Education and Communication, New Delhi

UNAIDS (2000), *India responds to HIV/AIDS*, UNAIDS, Geneva

UNDCP Regional Office for South Asia (1998) *Drug Demand Reduction Report*; UNDCP, New Delhi

UNDP Regional Project on HIV and Development for Asia and the Pacific (1997) *Involvement of people Living with HIV/AIDS in Policy and Programme Development*, Report of a Consultancy; UNDP, New Delhi

Vaypayee,A.B.(1998) *Address at the Meeting on National Programme for Prevention and Control of HIV/AIDS*. New Delhi

Verma R.K. et al (1999) “NGO Response to HIV/AIDS: A Focus on Women” in Saroj Pachauri (ed.) *Implementing a Reproductive Health Agenda In India: The Beginning*. Population Council, New Delhi