

# Maharashtra District AIDS Control Society visit Report, Mumbai

Maharashtra

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12<sup>th</sup> March,  
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## Introduction

**Place visited** : Mumbai, Maharashtra

**Dates of Visit** : 12<sup>th</sup> Mar, 2011

**Purpose:**

Follow up of the cases which appeared in the Public Hearing for the Orphan and Vulnerable children affected/infected by HIV/AIDS on 31.01.2010.

**Place visited** : Maharashtra District AIDS Control Society

**Team Members** :

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## Visit to Maharashtra District AIDS Control Society

### Context of the visit:

The issues and challenges faced by vulnerable HIV positive affected/infected kids are unimaginable, their plight unfathomable. They struggle for survival, for acceptance and recognition by the society every minute of the day. In an effort to touch these vulnerable kids, NCPCR conducted a public hearing at TISS Mumbai on 31.01.2010, where 19 kids deposed. Commission in turn issued personalized and generalized recommendations to the State government so as to facilitate the mainstreaming of these children. Repeated attempts were made to continue the follow up care and in this context the Commission decided to physically reinteract with all these children and assess their present health status and positive changes, if any.

### Activities-

1. Interaction with the authorities
2. Interaction and one to one communication with the kids
3. Interaction with the NGOs

### Information furnished: by the State Officials

1. There are total **19,203** children registered for Pre-ART care and regular screening done by the CD4 where in **6,097** patients are eligible for the ART.
2. There are 51 ART Centres and 123 Link ART Centres in Maharashtra where the medicines are freely available. The State officials elaborated on the treatment facilities provided, early detection of HIV cases, improvement in the follow up services, decreasing no. of HIV patients in the State.
3. There is only 30-40% conversion of Pre-ART to ART and that too only after 5-6 yrs depending upon the CD4 count. Out of **19,203** there were total deaths of 3.7% children

and adults 7.7%. Link ART centres at Sub District level are 123 and these centres are having provision for 70 patients on Pre- ART and CD4 facility.

### Action Taken and Status as of January 2010 as provided by MSACS:

S. No.	Cases deposited at the time of Public Hearing	Recommendations by NCPCR	Action Taken Report
1.	Case 1	<ol style="list-style-type: none"> <li>Shobha must be provided with a ration card and be linked to some livelihood program with the help of the officials from the Women and Child Development Department.</li> <li>Nutritional Support has to be provided to both the mother &amp; son as they are on ART and taking it once a month. Rohit is going to a government school and gets curry &amp; rice in the Mid Day Meal. He eats chappati or <i>poha</i> for breakfast. In the evening he has dal &amp; rice and sometimes chappati. Shobha says that the Doctor does advise them what to eat but she is not able to afford.</li> <li>Scholarship has to be provided to the child.</li> <li>Child can be covered under Bal Sangopan Scheme (Foster Care) with the help of the district Child Welfare Committee in Sangli. The officials were directed by the panel to prepare documents for the family. There are special homes for HIV+ children. There are 9 homes with a capacity of 525 children in Sangli. CCDT representatives raised the issue of separate homes for HIV+ children. They felt that such a system would only encourage the stigma and discrimination further. The officials insisted that the separate homes were due to the special medical needs of the children. CCDT gave the example of a home run by them for HIV+ and normal children who are affected by HIV/AIDS. There is no segregation. One of the panelist then mentioned that this is a policy issue.</li> <li>Dr. Rekha from NACO that the affected children must be provided with community based support like family and relatives and does not encourage putting them in homes.</li> </ol>	<p>He has been visited by Kranti foundation at Sangli. At present staying with Mr. Dutta (care taker) at Indira Gandhi Jhopadpatti. Currently on ART at Sangli ARTC No. 4724. He is not attending school and CABA coordinator is still taking efforts to bring him to school. In good and healthy condition. Getting benefit of Bal Sangopan Yojana.</p>
2.	Case 2 (Brother)	<ol style="list-style-type: none"> <li>Foster care should be provided to both Sushant and Sushma.</li> <li>Education Society College must provide both of them free education.</li> </ol>	<p>Was getting benefit of Bal Sangopan Yojana. Got married last month. Husband is PLHA working in MIDC.</p>

		<p>3. Free ART treatment has to be provided as Sushma has to pay Rs.2000/- for medicines other than ART. Her Opportunistic Infection condition has to be examined properly. There should be an enquiry as to why are they being charged money under the inspection of the officials from Women &amp; Child Development Department in Sangli. Protocol has to be presented to the Panel, they have at the ART centres. It should be examined and a report should be given to the panel.</p>	<p>Currently living with her husband at Kupwad (District Sangli). On ART from ART centre Sangli. In good and healthy. Now studying FYBA.</p>
3.	Case 2 (Sister)	<p>1. Foster care should be provided to both Sushant and Sushma.  2. Education Society College must provide both of them free education.  3. Free ART treatment has to be provided as Sushma has to pay Rs.2000/- for medicines other than ART. Her Opportunistic Infection condition has to be examined properly. There should be an enquiry as to why are they being charged money under the inspection of the officials from Women &amp; Child Development Department in Sangli. Protocol has to be presented to the Panel, they have at the ART centres. It should be examined and a report should be given to the panel.</p>	<p>Going to school. Attending Sangli ART Centre. Good and healthy. Living with paternal grandparents. Beneficiary of Bal Sangopan Yojana.</p>
4.	Case 3 (only one child not the sister)	<p>1. Every child has a Right to Education and should go to school. District Education officer should ensure that she joins school again.  2. Her piles condition needs treatment. The rural hospital has free treatment and one can avail of free treatment even for piles. She can get in touch with the Center Care Worker at the ART Centre in order to avail services from the Community Care Centre. She gets medicines and treatment at ART, the doctors don't do a thorough check up of her. The ART should have referred her to a hospital or concern department for piles treatment. Treatment for other illnesses should also be provided. NACO mentioned that each district has a Community Care Centre run by NGOs, funded by SACS and linked to ART with a facility to free food and stay by the NGO.  3. The children need to be protected from their father's abuse. There is a girls hostel at Sangli but there is no boys' hostel. Mr. Sachin Kamble have to take her to the hostel and see if she likes it and then only can stay there to study.  4. Probation Officer should go and visit the family</p>	<p>Kumar is attending school regularly. Living with father. Getting nutrition and support from NGO. Care taker is sister and uncle. Mother died. Healthy and in good condition. He is the beneficiary of Bal Sangopan Scheme.</p>

		<p>and warn the father that they are receiving complaints against him from some people.</p> <p>5. It would be better to provide shelter to the child at home, so that they can be empowered in their own home.</p>	
5.	Case 4	<p>1. She can be linked to the Positive People's Network. She should be counselled to continue in the school in her village. NACO has linked Kavthemahakal to rural hospitals.</p> <p>2. The nutrition requirement of HIV+ children is more. NACO even tried to store &amp; distribute food but it is very difficult to store. Their entitlements should be doubled under existing schemes like ICDS, MDM, PDS etc. Also currently in Maharashtra, there is a 75% concession on transport but NACO is recommending to make it free.</p>	<p>Patient living with grandmother. Economically stable, presently not attending school but will continue from June as her aunt is ready to take the responsibility of her education. Enrolled in CABA.</p>
6.	Case 5	<p>1. School needs to be told in a firm manner that they cannot throw out the child. A strict warning should be given to the school by not mentioning that the girl has complained.</p> <p>2. She deserves a foster care program. But if the child is staying in a hostel then they cannot avail foster care scheme. But it has been suggested that in such special cases, the child should get maximum benefits and there should be no criteria which prevent them from availing more than one scheme.</p> <p>3. She must avail all the facilities from the Schemes meant for girls like bicycle, shelter, Right to Education, free food, so that will not be stigmatized.</p>	<p>No discrimination at school now. Attending school regularly. Mother is getting benefit of Sanjay Gandhi Niradhar Yojana. Child is now beneficiary of Bal Sangopan Scheme. Child staying with mother. Both mother and child are attending o ARTC regularly.</p>
7.	Case 6	<p>1. He should be provide with foster care. His sister should get enrollment in an Anganwadi to get nutrition.</p> <p>2. NACO mentioned that children taking ART will get medicines in rural hospitals in their taluka itself and will not need to go to Sangli. Only once a pediatrician comes, they will start the service for children also.</p>	<p>CABA coordinator was continuously trying to get him to the school. Now from Monday he will be re- entered in the school. Will also get the benefit of Bal Sangopan Yojana, as it is already sanctioned. He is regularly attending ARTC Sangli. He is living with mother's peer sex worker who is taking care of the child.</p>
8.	Case 7	<p>1. She must be provided her part of share in the property.</p> <p>2. Somebody from the education deptt. must tell the teachers to include the child in every activity by not disclosing his positive status.</p>	<p>On ART child is getting benefit of foster care scheme. Attending ART Centre at Satara. Now there is no discrimination done at</p>

		<ol style="list-style-type: none"> <li>3. He must tell the doctor about his status of skin infections and medicines have to be given to him in ART. Ratmma was getting medicines for diarrhoea and vomiting. She has been on ART for the last 2 years.</li> <li>4. Teachers must be told to not to disclose his HIV infected status, so that he is not discriminated and teased.</li> </ol>	home/community level.
9.	Case 8	<ol style="list-style-type: none"> <li>1. She and her brother must be enrolled to the school, so that she can get Mid Day Meal also to meet her nutritional requirement.</li> <li>2. Free transport has to be provided to her by the State Government Authority with a card from ART center without mentioning her HIV+ status and medical condition.</li> <li>3. Both the children could get covered in the foster care scheme.</li> <li>4. Pension should be given to the old grandparents and age should not be the criterion to prevent them from availing it. Officials should make a home visit to the family and provide them the maximum benefit of the schemes.</li> <li>5. Child headed or Old headed households must be provided with all the benefits. Officials should be sent to the ART Centre and the entire list could be taken and all of them could be given the benefits.</li> </ol>	She is working on daily wages. Not facing stigma at present. Priyanka was taking first ART in Satara but from Feb 10. She is taking first ART in SDH Karad which is nearest to her village.
10.	Case 9	<ol style="list-style-type: none"> <li>1. The training of teachers about HIV/AIDS does take place. A specific circular has to be sent to the school. An official from the Sarva Shiksha Abhiyan will have to take care off. Also there is a need for a drop box for complaints in schools where children or families can put their grievances.</li> <li>2. The child is malnourished. Nutrition under ICDS has to be provided. In fact she said that all such children should be extended the benefit of food schemes irrespective of age and other criteria.</li> <li>3. Orders with proper terms and conditions for every department has to be circulated with a list of all such schemes, so that they can work properly.</li> <li>4. Free transport for the child has to be provided for her ART treatment. She has to travel a long distance, an appeal can be made to open ART centre from the Government.</li> </ol>	Regularly going to school. Currently there is no discrimination. Patient is under treatment of Gadhinglaj ART centre on 10/05/2010. Now, Grandfather takes care of the family.



11.	Case 10	1. She must avail all the Rights of the Girl Child.	Mother is HIV positive on ART, Father is HIV negative and a discordant couple. Initially they were staying separate but now staying together. Child is attending the school.
12.	Case 11	1. Officials from the Social Welfare Department have to give personal attention to this case and report the Jury as the Child have to face a lot of problems in the Bal Kalyan government departments. 2. The child must be provided with proper shelter and education under the supervision of the Commissioner and education department.	Child is attending ARTC. As immune status of the child is good, so not yet on ART.
13.	Case 13	Case did not deposited	Attending School. Living with aunt. Regularly attending ART centre Sangli. Getting TA from Sangram (NGO) and also getting benefit of Bal Sangopan Yojana.
14.	Case 14	Case did not deposited	Mother is on ART and holding the permanent job in a bank. Patient is in 7 <sup>th</sup> std. No discrimination at the school level.
15.	Case 15	Case did not deposited	Home visit done by Dilasa. Educational support and medical bill has been provided to the child. Currently in 11 <sup>th</sup> std. Regularly attending the college.

*\*Source: MSACS*

## On interaction with the kids:

Interaction with the kids was done on one to one basis without involving any agency.

- a. All of them appeared to be in good health. Though most of the children tried to present a brave face initially but gradually they opened up and started narrating their sorrows.
- b. On treatment aspect all of them were satisfied with the medical facilities, provided to them and confirmed timely distribution of medicines with proper follow up.
- c. Boys were more ambitious than girls. They have big dreams, wants to pursue one or the other career and were shy in admitting that they are discriminated. Though most of them have lost either one or both the parents they were staying either with grandparents or caretakers and accepted Step motherly facilities in their foster homes.
- d. Girls on the other hand were more vocal. Two of them broke down while narrating. They wanted to study but were not attending the school because of the peer pressure and teasing. In one case even the school management has allowed her to stay at home during regular days and come for examinations only. One of them was out of school, so that she can work for the family, she is staying with so that her younger brother (who is also HIV positive) can study. Optimism, enthusiasm, ambitions so characteristics of this age were totally missing. It appeared as if they have prematurely matured.

## Observations and Recommendations:

- a. HIV/AIDS being the multifactorial issue needs multisectorial remedies and medical management being one. The social, familial, regional issues often take the centre stage in the life of a budding child.
- b. Though medical management was not studied too deeply but one aspect which needs lot of debate is the **Pediatric age**. In ART Programme the age of child ratified is 12 yrs which is a stumbling block. A vulnerable child who is in constant touch with a Health Consultant and team whom he thinks is his health mentor and has developed a bonding, suddenly is being counted as an adult and the entire scenario changes. However, at this age he/she is not mentally mature enough to cope up with this newly developed situation, this leads to a major psychological stress and makes him vulnerable for drop out. Hence, we recommend that the age of the child should be raised to 18 yrs from 12 yrs.
- c. Relatives are usually forced by the society, government officials to take charge of doubly Orphan HIV positive child but as such there is no clear guideline to show that in case of non-availability of care taker who will take the responsibility of the child. Though family/foster care has always been modality of choice but it should be ascertained that foster home should not become a torture home for the child.
- d. Orphan HIV kids are entitled to the financial assistance from Bal Sangopan Yojana. But this scheme is only applicable for child who has been enrolled in school. Child who is not in the school for one or the other reasons (health may be one) is not entitled for it which is again a hard hitting fact as most of the cases leave school either because of frequent visit to the doctor or social discrimination or due to illness. These children should be encouraged to rejoin the school. Hence, these children should not miss out on the facilities offered to them by the government.
- e. The affected/ infected children and their care- takers faces a lot of problems in availing the schemes from the government like Bal Sangopan Yojana and Sanjiv Gandhi Yojana. A lot of paper work is required to fulfill their criteria. Just to give a glimpse of the documents required.

### Bal Sangopan Yojana

### Sanjay Gandhi Yojana

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|--|---|
| 1. Applicants mother's/ guardian's mental physical fitness certificates  | 1. Age proof certificate                  |
| 2. Two certificates from Social Workers e.g. MP/MLA/Sarpanch <i>etc.</i> | 2. Income tax certificate Rs. 21,000/-    |
| 3. CABA school bonafide certificate.                                     | 3. Photocopy of Ration Card               |
| 4. Income certificate Rs. 15,000/-                                       | 4. Death certificate of husband, if widow |
| 5. Residential Proof Certificate   | 5. Residential certificate                |
| 6. Photo of guardian in front of the house                               | 6. Affidavits of Applicants               |
| 7. Orphan Certificates   | 7. Identity photo                         |
| 8. HIV positive certificates of parents                                  | 8. Age below 65 yrs                       |
| 9. Parents Death Certificate   | 9. Disability Certificate                 |
| 10. Incurable disease certificate  |   |

*\*Source for the documents Bal Sangopan Yojana and Sanjay Gandhi Yojana: MSACS*

So much of documentation from an already distressed child and his-her caretaker becomes a hindrance in availing the schemes. A child who has lost both the vital cover and back pages of his life book should not be embarrassed more by asking for documents in fact after ascertaining the credentials of the care taker the assistance in form of scholarships, schooling, uniform books, nutrition, medical help *etc.* should automatically come to him with love, care and affection.

Despite of significant campaigning of HIV nutrition, the societies are yet to shed its inhibitions. Hence, more camps on health education on HIV positive children are required so that they can also lead a productive normal life.

## *Abbreviations Used*

NCPCR	National Commission for Protection of Child Rights
SACS	State AIDS Control Society
MSACS	Maharashtra State AIDS Control Society
TISS	Tata Institute of Social Sciences
ICDS	Integrated Child Development Scheme
ARTC	Anti Retroviral Treatment Centre
CCDT	Committed Communities Development Trust
MDM	Mid Day Meal
PDS	Public Distribution System
SDH	Sub District Hospital
TA	Travel Allowances
MP	Member of Parliament
MLA	Member of Legislative Assembly
NGO	Non- Government Organization
ART	Anti Retroviral Treatment
CABA	Children affected by AIDS
PLHA	People Living with HIV/AIDS
MIDC	Maharashtra Industrial Development Corporation
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
CD4	Cluster of Differentiation 4
NACO	National AIDS Control Organization

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