

**Barriers to services for children  
with HIV-positive parents  
in five high HIV prevalence states of India**

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## **Executive summary**

According to the National AIDS Control Organisation (NACO) India has 5.2 million HIV-positive people and an HIV-prevalence of 0.9 percent of adults – about the same as the global average, or the sero-prevalence in North America, Eastern Europe and Central Asia.

India's epidemic is concentrated in some 200 districts, most of them in six of the country's 28 states – namely Andhra Pradesh, Karnataka, Maharashtra, Manipur, Nagaland and Tamil Nadu – where HIV-prevalence is more than one percent.

Although the literature often describes India's epidemic as getting worse, this is not always supported by the available data. NACO had not published figures for 2006 at time of writing while UNAIDS, in their December 2006 update, said India's diverse epidemics were "stable or diminishing in some parts, while growing at a modest rate in others".

There are also limited data on the number of children infected with HIV in India. NACO has not published an official estimate, while numbers published elsewhere vary between 50,000 and 300,000 positive children. However it is likely that for every child who is infected there are another fifty who have an HIV-positive parent or who have been orphaned by AIDS.<sup>1</sup>

Collectively they make up the "children affected by HIV/AIDS" – the subjects of this study.

The research hypothesis was that many affected children are excluded from services and benefits which are available to other children in their communities – including education, health care and the support of their extended families and communities. While this belief is widely supported by networks of HIV-positive people and NGOs working in the field of HIV/AIDS, no formal studies had been conducted in India to test it.

The study objectives were to establish whether this hypothesis is true and, if so, the nature and severity of barriers to those services, and what steps can be taken to overcome them. The underlying rationale was that removing barriers to mainstream services could materially benefit a large proportion of children affected by HIV/AIDS, and reduce the number of children requiring targeted interventions.

The study was qualitative in nature and was conducted in two phases:

- focus group discussions with "service consumers" – affected children and their adult caregivers – who were recruited by NGOs and networks of positive people, and
- key informant interviews with selected "service providers" in education, public health and social welfare.

Research was undertaken in 54 sites – nine in each of the high-prevalence states.

Unfortunately the analysis of data in Manipur was not completed in time for this overview, which is therefore limited to 45 sites in five states.

The study was coordinated by UNICEF in association with NACO and the Ministry of Women and Child Development, and was conducted concurrently by independent research teams in each state, using a common methodology to ensure comparable results.

Each state research team produced their own report. This document is a synthesis of the reports, supported by a review of current research and best practice around the world.

## **Findings**

There was a high level of consistency between the experience of affected children and their caregivers across the country. They described how neighbours and relatives treat these

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<sup>1</sup> See the body of the report for a discussion on the numbers of children who are HIV-positive, orphaned by AIDS, or living with an HIV-positive parent

children differently to other children. Affected children said they are teased, shunned, shouted at or ignored in their homes and neighbourhoods. Exclusion from family events, ceremonies, festivals, birthdays, puja and marriage are common.

In terms of education, adult caregivers in all five states listed mistreatment by teachers above all other concerns. Affected children confirmed they are made to sit separately, get less attention than their classmates, and said their parents' illness is used to humiliate them. Their classmates are told by their parents not to have any contact with affected children, and some schools bow to public pressure to refuse admission to affected children.

Some children spoke of being withdrawn from school to care for sick parents, or to supplement household income, although this was listed as a priority concern in only one state, Andhra Pradesh. Children in Karnataka and Tamil Nadu referred to the impoverishment of their families due to HIV/AIDS, but in the context of where they lived and how they were raised, rather than as a barrier to public services.

In terms of routine (non-HIV) medical treatment, if affected children can get someone to take them to a health care centre, they may be made to sit separately, wait until last, have nurses refuse to dress wounds or give injections, be placed in a corridor rather than a ward, referred to another centre, or simply turned away. They say it is assumed they are HIV-positive.

When asked about exclusion from other services, ten focus groups in Nagaland reported discrimination by anganwadi<sup>2</sup> workers in giving food aid while two groups in Maharashtra said subsidised food grains did not reach affected children.

Other children, influenced by their parents and role models, are often the instruments of the exclusion and abuse of affected children, although exclusion is also self-imposed by affected children or their caregivers in an attempt to avoid mistreatment and further stigmatisation.

Both affected children and caregivers said the main reason for their exclusion was other peoples' fear of HIV/AIDS. They said this fear arose from a common belief that children with positive parents are always HIV-positive themselves, and that infected children can transmit the virus through casual contact with other children and adults.

For their part, only a minority of service providers said they were aware of barriers like those described by affected children and their caregivers. Key informants were less likely to have heard of barriers to education than to children's wellbeing or medical care, and far less likely to have encountered barriers in the north east than in the southern states.

An overwhelming majority of key informants said the best way to overcome barriers which prevent children affected by HIV/AIDS from accessing all kind of services was to raise the awareness of the general public and, to a lesser extent, of the service providers themselves, particularly on the ways in which the virus is transmitted.

The second most common recommendation from key informants was for various forms of targeted financial support for affected children and their caregivers, ranging from educational scholarships to health insurance, or reserved jobs for their parents.

A few key informants proposed measures to regulate service provision to people affected by HIV/AIDS, while a very small minority proposed mandatory HIV-testing and disclosure, or separate facilities for children with positive parents or who are infected themselves.

## **Observations and conclusions**

In contrast to many studies elsewhere<sup>3</sup>, poverty was not the barrier most frequently cited by affected children and their caregivers. One likely reason for this difference relates to the

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<sup>2</sup> Under India's Integrated Child Development Scheme one Anganwadi worker serves a population of 1,000 in terms of health, nutrition and child development including regular check-ups, immunisation, health education and non-formal pre-school education. [http://www.manage.gov.in/RRSites/Ghatkesar/anganwadi\\_worker\\_health.htm](http://www.manage.gov.in/RRSites/Ghatkesar/anganwadi_worker_health.htm)

research method – focus group participants were asked to identify barriers which are unique to children affected by HIV/AIDS, and to exclude those which also affect their neighbours.

Another likely reason is that most children from poor households in India have nominal access to essential public services<sup>4</sup>. Unfortunately many are effectively excluded from these services by social factors such as gender, caste, parental expectations and, most recently, by HIV/AIDS<sup>5</sup>. Although poverty is unquestionably linked to HIV/AIDS in India as it is elsewhere, the immediate problem may be that the stigma attached to HIV/AIDS prevents people from accessing the very services which will allow them to escape their poverty.

Despite the existence of poverty reduction and mitigation services, a significant number of public service providers recommended separate economic strengthening measures for HIV/AIDS-affected households. Unfortunately other countries have found that people exclude themselves from benefits and services which are unique to those living with HIV/AIDS for fear their participation will expose them to stigma. Indeed, this study found that members of affected households want to be treated like everyone else, not singled out for special benefits.

From a programming perspective the first priority is clearly to ensure that HIV/AIDS-affected children and families are not excluded – by officials, by communities, or by their own fear or lack of information – from the same services and benefits that others are getting. However, one of the chief impediments to overcoming these barriers is likely to be that many service providers are not aware – or do not believe – that children with HIV-positive parents are being excluded or treated any differently to other children.

Another impediment to accessing services is the widespread belief among both public officials and society generally that children affected by HIV/AIDS pose a public health risk, and need to be separated or treated differently to other children.

When asked for suggestions on how to overcome these barriers, the overwhelming majority of service providers recommended raising public awareness of HIV/AIDS, to overcome stigma and discrimination. This view was shared by many affected children and caregivers, who specifically called for greater awareness that:

- children with positive parents are not necessarily infected themselves;
- even if they are HIV-positive, children cannot infect others through regular contact;
- HIV-positive children and parents can lead perfectly normal lives, thanks to advances in medical treatment.

This awareness needs to be reinforced by:

- messages to public service providers – including teachers, doctors and anganwadi workers – that they have no reason (and are not allowed) to discriminate against children with HIV-positive parents or children orphaned by AIDS;
- messages to the general population that HIV/AIDS-affected children and families have the same rights and entitlements as others, and that there is no reason to exclude them from the same public facilities and family life enjoyed by other children;
- messages to the general population to tell them who they should turn to for redress if they are excluded from public services or entitlements for any reason, including HIV/AIDS.

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<sup>3</sup> For a summary of global and regional literature, see *Children affected by HIV/AIDS in South Asia – a synthesis of current global, regional and national thinking and research*, UNICEF Regional Office for South Asia, April 2007

<sup>4</sup> *Index of Programming Effort in six high prevalence states of India, 2006*. UNICEF (in draft).

<sup>5</sup> For example see G Köhler, J Keane, Analytical workshop report, in: *Social Policy: Towards Universal Coverage and Transformation for Achieving the MDGs*. UNICEF ROSA 2006; G Köhler, *The South Asian Development Paradox*. In: *Himal Magazine*, August 2006

## Introduction

In many respects HIV/AIDS is just like other disasters which can befall a family, incapacitating parents and placing the future of their children in question. Indeed, most of the practical implications of the HIV epidemic are difficult to distinguish from those which accompany wars, natural disasters, and other epidemics.

However in at least one respect HIV infection is unusual, because the fear and shame attached to the virus often prevents those who are affected by it from accessing services which would otherwise be available to them. Time and again international research highlights the exclusion – intentional or otherwise – of children and families affected by HIV/AIDS from services which are available to others, although it seems little attention has been given to this issue in India until now.

These “barriers to services” are seldom simple. They may be imposed by the provider of services, such as a school or hospital, or they may be self-imposed by those who need the services, for fear they will be abused or ostracised. Poverty, caste, location, age, gender and religion will often complicate the situation.

UNICEF, in association with the National HIV/AIDS Control Organisation (NACO) and the Ministry of Women and Child Development (MWCD), undertook this study with the governments of five high HIV-prevalence states in India to investigate the nature and extent of these barriers, and to propose measures on how to overcome them. These states were Andhra Pradesh, Karnataka, Maharashtra, Nagaland and Tamil Nadu. The study was also undertaken in Manipur, but the analysis of data was not completed in time for this national overview.

The study was based on the belief that, next to keeping HIV-positive parents and children alive and well, removing barriers to services may well be the single most important action which can be taken by state governments to make the biggest difference to the largest number of children for whom the impact of HIV/AIDS is greatest.

## HIV/AIDS in India<sup>6</sup>

The first case of HIV in India was detected in the state of Tamil Nadu in 1986. NACO says the number of HIV-positive persons has risen from 3.5 million in 1998 to more than 5.2 million in 2005. Several states in southern and north-eastern India have shown higher HIV prevalence and more diverse patterns of HIV transmission, but even low prevalence states are characterised by pockets of high risk, increasing the potential for the spread of the epidemic.

Based on data from antenatal clinics, NACO has identified six states in India as “high prevalence”<sup>7</sup>, with more than one percent HIV prevalence in general population; three states as moderate prevalence states (concentrated epidemics with HIV-prevalence of than 5% within high risk populations) and the rest as “low prevalence” states, although these have been further classified as “highly vulnerable” and “vulnerable” to increasing HIV-prevalence:

High Prevalence	Moderate Prevalence	Low Prevalence	
		Highly Vulnerable	Vulnerable
Tamil Nadu Andhra Pradesh Maharashtra Karnataka	Gujarat Goa Pondicherry	Assam; Bihar; Delhi; Himachal Pradesh; Kerala; Madhya Pradesh; Punjab; Rajasthan; Uttar Pradesh;	Arunachal Pradesh; Haryana; J & K; Meghalaya; Mizoram; Sikkim; Tripura; A & N

<sup>6</sup> This section is extracted from the National AIDS Control Programme Phase III (2007–2012), National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India. November 2006 Draft.

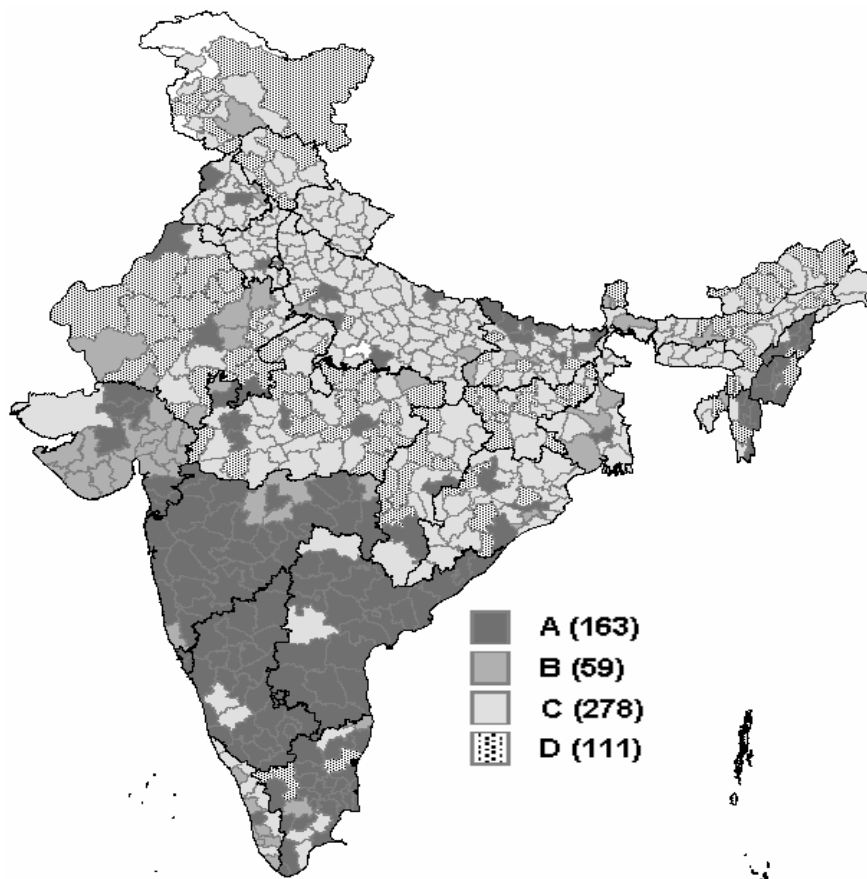
<sup>7</sup> The term is relative to other states in India – in global terms, all of India is “low prevalence”

Nagaland Manipur		West Bengal; Chhattisgarh; Jharkhand; Orissa; Uttaranchal	Islands; Chandigarh; D & N Haveli; Daman & Diu; Lakshadweep
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Based on HIV surveillance data, epidemiological profile, risk and vulnerability, NACO has classified the 611 districts in the country into four categories, characterised by:

- A. greater than one percent prevalence at antenatal clinics and through prevention of parent-to-child transmission at any time in any site in the last three years;
- B. less than one percent prevalence at antenatal clinics and through prevention of parent-to-child transmission in all sites during last three years, but greater than five percent prevalence in any high-risk group (sexually transmitted disease patients, commercial sex workers, men who have sex with men, and injecting drug users);
- C. less than one percent prevalence in antenatal clinics in all sites during last three years with less than five percent prevalence among all sexually transmitted disease clinic attendees or any high risk group with known hot spots (migrants, truckers, large aggregation of factory workers, tourists etc);
- D. less than one percent prevalence in antenatal clinics in all sites during last three years with less than five percent among all sexually transmitted disease clinic attendees or any high risk group, or no or poor HIV data with no known hot spots.

The location of these districts is indicated on the following map (source: NACO):



## **Children affected by HIV/AIDS**

It is not possible to know exactly how many children are affected by the sero-status of their parents. One of the main reasons is that HIV-positive people are submerged within the community, living with a secret that they dare not reveal even to those they love and trust.

Another reason is that the majority of infected people do not know they are, in fact, HIV-positive. Suggestions are regularly made (and were repeated during this study) that entire populations should be routinely tested. However, many people who know or suspect they are HIV-positive will actively resist any attempt to find them, count them, even to help them because they believe the help they get by revealing their status is less than the suffering this disclosure will cause, both to them and those closest to them.

Unfortunately this fear of disclosure is amply justified, as this study shows.

But if we cannot be exact on the numbers, can we at least get some idea of scale and proportion? As described in the previous section, mathematical modelling based on the number of pregnant women who test HIV-positive at antenatal clinics, and on sero-prevalence among members of high risk groups such as commercial sex workers and injecting drug users, give us a good idea of the magnitude of the epidemic and whether it's getting better or worse.

But what of the number of children whose lives are affected by the virus? They fall into three groups:

- Children who are HIV-positive themselves.
- Children who have a parent (or two) who have died from AIDS-related diseases;
- Children who have a parent (or two) who are HIV-positive.

A fourth group is made up of young people who are especially vulnerable to HIV infection but, for reasons explained below, they are not usually "affected" by the virus.

"Children" here refers to anyone who has not yet had their 18<sup>th</sup> birthday.

### **Children who are HIV-positive**

These are children infected at birth by an HIV-positive mother (vertical transmission) and young people infected by sexual intercourse or sharing hypodermic needles with HIV-positive people. Children infected through sex and needles tend to be adolescents and, although they are certainly "affected", they are generally grouped with adults or treated as a separate group entirely in the design of programmes. This group is not covered by this study.

There is very little agreement on the number of HIV-positive children in India. NACO say about 57,000 children are infected at birth in India each year, but do not estimate how many are living with the virus. In 2004 UNAIDS estimated 202,000 children were HIV-positive, but their December 2006 estimates are mute on the number of HIV-positive children in India.

To reassure ourselves that these data are "in the ballpark" one could take the number of women believed by UNAIDS and NACO to be HIV-positive (1.6–2 million) and estimate the average number of children each one has produced (say 1.5). We could guess that half of these babies were born before their mothers became infected, and we know that only a third of those born once their mother is HIV-positive will themselves be infected at birth, even without medical intervention. Unfortunately we also know that without diagnosis many – perhaps most – HIV-positive babies die within two years of birth. This rationale supports the belief that India has somewhere between 50,000–300,000 infected children.

## **Children orphaned by AIDS**

The second group are children orphaned by AIDS. Once again there are no official data, but the World Bank estimated that India had 1.2 million AIDS orphans in 2001.

Clearly, to be orphaned by AIDS, one or both of a child's parents must have died of AIDS. However, the international definition of orphan applies only to children, so a person ceases to be an orphan on their 18<sup>th</sup> birthday – at least for statistical purposes. So if we know how many men and women have died of AIDS, when they died, and how many children they had when they died, we can estimate the number of children orphaned, and how many are still children.

UNAIDS estimated there were 270,000 – 680,000 AIDS deaths in India to the end of 2005. A UNDP study said 111,608 AIDS-deaths were reported to mid-2005. We know most of these deaths were adults, and most were men. Making some assumptions about how many babies these adults may have produced before they died, and how many of their offspring are still under 18 years old, it seems reasonable to believe that anywhere between half a million and two million children in India today have lost one or both parents to AIDS.

Another way to look at this is to say that, since India is home to around 14% of the 40 million people who are HIV-positive globally, it could have a similar proportion of the 15 million children orphaned by AIDS<sup>8</sup> – which works out to around two million children. This will be pessimistic since the epidemic is younger in India than in many African countries.

## **Children with HIV-positive parents**

The third group is made up of children who have one or two HIV-positive parents. There are no available data but, if we know how many mothers and fathers are HIV -positive, and how many children they have, we can calculate how many children have an infected parent.

NACO estimates there are more than five million HIV-positive adults in India, approximately three million of whom are men. If the men have an average of two children, this means roughly six million children have an HIV -positive father.

A further four million or so children may have HIV -positive mothers but in most cases they will be the same children who have HIV -positive fathers. However, there may be another million or so who have an HIV-positive mother, but not an HIV -positive father – mothers who have contracted the virus from someone other than the father of their children.

Naturally there are a lot of variables in this estimation, as there are for the other categories of affected children, but it is likely that the number of Indian children with an HIV -positive father, mother or both is somewhere between six and eight million.

## **“Vulnerable” children**

The last group are referred to in India as “vulnerable children”, meaning they are unusually vulnerable to being infected with the virus.<sup>9</sup> They include street children, orphans, child prisoners, child labourers, the children of sex workers and, confusingly, children who are orphaned by AIDS or have an HIV-positive parent. Unfortunately in India this adds up to a very large number – certainly tens of millions of children.

However the majority of these children are not “affected”, since neither they nor their parents are HIV-positive. From a programming perspective, the emphasis for this group is to make sure they don't become infected – in other words, the goal is prevention, whereas for “affected” children the primary goal is mitigation of impact.

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<sup>8</sup> UNAIDS December 2006

<sup>9</sup> In many other HIV/AIDS-affected countries the word “vulnerable” is analogous to the word “affected”, referring to the vulnerability of a child's rights and wellbeing because a member of their household is HIV-positive.

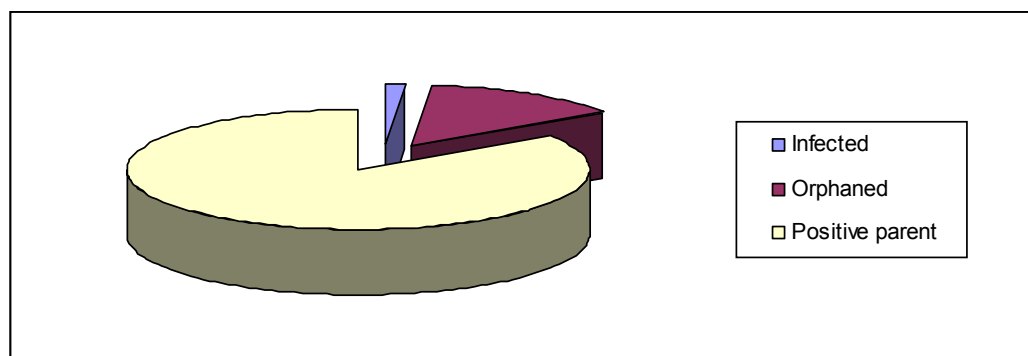
This study did not investigate “vulnerable” children, nor focus on prevention of infection.

### Summary of numbers

To summarise, the numbers of “affected” children are likely to be in the order of:

- 150,000 vertically infected children
- 1,500,000 children orphaned by AIDS
- 7,000,000 children with HIV-positive parents

Note that these categories are not mutually exclusive – an infected child will usually have a positive parent, and may also be orphaned by AIDS, while an AIDS orphan will often have another HIV-positive parent. So the total number of affected children is not necessarily the sum of these three categories. However, these numbers are sufficient to give a sense of scale and proportion. Presented in graphic form, the categories of affected children look like this:



The important messages from all of this are, firstly,

- that only a tiny proportion of affected children are actually infected – perhaps two percent and, secondly,
- that it is likely that anywhere between six and ten million Indian children have an HIV - positive parent, or have been orphaned by AIDS.

Another way to express this is to say that, while

- less than one percent of adults in India are HIV-positive,
- about two percent of all Indian children are “affected” by the epidemic
- about two percent of “affected” children are actually infected.

### Study objectives

- To identify barriers encountered by HIV/AIDS -affected children and their caregivers to services in the education, health and social welfare fields, particularly those barriers which are specific to or aggravated by HIV/AIDS, and those services which are or should be provided by state governments;
- To identify actions which can be taken by relevant departments in the state governments to overcome these barriers .

### Study process

The need for this research was identified during a series of workshops in the five high HIV-prevalence states during August and September 2006. The meetings were convened by the

State AIDS Control Societies at the request of UNICEF and attended by senior officials from state government departments concerned with providing services to children in the fields of education, health and welfare, as well as NGOs and networks of HIV -positive people.

Each meeting began by conducting the Index of Programming Effort exercise. This exercise measures programmatic efforts to mitigate the impact of HIV/AIDS on children and solicits the views of local stakeholders on priorities for future action. The exercise identifies areas of strength and weakness to guide planning, and provides baseline data to measure the impact of future action. Data from this exercise are incorporated into this report.

Participants in the state workshops were asked whether they would actively support research to establish whether children affected by HIV/AIDS were treated differently to other children in the delivery of social services such as education, routine health care and family support. Each state agreed to establish a “Core Group” to advise a state research team on the location of research sites, to open doors for the researchers by contacting their colleagues in those areas, and to review the recommendations emerging from the study.

UNICEF recruited a research team in each state consisting of a Lead Researcher and six Research Associates. The Lead Researchers attended a workshop in Manesar, Haryana, from 9–13 October 2006, at which the research design was finalised and the method for the first phase – the focus group discussions with affected children and their caregivers – was developed and tested. The Lead Researchers trained their teams, field -tested the tools, identified research sites and established contact with NGOs and networks of positive people who were asked to recruit children and adult respondents for the focus group discussions.

When the focus groups were completed in all five states, the Lead Researchers met again in Delhi on 25/26 November 2006 to review the outcomes and develop a questionnaire for key informants based on their findings. Once again they trained their Research Associates and recruited key informants with the support of the Core Groups and UNICEF personnel.

When the key informant interviews were complete the Lead Researchers collated and analysed the data according to a standardised method which was developed collaboratively, and submitted their data to UNICEF in February 2007 for incorporation into this overview.

The key findings of both focus groups and key informant interviews were extracted and presented to the Core Groups in most states in March and April 2007 for their reaction and suggestions on the way forward.

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This study was jointly developed and conducted by the following team:

UNICEF project supervisor	Dr Vidhya Ganesh
UNICEF project coordinator	Ms Mini Bhaskar
UNICEF technical facilitation and reporting	Mr Mark Loudon
Lead Researcher Andhra Pradesh	Mr K Nelson Royal
Lead Researcher Karnataka	Mr S B Saoor
Lead Researchers Maharashtra	Prof. C P Prakasam, Prof. Abhay Deshpande
Lead Researcher Nagaland	Dr Yonah Bhutia
Lead Researcher Tamil Nadu	Ms Rani Mohanraj

This project could not have been undertaken without the active support of many people. At national level thanks are due to the National AIDS Control Organisation and the Ministry of Women and Child Development who, together with other members of the National Task Team on Children Affected by HIV/AIDS, endorsed the research concept and opened doors at state level for the research teams. A special word of thanks to Ms Rachel Odede, HIV/AIDS Specialist at the UNICEF Regional Office for South Asia, for her constant support.

The study was carried out in each state by a team of research associates, supported by a Core Group made up of senior personnel from State AIDS Control Societies, networks of HIV - positive people, various government ministries and NGOs, and UNICEF project officers. They in turn relied upon the goodwill and energy of many NGOs and networks working at grass-roots level, who recruited children and caregivers for the focus group discussions. Many of these agencies are named in the state reports, but our gratitude extends to them all – not only for their help with this study, but for their investment in our future.

However our greatest debt is owed to the respondents who gave unstintingly of their time, their trials and their trust, through focus groups and individual interviews. We truly hope we have represented them accurately and that this study leads to action which brings a measurable improvement to their lives. In particular, we dedicate this report to the hundreds of young people who spoke up bravely, and who told us what it means to be a child with an HIV-positive parent, or to be orphaned by AIDS. Never again can we say: “we didn’t know”.

## Research method

The study tests the hypothesis that children whose parents are HIV -positive, or who have been orphaned by AIDS, are less able to access essential services than children from unaffected households. “Services” include those provided by families and communities, and by government and civil society agencies.

The research objective was to establish whether this is the case and, if so, the nature and severity of the barriers, the type of services from which these children are excluded, and to develop recommendations on how to overcome those barriers.

The study focused specifically on family care, education and general medical services although respondents were invited to point out barriers to other essential services. This study did not focus on children in institutional care; on medical treatment of HIV-positive children; or on HIV prevention activities, as each of these were the subjects of separate research.

The subject of this study was a child with a parent who is, or was, HIV -positive. This definition included children with one or both parents who were HIV-positive, and children who had lost one or both parents to AIDS.

Qualitative research methods were used in a two -phase approach. The first phase employed focus group methodology with service consumers – adolescents and pre-adolescents with a parent who is or was HIV-positive, and caregivers of these children, both men and women.

Data from the focus groups were used to develop questions for service providers in the second phase, to establish whether they were aware of the barriers faced by HIV-affected consumers, and to explore the nature of this exclusion and the means by which it could be overcome.

Lead Researchers were also asked to review available literature to establish whether there were any other data relevant to the research objectives, emanating from or directly relevant to their state. In their reports they were asked to formulate action recommendations to state governments on overcoming barriers which place children in HIV -affected households at a disadvantage to their peers from non -affected families.

## Sampling

Nine research sites were selected in each state, in consultation with the Core Groups established at preliminary workshops, according to the following protocol:

- a minimum of one third of sites (at least three sites out of nine) had to fall into “C” and “D” districts (low prevalence) in terms of current NACO definitions<sup>10</sup>. The balance were located in “A” and “B” (high prevalence) districts ;
- a minimum of one third of sites had to be classified as “urban” and a minimum of one third of sites to be “rural”. The balance could be urban, rural, peri -urban etc., as determined by the Core Group and research team;
- a minimum of one third of the focus groups in each respondent category had to be made up of members not recruited by networks of positive people, to reduce the natural tendency of members of any organisation to propagate the views of that organisation.

In each research site one focus -group discussion was planned for each of the following categories of respondents:

- boys and girls aged 9–12 (pre-adolescents);<sup>11</sup>

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<sup>10</sup> The criteria for this classification are given in the earlier section on HIV/AIDS in India

<sup>11</sup> No siblings within the same focus group, but siblings may attend different groups (eg: a younger sibling in the pre-adolescent group, and the older sibling in the adolescent group).

- boys and girls aged 14–17 (adolescents);<sup>12</sup>
- female primary caregivers of children who have, or had, an HIV -positive parent;<sup>13</sup>
- male heads-of-households which include at least one child who has, or had, an HIV -positive parent.

Intermediary organisations – networks, NGOs, State AIDS Control Societies etc. – were asked to recruit 15 people for each focus group. The number of participants in each group was ideally in the range 8–12 with an absolute minimum of 7 and an absolute maximum of 15.

The actual sample size is shown in the table below.

	Pre-adolescents		Adolescents		Caregivers		Heads of Household		Totals	
	Groups	People	Groups	People	Groups	People	Groups	People	Groups	People
AP	9	86	9	77	9	92	9	79	36	334
KN	4	37	7	64	10	92	9	83	30	276
MAH	7	59	8	83	9	114	8	102	32	358
NG	4	35	4	31	9	81	9	69	26	216
TN	8	64	5	40	9	108	9	108	31	320
Totals	32	281	33	295	46	487	44	441	155	1504

In the second phase of the research, key informants were recruited by the Lead Researchers with the help of Core Group members, and comprised individuals who were considered to be expert in one of the three fields of enquiry – children’s wellbeing, education and routine medical care – as well as a group of people who had insights into all three of these fields, the so-called “cross cutting” respondents.

Key informants were located at block/local level, district level and state -capital level. As far as possible block and district interviews were conducted in the same areas as the focus groups in the first phase of the study. The key informants are described in the following table:

Level	Wellbeing	Education	Medical Care	Cross Cutting
Block/ village	Supervisor of Anganwadi worker/ ICDS workers/ Self Help Group  Leader/ president Panchayat Samiti {village council in Nagaland}  Member of peer group/ youth clubs/ Nehru Yuva Kendra/ students’ federation	School teacher [mix private and government..]  School principal [not from same school as teacher]  Inspector of schools/ member of education committee of Panchayat {village council in Nagaland}	Medical Officer in charge of Primary Health Centre/  Para-medical staff [“gatekeeper”, first person to meet/ screen child at PHC]  Private [non government, alternative] medical practitioner/ Registered Medical Practitioner	

<sup>12</sup> Children aged 13 can join either group, depending on their apparent maturity.

<sup>13</sup> Respondents need not be HIV-positive, eg: the aunt or grandmother of a child who has an HIV-positive parent or who is orphaned by AIDS. Only female caregivers will be included to keep the group homogenous. A similar rationale applies to the male heads-of-household group. If possible the men and women should come from different households.

District	Chief Executive Officer of Zilla Parishad District Social Welfare Officer or equivalent	District Education Officer [Elected] chairman of education committee Zilla Parishad	Chief of hospital/ health care centre medical service (eg: Civil Surgeon) Elected member of Health Committee, Zilla Parishad	Collector: ensuring access to shared facilities Deputy Superintendent of Police: action in cases of discrimination
State	Director [technical] DWCD Secretary [policy] DWCD Minister of Social Welfare/ Women and Child Senior person in NGO implementing programmes in that state with children's wellbeing, children's rights	Secretary [policy] Department of Education Director [technical] Department of Education [primary education] Director [technical] Department of Education [secondary education] Minister of Education Senior person in NGO working in education/ advocacy	Indian/ State Medical Association [ethics officer] Secretary [policy] Department of Health [medical] Director [technical] Department of Health Minister of Health	Project Director of SACS State network of positive people UNICEF (where applicable) State core group members (if not covered elsewhere)

The actual number of key informants interviewed is shown in the table below:

	Wellbeing	Education	Health Care	Cross-cutting	Totals
AP	18	17	17	10	62
KN	18	19	17	7	61
MAH	16	18	16	10	60
NG	18	20	18	8	64
TN	17	15	17	9	58
Totals	87	89	85	44	305

In total, therefore, more than 1,800 people were interviewed across the five states, either by means of focus group discussions or key informant interviews.

### Focus group discussion methodology

Focus groups were conducted in the local language. The areas of enquiry for children's and adult focus groups were essentially the same. In each case, the moderator drew a picture of two children and said:

*Here we have a child who has a parent living with HIV, and here we have another child whose parent died of AIDS. Everyone in the community knows that (child A) has a parent living with HIV/AIDS, and that a parent of (child B) died from AIDS. However, these children are not themselves HIV-positive – although the community may not know this, or believe it.*

*We want to know, from your own experience and observations (not your imagination!) how the status of that parent affects the life of these children – specifically whether they have difficulty accessing any kind of support or service which is available other children in their community in the following areas:*

- *where that child lives, how s/he is raised*
- *attending school*
- *getting (non HIV) medical care (doctor, dentist etc.)*

In addition, adult focus groups were also asked about barriers to other essential services, and children's groups were asked whether affected children had difficulty

- getting advice and emotional support
- having a say in decisions which affect him/her.

In each case the data supplied by the group were subject to a screening ("does this barrier only apply to affected children?") and ranking process (choose the three most important barriers and rank in descending order of importance) by the group itself, in order to ensure that the barriers described applied only to affected children, and that they were considered by the respondents to be the most frequent and serious forms of exclusion facing those children.

### **Key informant interview methodology**

Service providers were given some background on the study and presented with three sets of examples of exclusion which were common to the experience of focus groups across all five states. These examples correlate with the findings given in the next section of this report<sup>14</sup> and were grouped under the following headings:

Wellbeing – barriers which

- affect the quality of life of the child;
- affect the social relationships and self esteem of the child;
- affect the ability of the child to influence decisions which affect him/ her.

Health – barriers which

- affect the child's access to professional medical care;
- affect the child's access to medical care at home;
- subject the child to stigma in a health care context.

Education – barriers which

- affect the child's ability to get an education;
- affect the quality of education given to the child;
- affect the self-esteem, socialisation of the child.

Cross-cutting – barriers which

- affect the quality of life, social relationships and self esteem of the child
- affect the child's ability to get an education, and the quality of that education
- affect the child's ability to get professional medical care and medical care at home

In respect of each set of examples of exclusion, the informant was asked:

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*What should be done to overcome this barrier? If it does not happen in your area, what advice would you give to people in areas where it does occur?*

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<sup>14</sup> For the tool used in the key informant interviews, see Annex ...

## **Data analysis**

In order to produce comparable data from all five states, a manual analysis method was developed collaboratively by the Lead Researchers and national coordinators, using summarisation and aggregation of responses. The output of the analysis was a set of frequency files from both focus group discussions and key informant interviews. These are contained in the individual state reports.

## **Ethics**

Informed consent [Annex 4] was obtained from adult focus group participants and from the legal guardians of child participants by the NGOs and networks who recruited them. At the time of the focus group meetings, moderators confirmed that all adult respondents had given informed consent and children were individually interviewed to confirm that they were:

- aware of the nature of the meeting (that it concerned families affected by HIV/AIDS) but that they would NOT be asked to disclose anything about themselves or their own family (questions would relate to an imaginary child);
- willing to participate and express their point of view in front of other boys and girls of their age, some or all of whom may be strangers;
- free to decline to participate, or to leave the session at any time.

Children were also asked individually whether they had any questions or uncertainties about why they were chosen and why they were there. If they had any doubts or appeared at all distressed they were not included in the group discussion, but cared for separately until the session was over. In practice a number of groups were cancelled because sufficient qualifying children could not be found (see following section).

Key informants were approached in their official capacities and, as such, were not required to give written consent but were told that the interview was “on the record”. If they had any objection, the interviewer was instructed to terminate the interview.

## **Limitations and constraints**

### **Design limitations**

This study did not investigate:

- the medical treatment of HIV-positive children;
- the prevention of HIV-infection of children, either through behaviour modification (especially among adolescents) or prevention of vertical transmission (mother to child);
- custodial issues for affected children, such as family reconstruction, fostering, adoption and institutional care.

The selection of research sites was designed to cover a range of socio-economic conditions, but did not attempt to sample specific sub-groups such as the children of commercial sex workers, migrants or child labourers.

Due to limitations of resources – particularly time, the study did not collect household demographic or economic data on respondents, nor were focus groups conducted with children and adults who were NOT affected by HIV/AIDS for control purposes.

## **Children's awareness of parents' status**

The research team understood from the beginning that there was no way to get a truly representative sample of any group whose first priority is to remain invisible. They were obliged to work with adults who had chosen to make themselves known to networks of positive people, or had contacted NGOs working in the field of HIV/AIDS and, through them, with the (very few) children who were aware they had an HIV-positive parent or had lost a parent to AIDS.

The team engaged in considerable introspection on the subject of affected children's rights and wellbeing, and decided to stand firm on the principle that every young participant must be aware of their parent's status. Children who were not aware would naturally wonder why they were selected, and would inevitably suspect that their mother or father was infected with HIV or had died of AIDS – which would be an extremely traumatic realisation for them.

There were also concerns that, in their desire to support the process, parents or recruiting agencies might say that children were aware of their parents' status when, in fact, they were not or, worse, would tell their children about their status shortly before the focus group. It was therefore stipulated that children must have known for some weeks of their parents' status, and that each child would be individually interviewed before the group work to ask if they knew why they had been selected.

Where a minimum of seven qualifying children could not be found, the focus group was cancelled. In some cases Lead Researchers were able to constitute children's groups in other places, while in other states the number of children's groups fell short of the target.

## **Purposive sampling**

Since it was not possible to randomly select affected children and their caregivers, purposive sampling was unavoidable and a certain level of bias was expected as a result, although various tools were employed to limit this bias:

- Children were interviewed separately to adults, younger children separated from teenagers, and women from men. At least a third of all respondents in all states were NOT recruited by networks of positive people, but by NGOs or other service providers.
- The methods used were designed to weed out answers which were rehearsed but not heart-felt. Perhaps the best evidence of veracity was the sincerity and deep emotions displayed by those who participated in focus groups.
- Research associates in different states had no contact with each other. Lead Researchers collaborated on methodology but did not share their data until each phase of the study was completed.
- The screening and ranking of barriers by participants was designed to limited bias from the researchers, and this overview focuses on issues which were prioritised by multiple groups, in a majority of states.

While we cannot say the findings represent the experience of most affected children (the majority live in secret, or do not know they are affected and are therefore not treated differently to other children) the study provides clear evidence of how children affected by HIV/AIDS in five states and a wide range of social circumstances expect to be treated if their parents' status becomes public knowledge which, surely, is reason enough to act.

## **Coordination**

Two interconnected objectives made the coordination of the study particularly challenging. First, the need to produce comparable data from what were essentially five independent

studies and, second, a research design which called for the first phase – the focus group discussions – to be completed before the second phase of key informant interviews began.

This meant not only careful orchestration of design, method and analysis, but also that the overall pace of the study was dictated by the slowest state, which meant a study which was originally expected to take three months actually took six – and that one state was lost to this overview in the process (although it is hoped that it will be completed in the future).

### **Other constraints**

Other constraints during the research phases were encountered at state level, and are recorded in the individual state reports, but none are believed to have affected the outcome for India as a whole.

Different content and writing styles in the respective state reports have intruded to some extent in this overview document – for example not all of the state reports captured direct quotes from respondents and, where they did, their style varied. This may create the false impression that respondents in some states had more to say than those in other states.

However this does not affect the substantive findings given in the next section, which were compiled from the original frequency files, rather than the final state reports. For the sake of brevity, the findings draw attention to individual states only where they diverge significantly from the norm.

## **Findings**

### **The wellbeing of children with HIV-positive parents**

#### **Barriers to where a child lives and how s/he is raised**

Affected children focused on their exclusion from neighbours' homes and from playing with their friends, being forbidden to touch cups or plates, and barred by the community from common facilities like drinking water and shops. Children also mentioned discrimination by their own relatives in terms of food and clothing; indifference to their material and emotional needs; exclusion from rituals, festivals and marriage; and withdrawal from schooling – often so they can be put to work.

They spoke of being verbally abused, scolded, harassed, mocked and kept at arm's length by elders, neighbours, family and peers, and even separated from their parents to prevent them from being stigmatised or infected.

Children were very clear that the cause of their ostracism and mistreatment was fear of infection because it was assumed that they are HIV positive like their parents. They spoke of depression, loneliness, insecurity and feelings of worthlessness. “A single wrong step can lead to hell,” said one child.

Caregivers in all five states accused their relatives, friends and neighbours of mistreating and discriminating against their children. They confirmed that affected children could not find other children to play with and were excluded from access to common facilities.

Many adults referred to financial and health difficulties due to their illness, but this was only ranked as a priority – by both adults and children – in Karnataka and Tamil Nadu. Caregivers also mentioned the tendency of relatives to separate affected children from their HIV-positive parents, and their concern that their children would be orphaned and become street children.

Caregivers said affected children were growing up rejected and isolated, fearful of the future and always worrying about their parents' status. As with the children themselves, they blamed the “fear psychosis” surrounding infection, and one group said the public believed an infected family was cursed.

#### **Barriers to getting advice and emotional support**

Affected children laid equal emphasis on the fact that they don't get love and warmth from community elders, relatives and friends who don't bother giving them advice and support, and how they are ashamed, afraid to confide in others, unable to share their feelings and reluctant to approach friends and relatives for fear of rejection or public exposure.

Being treated like an untouchable at school, at social gatherings and in the community also makes it very difficult to establish contact with potential mentors. The child has no friends, does not know who to approach, and nobody is available in times of difficulties to support, guide, share problems and help them resolve issues.

Children in Andhra Pradesh said the biggest barrier was the lack of love and warmth from their elders, relatives and friends, who would not play, touch, kiss or hug them. Even their own parents are inclined to keep them at arm's length for fear of infecting them.

Not surprisingly the outcome for children is loneliness, exclusion and demotivation. Several groups spoke of hatred and depression, while others said they were labelled as children belonging to family with bad character.

## **Barriers to influencing decisions which affect their lives**

This question for children's groups was not well answered – some groups ran out of time before they could get to it, while others repeated information about social exclusion. Answers were more diverse, with fewer strong threads, and it was not clear whether all participants understood the question – or indeed the concept of having a say in decisions which affect their lives. It was also not clear whether the situation of children affected by HIV/AIDS was any different to other children.

The strongest message to emerge was that affected children had very little say in decisions which affect their lives and that no advice was given to them, nor were their opinions sought on their studies, careers, marriage or even trivial issues such as the stationery given to them for school. Their views were given no importance by others, with one group saying it was because their parents' decisions and choices in life were wrong.

Even if their desire to study further was heard, their parents were often unable to support them due to ill health or lack of income, and their recreational choices were limited because they were forbidden from playing with other children, or participating in social gatherings. Orphaned girls were often “looked upon with doubt and forced to marry early”.

## **Barriers to other essential services**

This question for adult focus groups produced a long list of diverse answers, rather than a few clear priorities. No two states prioritised the same issues – in Andhra Pradesh caregivers highlighted the exclusion of their children by barbers and rickshaw pullers; in Nagaland they singled out exclusion from public facilities like public toilets ; and in Maharashtra they top-ranked children's exclusion from religious and cultural ceremonies.

Quite a strong thread in the north-east was discrimination by anganwadi workers in giving food aid, with 10 groups in Nagaland listing it as a priority, while two groups in Maharashtra said the benefits of the social welfare schemes such as subsidised food grains did not reach affected children.

A frequent answer in many states, although only prioritised in Tamil Nadu, related to the parents losing their income or being evicted from rented accommodation and unable to find alternative housing because of their sero-status. Another concern was that affected children were often deprived of their entitlement to property by their relatives.

Comments which were interesting, although not frequently stated or ranked by participants as a priority in any state, included:

- priests do not allow affected children to enter their temples, telling them to pray from distance, while church elders discriminate against children “cursed with HIV/AIDS” ;
- affected girls do not get marriage proposals and are humiliated in the street with vulgar comments, while the “community spreads the status of the child like wild fire”;
- positive parents cannot take life insurance for their children ;
- police do not provide any help .

## **Panel 1: Children's wellbeing – the consumers' perspective**

“They (relatives) will not give proper food or drinks, only the leftovers after everyone has finished eating.” Boy, 10, Nagaland.

“In an argument, when we voice our opinions, it is not considered. People right away point

out our parent's status and refuse to consider what we are saying." Boy, 16, Namakkal.

"No one has told me about my father's health condition. I see him falling sick often and I have no idea how to deal with this, what sort of medication or treatment needs to be given. I wish someone would guide me on how to deal with all this." Girl, 15, Madurai.

"It is difficult to seek somebody for advice. What if they tell about our parent's HIV status to others?" Girl, 17, Chennai.

"While I am still alive my relatives ill-treat the child. I cannot think of what will become of my child after I die." HIV-positive mother, Nagaland.

"They think that if the mother is positive then the child also is positive." Caregiver, 74, Chennai.

"Usually the community brand the HIV affected families with those having bad character and no values. Thus they believe that the children also, especially the adolescent girls, have immoral behaviour. Hence most of such girls remain unmarried. Instead of supporting, neighbours spoil the alliances when groom's family makes enquiries." P.L., Andhra Pradesh.

"When the child goes to neighbour's house, they close the door on the child's face." Man, 40, Chennai.

"Within one year, I have changed six houses due to the peoples' behaviour and owner's objection because I am HIV positive. Due to this my children's study and his friend circle is getting affected." N. S., Andhra Pradesh.

"In few villages, some neighbours have raised their walls so that they cannot see the faces of the HIV infected neighbours in the early morning, which according to them is a bad omen." T.G., Andhra Pradesh.

"There was a time in the village when people were scared that just by looking at an infected person they might get infected. Now due to some awareness programme people have got over that misconception." Household head, 62, Nagaland.

"My husbands' relatives have cast an evil eye on our property. They want to separate my kids from me as I am HIV infected, in the pretext that the infection may spread to the kids. Their hidden intention is to join the kids in the orphanage and snatch our property." P. G. Andhra Pradesh.

### **Overcoming barriers to the quality of life of affected children**

Service providers across the five states differed widely on whether affected children did indeed face barriers to their quality of life because of the sero -status of their parents, with those in Andhra Pradesh and Karnataka more likely to have encountered cases, while those in Tamil Nadu and Nagaland were least likely to be aware of this exclusion<sup>15</sup>. However, they were all asked to make suggestions on how to overcome these barriers, either in their own areas or in those areas where this exclusion might occur.

By far the most frequent recommendation by key informants across all states was to build awareness of HIV/AIDS. Respondents offered a wide range of suggestions on who should benefit from this awareness-raising (mostly the general public); who should conduct it (various government and civil society organisations); and the media and messages that should be used (generally modes of transmission). Details are contained in each state report.

The second most frequent recommendation in four states, but afforded top priority in Andhra Pradesh, was to build the capacity of positive parents and AIDS widows – for example through financial assistance, employment opportunities, vocational training courses, pension and housing schemes, free food, medicines, education and access to medical facilities.

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<sup>15</sup> See table in the next chapter for data on the proportion of informants who were aware of cases

Reducing stigma was also a popular recommendation, for example by training government officials and grass-root workers to remove misconceptions, change their behaviour, and to reinforce the humanity and moral values of society.

Yet another suggestion from most states was that village administrative officers or Panchayat members should identify the most vulnerable widows, assess their needs and provide services, or offer peer-group support and help for the terminally ill.

### **Overcoming barriers to social relationships and self esteem of affected children**

Once again there were divergent opinions among service providers as to whether affected children face difficulties which other children do not. Key informants in Karnataka were very likely to have come across examples of this kind of barrier, while those in Tamil Nadu and Nagaland were unlikely to be aware of cases.

Awareness-raising was once again the most frequent recommendation in all states, with respondents suggesting that efforts focus on sensitising local leaders and rural communities, encouraging all to consider HIV/AIDS just like any other disease.

The second most popular recommendation was that government should provide free education, hostel facilities, and preferential employment to positive parents or affected children. NGOs should ensure affected children are allowed to stay in the community and neighbours are compassionate; build the capacities and confidence of positive parents; and encourage affected children – for example through sports and extra curricular activities.

In this question, as in others, a small number of key informants suggested separate facilities such as residential schools (hostels) for affected children. This thinking appears to be somewhat more prevalent in Maharashtra and Tamil Nadu than in the other states.

Conversely, a limited number of key informants called for legal action against people who discriminate against positive parents or affected children, while a few respondents proposed working towards eliminating stigma among public and private service providers.

Some of the less frequent suggestions were to:

- stop projecting HIV as deadly/scary/ugly disease which instils fear among people;
- test all affected children and issue a certificate to be used whenever they need “to prove themselves” or access benefits or services;
- set up separate centres for affected children; provide hostels for the children of positive parents; set-up separate corporation for positive people.

### **Overcoming barriers to affected children’s ability to influence decisions**

None of the key informants in Nagaland, and very few in Tamil Nadu were aware of barriers facing affected children in influencing decisions which affect their lives – although nine out of ten service providers in Karnataka were aware of such cases.

Once again raising public awareness was the first choice of action in most states, on issues ranging from early child marriages and married life, to HIV/AIDS transmission and supporting HIV affected families.

However, key informants in Karnataka gave top priority to building the capacity and confidence of positive parents and children, while respondents in Tamil Nadu overwhelmingly proposed counselling for parents of affected children, to help them plan for their own and their children’s futures.

Financial assistance to affected families was another recurrent theme, particularly in Andhra Pradesh where it was suggested government and “well-off people” should pay for education

and other opportunities for HIV-affected families and children to avoid social imbalance. In Maharashtra a number of key informants said government should provide funds for the welfare of affected children, and for subsidised food or rations to their families.

The necessity of educating children and the community generally on children's rights and on the services available for their benefit was mentioned by a few respondents in several states.

Less frequent recommendations included:

- boys and girls eligible for marriage need to be tested and the results shared with the community; social workers must make parents aware of their children's wishes ;
- people in respectable position should practice what they preach about discrimination against HIV/AIDS; each district officer or local politician should take care of at least one affected child or AIDS orphan with their own resources ;
- take legal action against people who discriminate, enforce a law to reduce all kinds of discrimination; (public awareness) messaging needs to be changed from a sympathetic, welfarist approach to a confrontational, rights-based approach.

## **Panel 2: Children's wellbeing – the service providers' perspective**

### **Children's wellbeing – the service providers' perspective**

"These children are not allowed to play with other children in the neighbourhood."  
Krishnaveni Palpandian, President, Panchayat, Vadipatty, Madurai district.

"I have seen relatives not allowing PLHAs (people living with HIV/AIDS) or family members to come for family functions and insulting them." Amudha, Supervisor, WB Assisted ICDS project III, Chennai.

"Yes, I am aware of such things, fear of social discrimination makes the HIV-positive parents to force their children to accept their decisions." Dr. Premleela B S, Additional project Director, Karnataka state AIDS prevention society.

"When President of India visited Hyderabad, the affected children were reported as infected children by the media. This triggered lot of doubts and discrimination to one girl child and their family members. The issue was partly resolved after we got the child tested for HIV and the negative result was distributed to the neighbourhood and counselled them. The media need to be sensitized and trained to cover issues related to HIV/AIDS."  
Govind Prasad, Project Coordinator, Lepa Society, Hyderabad.

"Few months back some people came to me and complained that there is an infected family in their locality and that they should be evicted from the colony because they might infect others. But I didn't know of the ways how to protect them. I tried to tell the people who complained that I have no such right to evict them and that they have equal right to stay in the colony. I called an NGO who is working for HIV/AIDS and asked them to hold awareness meeting in that locality. But even then I heard that the family left the area".  
Toshi Yanger, Ward Representative, Dimapur Municipal Council.

"There is no such problem in Namakkal because the district administration has prioritised HIV care programmes. There is monthly income schemes, loan assistance, help in getting subsidies, etc. I have instructed to recruit all PLHAs who have applied for anganwadi post. And we are give priority in allotting houses or plots for those people living with HIV/AIDS." Sundaramoorthy, District Collector, Namakkal

## The education of children with HIV-positive parents

### Barriers to education

The greatest concern of affected children in relation to their schooling was ostracism and humiliation by their peers, who refuse to share tables at school, share lunch, or play with them. Young participants spoke of becoming demotivated at school, losing interest, falling behind in their studies, becoming depressed and angry, and even dropping out of school.

They say their friends behave in this way because their parents tell them not to play with affected children, while other parents try to get schools to refuse admission to children with positive parents. Unfortunately it appears they sometimes succeed because a number of affected children said they were refused school enrolment by principals or administrators.

It is also clear that many teachers actively discriminate against or mistreat affected children in the classroom by avoiding, neglecting or abusing them – for example by using their parents' status and supposed transgressions to humiliate these children in class.

A number of children's groups also mentioned financial difficulties arising from their parents' infection – through discrimination at work, or incapacitation by illness – as a barrier to their education, although this was only ranked as a priority in Andhra Pradesh. Some children have to abandon their schooling to care for parents, or to supplement household income.

Adult caregivers across all five states were unanimous that the most important barrier to education for their children was discrimination by teachers. A significant number also mentioned that children with positive parents are refused admission to school, some pointing out that the headmaster or school administrator was influenced by other parents.

Caregivers also emphasised the shabby treatment their children receive from other children, and referred to discrimination outside the classroom – for example exclusion from extra curricular activities, being forced to sleep outside hostel rooms, and even being refused access to drinking water and toilets by school helpers.

### Panel 3: Education – consumers' perspective

"Children don't say anything. It is their parents who tell them not to be friendly with us."  
Boy, 10, Madurai.

"They humiliate us by talking ill of our parents." Girl, 16, Madurai.

"It is difficult to have our own ambitions. Parents or relatives don't ask us to aim big. There is no confidence in us." Girl, 15, Chennai

"A teachers says: 'Don't go near that child – you also will get infected.' In school van, other children won't sit near children who have HIV-positive parents." Girl, 12, Chennai.

"I have no interest or motivation to study. My parent's sickness is always on my mind. I am also worried that my friends might find out about their status. It is a nagging feeling."  
Girl, 16, Chennai

"I was told (by the school authorities) not to mention my HIV status to anyone in school as this would affect their admission rates." Woman, 32, Namakkal.

"The headmaster requested me to take all books from the school and teach the child at home but refused to allow child in the school." HIV-positive father, 38, Nagaland.

"Even if the child is very intelligent he will not be able to pursue his studies because admission is denied." Grandmother, Nagaland.

"My child was given mid-day meal in a separate room in school because I am HIV

positive.” Household head, age 46, Nagaland.

Ms. S said that at the time of admission of her child in the school she was asked to bring the health report of the child that he is HIV negative. But she didn't enrol the child in the school thinking that other children might humiliate him later on. Andhra Pradesh.

“When I took my child to Government High school for admission, the Principal refused to take admission. The reason stated was that he has to face other parents, who will pressurise him and that school may lose its reputation”. K.R. Andhra Pradesh.

Ms. K shared that her son was sent out from the school after knowing that he has HIV positive parents. He was again joined back into the school after one of local NGO head intervened. This tragic experience depressed her husband so much that he died after few days. Andhra Pradesh.

Ms A. described a pupil's experience, when a teacher pointed to him and said: “Even after my insistence to headmaster not to join you, he allowed you to join in the school. Now you will spoil and infect others.” Andhra Pradesh.

### **Overcoming barriers to accessing education**

More than six out of every ten educational service providers interviewed in Karnataka, Maharashtra and Tamil Nadu had come across examples of affected children being excluded from education, whereas fewer than 30% of informants had encountered similar cases in Andhra Pradesh, and none had done so in Nagaland.

Key informants in all five states overwhelmingly recommended awareness raising programmes targeting school principals, teachers, other school staff, parents and children. Several respondents said teachers should receive special training and should spread HIV/AIDS messages to their peers and the community generally. Some proposed that teachers should act as counsellors for children and affected families or to “educate complaining parents and students” – for which they should be paid special allowances.

In all states, but most often in Andhra Pradesh, Karnataka and Nagaland, respondents called for stern action against teachers found guilty of discrimination or neglect of affected children, for example proposing that School Development and Monitoring Committees and Panchayats should monitor teachers' behaviour and take action against transgressors, including suspension and financial penalties.

A number of key informants, particularly in Andhra Pradesh, Maharashtra and Tamil Nadu, recommended supporting affected children who cannot afford education – for example with financial assistance, scholarships, books and educational equipment, or employment opportunities for family breadwinners.

In common with many questions posed to key informants, there were isolated suggestions of mandatory testing for affected children (to prove that they are NOT infected!) or the establishment of separate schools for affected children, although there were also balancing voices saying that separation is not the answer.

### **Overcoming barriers to the quality of education**

In three out of five states none of the service providers had encountered cases where the quality of education given to affected children was different to that given to other children. However in Karnataka more than one third, and in Maharashtra nearly two thirds of respondents confirmed that they were aware of such cases.

Respondents in four states prioritised the same actions – awareness raising and discipline – as they did to ensure access to education. Several suggested the education department should have a monitoring-and-complaint mechanism to pick up cases of discrimination in schools ;

that legislation and regulation should be updated; and that relevant departments should be asked to intervene on behalf of affected children. One suggested appointing a coordinator in every Panchayat.

In addition a significant minority of service providers in Andhra Pradesh, and a majority in Maharashtra said headmasters, teachers and administrators should give special attention to affected children – for example by sharing lunch with them, encouraging them to participate in games and cultural programs, and building their capabilities and skills inside and outside the classroom.

### **Overcoming barriers to self-esteem and socialisation**

More than 60% of service providers in Maharashtra were aware that having an HIV -positive parent could adversely affect a child's self esteem and social skills. However only a quarter or fewer of the respondents in the other four states had seen similar cases.

In Andhra Pradesh, Karnataka and Tamil Nadu the most frequent recommendation related to counselling and HIV/AIDS awareness among school pupils, for example to educate children on how to behave toward affected children and to remove their misconceptions in relation to the virus. Respondents in Maharashtra and Nagaland may have had the same idea in mind when they prioritised the training of teachers and school principals.

### **Panel 4: Education – service providers' perspective**

“A child was refused admission in a school in Madurai on account of parent's HIV status. The district education officer intervened and the child was admitted. Sometimes other parents complain and school authorities try to please them. Lack of proper information about disease is the reason.” Mr. Rajendran, assistant Elementary education Officer, Madurai

“Teachers in the schools are aware about HIV. So they don't discriminate these children. Rather they are helpful and understand the children's emotional needs.” Mr. Ramanujam, School Teacher, Melur, Madurai

“A regulation should be made to ensure that affected children's rights are protected.” Mr. Chidambarasami, Inspector general and Commissioner of Police, Madurai.

“In Hyderabad one auto driver was living in Alwal slum from last 10 years and recently he was found HIV positive. For last two years his daughter was going to anganwadi centre in the area. When the anganwadi teacher knew her parent's status, immediately she was sent out of the centre.” Govind Prasad, Project Coordinator, Lepa Society, Hyderabad Andhra Pradesh.

“An employer of Zilla Parishad died due to AIDS, putting his family into financial crisis. His wife applied for the post of Anganwadi teacher for her son. But due to fear of infecting other children who are attending the Anganwadi School from her village, she later took back her son's application.” T. Kavitha Bhasker Reddy, Chairperson, Education Standing Committee, ZP, Anantapur, Andhra Pradesh.

“In this district both in urban and rural areas, the HIV-positive people will not reveal their status to the community and to the school authorities, so there is no question of deny in enrolment or other parents opposing enrolment.” Mr. Hiremath, Deputy Director of Public information, Education department, Bijapur.

“A teacher died last year and after his death it was known that he was HIV positive. His wife is still a teacher and I have never found her or her children to be treated differently by anybody.” John Mathew, teacher, I.T.M School, Jalukie.

“We have initiated training and orientation to all school teachers and officers in education

department and this is being carried out regularly. So such incidences don't happen now. All schools are aware of stringent action if admission is denied on parental HIV status or the child's." Dr. Perumalsami, Director, Directorate of Teacher Education Research and Training, Chennai

## **Regular health care services for children with HIV-positive parents**

### **Barriers to accessing routine medical care**

Affected children across all five states were very clear about the mistreatment they receive in health care centres, saying that doctors kept them waiting until last, failed to examine or treat them properly, referred them elsewhere, or simply refused treatment. If they were seen by medical personnel, nursing staff sometimes refused to give them injections, dress wounds or dispose of used bandages.

Medical support staff often treated them in a demeaning manner, publicly labelling them as HIV-positive, scolding or humiliating them, while other patients refused to share waiting rooms or wards with them. Some children said that sweepers declined to clean their rooms. Even getting to a health centre was not easy, since relatives and neighbours would not take affected children to hospital and public transport would refuse to carry them.

Children in three states – Andhra Pradesh, Karnataka and Tamil Nadu – prioritised the difficulty they encountered in getting to medical facilities, or being admitted once there.

One group of children spoke about the fear, trauma and stigma they face when they accompany their HIV-positive parent on one of their frequent visits to a hospital for treatment, while several groups of children referred to their reluctance to go for medical treatment in case other patients objected.

Caregivers of affected children in all five states said the most important barrier in the health care context was the reluctance or refusal of doctors and staff to touch, examine, test or treat their children, with delays, referrals, hesitation and humiliation being the order of the day.

They condemned medical staff and other patients for disclosing their status to others and for insisting on separate seating or wards – even if this meant placing their children in corridors or refusing them admission. Like their children, caregivers in some states pointed to the reluctance of relatives and neighbours to take their children to get medical attention, and said they were sometimes asked to pay more than other people for treatment.

Several groups said private hospitals were worse than government facilities because they were concerned about other patients taking their business elsewhere, or had doctors who were reluctant to become known as “AIDS doctors”.

A number of caregivers referred to financial difficulties arising from their condition, which prevented them from obtaining health care for their children, although this was only listed as a priority in Tamil Nadu.

The reason for this discrimination was obvious to all focus group participants – the belief that a child with a positive parent is also infected, and that they can pass the infection on to others through casual contact. This fear of infection is compounded by moral judgement, as one participant put it: “they say AIDS mainly comes from IDUs<sup>16</sup> and whores.”

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<sup>16</sup> Injecting (or sometimes intravenous) drug users

## Panel 5: Medical care – the consumers’ perspective

“When the doctor knew my father was HIV positive, he did not want to give me injections... He gave tablets instead.” Boy, 15, Madurai.

“The doctors think twice before they treat us. They see us after seeing all other patients.” Boy, 14, Madurai

“Even when we are sick, parents do not take us to doctor. Therefore, we are scared that if we are not taken we may die.” Pre-adolescent, Mangalore.

“I don’t tell about my HIV status in hospitals. It would definitely affect my child’s treatment.” Male, 38, Chennai

“Other patients and nurses pass sarcastic comments about us. It is very disturbing for the children too.” Woman, house wife, 37, Chennai

“Intentionally they do not treat the child because they are aware that these are children with positive parents” Caregiver/counsellor, 38, Nagaland.

“One of the hospital staff spat on my child when she came to know that I am an HIV-positive parent.” HIV-positive parent, Moodbidri, Mangalore district.

“I went to show a doctor for TB. The doctor asked whether we wash clothes of all family members together or separately. He informed that contact with clothes can even spread the HIV virus.” S. S. Andhra Pradesh.

“Doctors scare that within three months, usually the AIDS patients die. That creates panic among the patients and their family members especially children. My husband is still living with AIDS since last 15 years.” K. S. Andhra Pradesh.

N. narrated the experience of one of his neighbour’s children, whose father died of AIDS. One day, he was suffering from fever and his mother was away at work. The neighbours refused to take the child to the doctor. There is a nurse staying in the same village, even she refused to come and attend on the child. Andhra Pradesh.

## Overcoming barriers to professional medical care

Nearly nine out of ten medical service providers in Maharashtra confirmed they had come across cases where children with positive parents were denied medical care, although only a third or fewer of key informants in the other five states were aware of this.

Informants in all states suggested intervening with the medical community, for example through regular training and counselling for private and government doctors and paramedical staff, the introduction of universal precaution measures, and communication to “change their adverse attitude” and create confidence among affected children and families.

The second most frequent recommendation was to build AIDS awareness within the general population, reduce stigma and trigger behaviour change. “We should create awareness to accept affected children at par with others” said one, while others spoke of “eradicating of corruption and delivering equal services to one and all.”

According to key informants – particularly in Andhra Pradesh and Nagaland – higher authorities should intervene if medical professionals are found guilty of discrimination while all hospitals should practice universal precautions and have sufficient staff to treat HIV patients. Less frequent recommendations included paying a risk allowance to medical staff, and training everyone in yoga.

## Overcoming barriers to medical care at home

More than three quarters of service providers in Karnataka and Maharashtra had encountered examples where children with positive parents had reduced access to medical care at home, while in the other three states only a third or fewer informants were aware of such cases.

The most popular recommendation across the five states was once again to conduct awareness campaigns within the general community. Some, such as the respondents in Nagaland, proposed lists of people in government and civil society who should be engaged in activities like sharing meals, kissing and shaking hands with affected children to illustrate that the virus is not transmitted through casual contact.

In Karnataka, the most frequent recommendation was to educate and support positive parents so they can take care of their own children, while in Maharashtra and Tamil Nadu a majority of respondents called for medical outreach programmes to treat affected children at home.

## Overcoming stigmatisation of affected children in a health care context

Most service providers in Maharashtra and Karnataka were aware that affected children were sometimes stigmatised in a health care context, while about one in eight respondents in the other states knew of such cases.

Promoting public awareness was the first recommendation to overcome this stigma, and a number of respondents said campaigns should focus on how HIV/AIDS is not transmitted.

The next most frequent recommendation was that doctors should show compassion to affected children and families to build their confidence, and should encourage other health workers to provide moral support to these patients.

Some respondents referred to the importance of empowering HIV-positive people to know their rights, and mobilising government and voluntary organisations to identify problems encountered by affected families and taking the necessary action.

One informant pointed out that “peoples’ behaviour has a lot to do with the system, culture and beliefs, which need to be addressed first.”

## Panel 6: Medical care – the service providers’ perspective

“Children get stigmatised because the integrity and moral values of parents is questioned.” Sampath Kumar, Deputy Director of Health Services, Namakkal

“Some health care professionals have turned away HIV-positive clients because they are afraid to treat them. Sometimes children also could face the same situation. Other patients don’t want them nearer to their beds because of fear of infection.” Dr. Karthikeyan, Paediatrician, Private hospital, Namakkal.

“In Wenlock hospital only it is happening, medical staff with the fear not treating without gloves and all. Treating these parents and children differently, by giving them disinfectant to spill on their beds and clean the toilet from them only, by giving cleaning agents after they use the toilet. It is applied to their children also.” Ms. Mynavathy, Staff nurse, Wenlock hospital, Mangalore.

“Heard many such things happening in the private hospitals, because of fear of losing other patients, the private hospitals will never allow the HIV-positive parents and their children to take treatment in their hospital.” Dr. Ramakrishna Rao, District TB Officer, Mangalore

“Discrimination is very high in private hospitals; most of the private hospitals will not entertain HIV-positive persons and their family members to enter in to their hospital

because of the fear of losing other patients.” Shivraj Sajjan Shetty, District Surgeon, district hospital, Bijapur

“Children of HIV infected can have a certificate which states that they are negative. This will help the child avoid discrimination.” Dr. Thiruvalluvan, Senior civil surgeon, Government Primary Health Centre, Ernapuram, Namakkal.

“Special wards for HIV affected or infected children may help prevent this stigmatization by other patients. Though this may segregate them, this is the only solution.” Dr. Krishnakumari Selvaraj, Medical Officer, Corporation Dispensary, Kodampakkam, Chennai

## Conclusions

Focus group participants told the research teams that the exclusion of children affected by HIV/AIDS from family, community and government care is widespread and damaging, and that it arises from a set of widely held misconceptions, specifically:

- that the child of an HIV-positive parent is likely to be infected;
- that an infected child is likely to infect others;
- that infected adults and children will die soon.

In addition, there appears to be an underlying belief among many members of society that isolating or mistreating people who are linked with HIV/AIDS will demonstrate their own morality, or act as a deterrent to others who are engaged in risky or immoral behaviour.

One may sympathise with such misconceptions when they are harboured by illiterate and underprivileged people, but when these people draw their cue from the behaviour of educated school teachers and community health professionals, the course of action is clear.

Interviewing key officials in each of the service sectors allowed the research team:

- to establish whether service providers were aware of the barriers faced by children with positive parents in accessing or benefiting from their services;
- to learn more about these service providers' own attitudes towards affected children;
- to ask for suggestions on how to overcome these barriers.

It is instructive to analyse their responses in each of these areas. Firstly, a majority of key informants were not aware of barriers like those described by the focus groups, as shown in the following table:

**Service providers who were aware of the exclusion of affected children (%)**

Sector	wellbeing			education			health		
	1	2	3	4	5	6	7	8	9
Barriers*									
Andhra Pradesh	72	44	33	29	0	24	29	35	12
Karnataka	89	89	89	74	35	26	35	76	59
Maharashtra	50	50	50	61	61	61	88	88	88
Nagaland	17	11	0	0	0	5	11	22	11
Tamil Nadu	24	12	12	64	0	0	18	35	12
Average for question	50	41	37	46	19	23	36	51	36
Average for sector	43			29			41		

\*Wellbeing – barriers which 1: affect the quality of life of the child; 2: affect the social relationships and self esteem of the child; 3: affect the ability of the child to influence decisions which affect him/ her. Education – barriers which: 4: affect the child's ability to get an education; 5: affect the quality of education given to the child; 6: affect the self-esteem, socialisation of the child. Health – barriers which: 7: affect the child's access to professional medical care; 8: affect the child's access to medical care at home; 9: subject the child to stigma in a health-care context.

In general, key informants were less likely to have heard of barriers in the area of education than for children's wellbeing or health. Respondents in the north east were far less likely to have witnessed these barriers than those in the southern states. Unfortunately the reasons for this diversity of experience across the states are not clear from the data.

Taken as a whole, however, the response of service providers could mean the exclusion of affected children is not as severe as the children themselves suggested, or it could mean that service providers are not in touch with the experience of these children. Before this study there was no solid evidence that children affected by HIV/AIDS were treated any differently, so it may not be surprising that public officials are not aware of their exclusion.

However the consistency of the data given by affected children, and backed up by their caregivers across five states, coupled with the awareness of their exclusion by a significant minority of service providers, strongly suggests that the plight of affected children is passing unnoticed by those who are in a position to do something about it.

The recommendations made by some service providers require further probing. For example, how would food rations for an affected family improve their children's ability to influence decisions which affect their lives? And why recommend targeted financial support so that affected children can attend school, when those children are already entitled to free education? Why resort to charity, instead of demanding their rights be fulfilled?

It is possible – and even likely – that some of the subtleties of the lesser recommendations been lost in the process of translation, aggregation and analysis. However, there can be no doubt at all about the views of the majority across all five states:

### **Awareness raising**

The most popular recommendation by far, to overcome every kind of barrier faced by affected children, was “awareness raising” – usually in relation to the modes of transmission of HIV. However, research and experience around the world suggests that knowing how you can be infected does not necessarily reduce stigma – in fact some messages may actually promote exclusion, particularly if campaigns use messages of fear or if they provide incomplete information on treatment, life-expectancy, human rights and social entitlements.

Evidence to support these concerns abounds in the five state reports – for example in one district of Tamil Nadu a youth coordinator said there had been enough awareness raising to ensure there was no discrimination against affected children. However both the Panchayat chairman and the anganwadi supervisor in the same district called for separate facilities for affected children – a step which is, in itself, clearly discriminatory. It is significant that none of the affected children or their caregivers in that district or anywhere else suggested separation, and fortunate that the Secretary for Social and Family Welfare in Tamil Nadu strongly opposes separate facilities “because it endorses stigmatisation”.

Regrettably, there is no simple recipe to overcome stigma and discrimination. Yet, until we do, we are destined to live with HIV, because stigma discourages people from being tested, seeking treatment, or informing their partners of their condition. Much is made of “living positively” but this is nearly impossible when disclosure instantly exposes HIV-positive people and those they love to social judgement, ridicule and exclusion.

The solution to stigma and discrimination clearly lies with those who practice it, not the victims of it. So, while it may be necessary to counsel people affected by HIV/AIDS to help them cope with the abuse meted out by a fearful and misinformed society, emotional support does little or nothing to overcome the cause of their anguish. On the other hand, if we could overcome stigma and discrimination (a systemic intervention) the need for counselling (a targeted intervention) would be dramatically reduced.

At the same time there is no value in trying to modify the behaviour of ordinary people when stigma and discrimination are blatantly practiced by those they regard as role-models – the doctors, teachers, senior bureaucrats and politicians. Interventions must start with, and be sustained among, people who are elected or paid to serve the public.

Stigma is always rooted in myth and misinformation. The debate on whether HIV-positive adults “brought it on themselves” will rage no matter what is written here, but there can be no debate about affected children. They did not “bring it on themselves” and, in the unlikely event they are infected, they are not going to infect anyone else until they become sexually active or unless they engage in intravenous drug use.

While “awareness raising” may not be the whole answer, it is certainly a vital component. Not, in this case, awareness of how to avoid infection, but rather awareness that there is

practically no chance that anyone will be infected by a child with an HIV-positive parent – even in the unlikely event that the child is HIV-positive themselves<sup>17</sup>.

There needs to be greater awareness, too, that neither infected children nor their HIV-positive parents are at immediate risk of dying, thanks to antiretroviral drugs which are now widely available in India. And these messages need to reach the doctors and teachers first!

For their part, affected families need to be aware of their rights and entitlements – particularly their right not to be excluded from those services which are available to everyone else – and also who they should turn to in the event that their rights are not honoured.

Happily there is a growing recognition of the value of a rights-based response, for example in Tamil Nadu where the Minister for Social Welfare, Dr. Poongothai, recommended that affected children should be made aware of their rights so they are empowered to make decisions concerning their lives.

### **Financial support**

Second only to awareness raising were calls from key informants in all five states for various forms of targeted financial support for affected children or their caregivers, ranging from scholarships to health insurance, or reserved jobs for their parents.

Laudable as these may appear, targeted benefits for affected children and families have produced limited results in other countries, where they have failed to reach the vast majority of those who need help. It is difficult and expensive to find and support a small group of people within a large population – particularly when most do not wish to be found.

Even when an affected family qualifies for support, they may be reluctant to accept this help because they are afraid it will lead to social isolation – drawing attention to themselves, and reinforcing perceptions that they are “different”. From their perspective, the choice is between stigma and starvation. It is grotesquely unfair, and unnecessary, to put people in this position.

In recognition of this paradox, the international move is towards universalism – designing interventions for all children at risk, and making sure that children affected by HIV/AIDS are not excluded from those services. Examples include social transfer programmes, which ensure that all families are able to meet their basic needs, and birth registration to ensure that all children are able to access their entitlements.

Significantly, very few recommendations in the latest international guidelines<sup>18</sup> on programming for affected children actually mention HIV/AIDS, and where they do they generally relate to medical treatment for the (relatively few) infected children, or addressing AIDS-related stigma. All the other recommendations apply equally to every child at risk.

### **Recommendations**

- It is absolutely vital that professionals in the health, education and welfare sectors are informed immediately and unambiguously about the LACK of danger posed by affected children to themselves and others, and that those professionals have both a legal and moral duty to treat these children exactly the same as any other child ;
- Simultaneously children and the general public – particularly in high HIV-prevalence areas – need to be informed that children affected by HIV/AIDS (including those who are

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<sup>17</sup> See Panel 10 for statistics to support this.

<sup>18</sup> Eg: Enhanced Protection for Children Affected by AIDS – a companion paper to the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS, UNICEF, March 2007, and Global Partners Forum for Children Affected by HIV and AIDS – Priority Recommendations. DFID, UNICEF, WB and others, 2006

HIV-positive) have the same rights as other children, and that there is no valid reason to treat them any differently to others;

- Finally, children and caregivers in HIV/AIDS-affected households – along with others whose rights are threatened for any reason – need to have access to a mechanism that can intervene on their behalf if they are excluded from their rights or entitlements. Such a mechanism should ideally also be able to refer children to specialists for help – such as counselling or family reconstruction – but the priority is to ensure that affected children not only know they have rights, but are able to enforce them .

## **Annex 1: Explanatory panels**

### **Panel 7: Targeted and systemic interventions**

There are two ways to help people. One is to find them, or to enable them to find you, and then provide a service to them. The other is to remove the root cause of their problem, or to remove the barriers which prevent them from helping themselves.

The first is a targeted or case-work approach. The second is a systemic intervention.

Targeted interventions tend to be small-scale, needs-driven, flexible, short term and inefficient (ie: the cost per person helped is relatively high). It is this kind of intervention which NGOs do so well.

Systemic intervention tend to be large-scale, rights-driven, inflexible, long term and efficient (the cost per person is relatively low). This is government territory.

When NGOs find themselves running large-scale, long-term, rights-driven programmes – such as those which are needed for children affected by HIV/AIDS – this is a signal that it is time for government to get involved.

Targeted interventions for people affected by HIV/AIDS are difficult, because in high prevalence areas there are so many people needing help, while in low-prevalence areas the intended beneficiaries are scarce and reluctant to be identified.

For this reason, there is a global trend to using systemic, universal interventions for HIV/AIDS – making sure those affected by the epidemic are catered for in regular health, education and social welfare services.

Civil society organisations continue to play a vital role by identifying and helping people who are excluded from these mainstream services, and by drawing the authorities' attention to weaknesses in their systems.

## Panel 8: From OVC to ART: shifting the paradigm

A range of programmes were developed during the 1990s to help children affected by HIV/AIDS, who were usually referred to as “orphans and vulnerable children” or OVC. Many of these interventions were based on the premise that their parents would fall ill and die, so causing social, economic and psychological problems for their children.

Typical projects included

- food gardens, micro-lending schemes and nutritional support – to support parents impoverished by AIDS, or feed orphans who were fending for themselves;
- palliative home-based care schemes for bed-ridden, terminally ill parents, so their children were not withdrawn from school to care for them;
- psycho-social support such as counselling and memory books, designed to help children cope with bereavement and rejection by their relatives;
- hospices for HIV-positive babies and children, whose parents did not have the capacity or will to care for them until they died.

However the roll-out of anti-retroviral therapy (ART) in recent years has shifted this paradigm. ART means that most parents who know they have AIDS are able to raise and provide for their children. It also means that far fewer children are infected at birth, and those who are infected can lead a relatively normal childhood.

As ART reaches more parents, many of the interventions of the OVC era are changing – for example counselling, nutritional support and home-based care are now used to ensure that AIDS-ill people receive and remain on ART, and baby hospices are closing down as the number of infected babies declines, and the prognosis for infected children improves. ART has shifted the paradigm from dying with dignity, to living positively.

In the process, ART is forcing programmers to take a hard look at stigma. Stigma discourages people from shifting their own paradigm through testing and treatment. Even where people with AIDS are in good health, stigma often leads to ostracism by families and communities, and exclusion from public services.

While parents seldom infect their own children with HIV, the stigma attached to the virus is highly contagious, and children with positive parents are often subjected to the same mistreatment since everyone assumes they are also infected.

Programmes in the ART era must focus on stigma, addressing both the manifestations (exclusion and abuse) and the causes (the myths and misconceptions).

## Panel 9: Programming around paradoxes

Programmers working in the field of HIV/AIDS spend their lives confronting paradoxes – truths hidden inside contradictions – including:

- The paradox of sectors: HIV/AIDS is primarily an adult health issue but, paradoxically, it affects the wellbeing of much larger numbers of uninfected children, over a greater span of time. Solutions lie in inter-sectoral collaboration, but government ministries are notoriously bad at talking to each other and to the NGOs who have so far led the response to affected children. Until they do, the solutions to HIV/AIDS will be elusive.
- The paradox of diagnosis: most people who are HIV-positive don't know it, and many who are ill do not realise they have AIDS. They almost certainly need the kind of interventions which were popular before ART appeared – but they won't get them, because nobody knows who they are! Paradoxically, as soon as they are diagnosed, they will have access to ART, which means very few of them will need that kind of intervention!
- The paradox of numbers: the better we become at diagnosing and treating HIV, the worse the problem will appear! As more HIV-positive people receive life-saving drugs, the pool of HIV-positive people will actually increase for a time, since they won't be dying as fast as they become infected. Paradoxically, this is GOOD news, because those who are receiving ART are less likely to infect others, and more able to raise their children and be useful members of society.
- The paradox of stigma: most people who know they are HIV-positive want help, but many are reluctant to come forward for testing and treatment for fear of disclosing their status. Paradoxically, if it wasn't for stigma, many of these people would not have been infected in the first place, because the people who infected them would probably have been tested, counselled and treated, thus reducing the risk that they would pass the virus on.
- The paradox of counselling: many people become ill, and many children become orphans, without needing counselling. Counselling is a feature of many HIV/AIDS interventions because the age-old challenges of illness and death are combined with a painful measure of stigma and exclusion. Paradoxically, counselling doesn't address stigma or exclusion, it simply helps people to deal with the resulting trauma. If there were no stigma, there would be very little demand for counselling.

## Panel 10: The risks of accidental HIV infection

Readers of this report are unlikely to share the widespread misconceptions that people can be infected by sharing food, utensils, toilets, clothing, bedding; or by kissing, hugging or even breathing the same air as an HIV-positive person. Transmission can occur only by exposure to the blood, semen, vaginal fluid or mother's milk of an infected person.<sup>19</sup>

The US Centres for Disease Control (CDC) investigates every unexplained case of HIV transmission. They have concluded there is no risk whatever of infection from tears, sweat and saliva, and say there has never been a documented case of HIV transmission due to exposure of a small amount of blood on intact skin. They estimate the risk of transmission from exposure of non-intact skin, or the eye, nose or mouth, to infected blood at less than one in a thousand.<sup>20</sup> Add this to the extremely low chance of being exposed to infected blood in a low-prevalence setting like India, and there's effectively no risk to anyone outside of a medical setting.

As for nurses and doctors, the most significant risk of accidental HIV infection is through needle-stick injuries (NSIs). However, the CDC estimates that 99.7% of NSIs involving infected blood do not transmit HIV. A review of NSIs over 24 years (1980-2003) in 172 countries involving 22.2 million nurses and doctors found that 18 million occurrences of needle-stick injury produce more than 27,000 hepatitis C infections, but fewer than 500 HIV infections, around the world each year.<sup>21</sup>

To give perspective, one could compare the risk of accidental HIV exposure to accidental exposure to cigarette smoke. Lung cancer is at least as deadly as AIDS – of 180,000 people diagnosed with lung cancer in the USA each year, 86% die within five years<sup>22</sup> while of 440,000 Americans living with AIDS, only 17,000 die each year<sup>23</sup>. Accidental HIV infection is extremely rare, and death by no means a certainty, whereas it is estimated 600 people in Britain alone die each year from lung cancer caused by passive smoking.<sup>24</sup>

Simplistic though this analysis may be, it hopefully demonstrates just how absurd it is for both medical and non-medical personnel to use the extremely small risk of accidental HIV infection as a justification for the neglect, abuse or exclusion of children they assume are HIV-positive, let alone those kids who are actually diagnosed with the virus.

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<sup>19</sup> AIDS myths and misunderstandings, AIDS InfoNet, Fact Sheet 158.

<sup>20</sup> Exposure to blood – what healthcare personnel need to know. Centres for Disease Control and Prevention, updated July 2003

<sup>21</sup> Global country-specific incidence rates of occupational HIV and hepatitis C infections by needlestick injuries. Drain PK and Holmes KK. *nt Conf AIDS*. 2004 Jul 11-16; 15: abstract no. MoPeC3549

<sup>22</sup> <http://www.quit-smoking-stop.com/lung-cancer.html>

<sup>23</sup> <http://www.avert.org/statsum.htm>

<sup>24</sup> Passive Smoking, ASH (UK) January, 2000, cited in Building public awareness about passive smoking hazards. American Cancer Society and International Union Against Cancer, 2003

## Panel 11: Regional action priorities for South Asia<sup>25</sup>

According to a synthesis of global and regional research prepared by UNICEF for the recent SAARC Regional Consultation on Children and HIV/AIDS, the following actions are likely to have the greatest positive effect on the largest number of children affected by HIV/AIDS in South Asia:

1. **Make sure HIV-positive parents remain alive and productive** – find ways to diagnose more of the people living with HIV, especially parents, and ensure all have access to treatment, and remain on their treatment programmes
2. **Make sure public servants are part of the solution, not part of the problem** – re-educate government service providers, especially doctors, nurses, teachers and local officials, to overcome those myths and misconceptions which sustain stigma and discrimination, and establish and enforce standards of non-discriminatory treatment
3. **Make sure parents raise their own children, rather than getting rid of them** – establish/expand/strengthen the nation's capacity for family reconstruction and support, such as nutritional support, home-based care, skills training (parenting and income generation), through all relevant departments and drawing on communities and NGOs
4. **Make sure people don't exclude their own children from vital services** – educate the public on their rights, entitlements, and the services available to help them raise their children effectively, whether or not they are affected by AIDS
5. **Make sure everyone knows the truth about AIDS** – that it's no longer a sentence of death, that children of HIV-positive parents are not usually infected, that infected children won't infect other children, and that HIV affects (and infects) the innocent as well as those engaged in behaviour which society finds abhorrent
6. **Make sure protection failures are detected and corrected** – establish a mechanism (children's advice offices, child protection officers etc.) which is accessible to everyone to give real help to parents who are denied entitlements and children who are neglected or abused, and to refer cases to specialists where necessary
7. **Make sure children in orphanages don't stay long, and are treated well while they are there** – determine and enforce minimum standards of institutional care, including measures to restore children to families as soon as possible (see #3 above) and to ensure their integration in local community life.

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<sup>25</sup> Children affected by HIV/AIDS in South Asia – a synthesis of current global, regional and national thinking and research, UNICEF Regional Office for South Asia, April 2007

## **Annex 2: Selected bibliography**

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- AIDS in South Asia – understanding and responding to a heterogeneous epidemic , Stephen Moses et al, World Bank, 2006
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- Discussion paper on the impact of HIV and AIDS on children in lower prevalence countries (for Global Partners Forum), Mark Loudon, UNICEF, February 2006
- Enhanced protection for children affected by AIDS – a companion paper to the framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS, UNICEF, March 2007
- Global Partners Forum for children affected by HIV and AIDS – priority recommendations. DFID, UNICEF, WB and others, 2006
- National AIDS Control Programme Phase III (2007–2012), National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India, 2007.
- Providing support to children affected by HIV/AIDS and their families in the low prevalence countries of India and Cambodia: programming issues. A discussion document (in draft). Linda Sussman, USAID/POLICY Project, 2006
- Report on the global AIDS epidemic, UNAIDS/WHO, May 2006
- SAARC regional strategic framework for the protection, care and support of children affected by HIV/AIDS. South Asia Association for Regional Cooperation and UNICEF Regional Office for South Asia, May 2007 (in draft)
- Socio-economic impact of HIV and AIDS in India, Pradhan et al, UNDP, 2006
- Study on child abuse 2007, Ministry of Women and Child Development, Government of India, April 2007
- The economic and social environment in South Asia 2006: Implications for children, Gabriele Köhler and Mariana Stirbu, UNICEF ROSA, February 2007
- The Integrated Child Protection Scheme, Ministry of Women and Child, Government of India. 27<sup>th</sup> draft, 27 December 2006
- Where the Heart Is – meeting the psychosocial needs of young children in the context of HIV/AIDS, Linda Richter *et al*, Bernard van Leer Foundation, July 2006

## Annex 3: Focus group discussion guideline

### Research title

Full title:

- Study of barriers to services for children with HIV-positive parents in the six high-prevalence states of India.

Short title:

- Barriers to services for children with HIV -positive parents

### Research description

The study is based on the hypothesis that children whose parents are living with HIV/AIDS, or who have been orphaned by AIDS, are less able to access essential services than children from non-affected households. These services include those provided by families and communities, and by government and civil society agencies.

The research objective is to establish whether this is the case and, if so, the nature and severity of the barriers, the type of services from which these children are excluded, and to harvest any ideas on how to overcome these barriers.

The study will focus specifically on family care, education and general health services, although respondents will be invited to point out barriers to other essential services.

HIV/AIDS-specific medical treatment (anti-retroviral therapy and prophylaxis against opportunistic infections) for parents and children, and HIV prevention (awareness and behaviour change) are specifically excluded from this study, as these are the subject of other research.

The subject of the study is a child with a parent who is, or was, HIV -positive. This definition includes children with one or both parents living with HIV/AIDS and children who have lost one or both parents to AIDS.

The definition also includes children infected with HIV through vertical transmission at birth, although the research method focuses on children who are not themselves infected, to avoid the natural tendency of respondents to focus on medical issues.

Respondents during the first phase of the study will include:

- pre-adolescent children with a parent who is, or was, HIV -positive
- adolescents with a parent who is, or was, HIV -positive
- female caregivers of these children
- male heads-of-household which include these children<sup>26</sup>

Sampling criteria for each group are discussed in more detail below.

These respondents will be recruited for focus -group discussions. Data from these discussions will be used to develop questions for institutions which provide services (eg: through key-informant interviews) to further explore the nature of the barriers and the means by which they may be overcome.

The full data set will be used to formulate action recommendations to state governments on overcoming barriers which place children in HIV -affected households at a disadvantage to their peers from non -affected families.

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<sup>26</sup> It is not assumed that caregivers are always female, or heads-of-household always male. However the sample has been restricted to make focus groups as homogenous as possible.

## Sampling

A minimum of nine research sites will be selected in consultation with key stakeholders in each state (ie: the “core groups” established at preliminary workshops) according to the following protocol:

- a minimum of one third of sites (ie: three sites out of nine) must fall into “C” and “D” districts (ie: low prevalence) in terms of current NACO definitions. The balance will be located in “A” and “B” (high prevalence) districts
- a minimum of one third of sites will be classified as “urban” and a minimum of one third of sites will be “rural”. The balance may be urban, rural, peri-urban etc., as determined by the core group and research team
- a minimum of one third of the focus groups in each of the four categories defined below must be made up of respondents who are not recruited by networks of positive people.

Note that the focus groups must be homogenous in respect of these three criteria, ie: a group may not include respondents from urban and rural areas, or recruited by NGOs and networks (although, of course, it is possible that a person recruited by a n NGO is also a member of a network).

Note, too, that the core group and research team may propose additional criteria for a limited number of sites, to be approved by the project coordinator, such as the location of one site in an area characterised by a high-risk group such as commercial sex workers or injecting drug users.

In each research site, a minimum of one focus -group discussion will take place with each of the following categories of respondents:

- boys and girls aged 9–12 (ie: pre-adolescents)<sup>27</sup>
- boys and girls aged 14–17 (adolescents)<sup>28</sup>
- female primary caregivers of children who have, or had, an HIV -positive parent<sup>29</sup>
- male heads-of-households which include at least one child who has, or had, an HIV-positive parent

Intermediaries – networks, NGOs, SACS etc. – will be asked to recruit 15 people for each focus group. The number of participants in each group will ideally be in the range 8–12 with an absolute minimum of 7 and an absolute maximum of 15.

Moderation of each focus group will be done by two research associates. One will actively moderate the session, while the other will support that person and act as rapporteur. Women’s groups will be moderated by a woman, as far as possible.

## Method

General:

- Do not refer to “affected” people, children or households. Refer instead to children with HIV-positive parents and to children orphaned by AIDS (ie: one or both parents died of AIDS).

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<sup>27</sup> no siblings within the same focus group, but siblings may attend different groups (eg: a younger sibling in the pre-adolescent group, and the older sibling in the adolescent group).

<sup>28</sup> children aged 13 can join either group, depending on their apparent maturity.

<sup>29</sup> respondents need not be HIV-positive, eg: the aunt or grandmother of a child who has a parent living with HIV/AIDS, or orphaned by AIDS. Only female caregivers will be included to keep the group homogenous. A similar rationale applies to the male heads-of-household group. If possible the men and women should come from different households.

- Do not use the term “normal” to describe children, parents or families (although it is usually OK to describe experiences and things). Spell out who you mean, eg: children whose parents are not living with HIV/AIDS ( not “normal” parents!)
- Recognise that the answer may be unexpected (eg: that there is no difference between children with positive parents and other children). Do not attempt to get the group to modify their answer, eg: through prompting, no matter how unlikely their answer is. However, this does not mean you should not check all answers with the group, to confirm they all understand and agree.
- Avoid, or at least be sparing in the use of, the term “barriers”. As far as possible use synonyms such as impediments, exclusions, difficulties accessing etc. Barriers may be described indirectly by comparing the experience of children with positive parents and children whose parents are not living with HIV, and asking why there is a difference.

Individual interaction, immediately before the group session:

- For children – individual interview (see section on ethics);
- For all respondents – completion of registration form (attached).

Preamble with the whole group (to be translated into local vernacular):

- This is a study by the State AIDS Control Society and government of (state) and UNICEF, to find out about the experience of children who have an HIV -positive parent, or who have lost a parent to AIDS. We want to find out in what ways their lives are different to children whose parents are not living with HIV/AIDS.
- By participating in this study, you will be helping us understand what it means for a child to have an HIV -positive parent, and to make their lives better.
- However it is important to understand that we are not discussing medical treatment for AIDS, either for parents or children who are living with HIV/AIDS. Rather, we want to know how HIV/AIDS affects their lives in other ways. This will become clearer as we go on.
- For adults: confirm they all understand and have signed and the consent form.
- For all participants (adults and children): everyone in the group is free to say what they think, all views are equal, there are no right or wrong answers, and we must allow everyone to speak without interruption, even if we disagree with them.
- The meeting is being recorded, but the recording will not be made available to anyone outside the research team. None of you will be identified in the report. You do not have to answer any question, or take part in this focus group if you do not want to, and you are free to leave the room at any time.
- We are not going to ask you about YOUR experience, but rather your opinions about the experience of an imaginary child who has a parent living with HIV/AIDS, or who has been orphaned by AIDS. [Reinforce that we don’t want people to give lengthy personal stories?]
- This imaginary child may or may not be HIV -positive, but we are only interested in their HIV -status if it makes a difference to their non -medical experience.
- It is important to know that the parent of this imaginary child is known by the community to be living with (or to have died from) HIV/AIDS – we are interested to know whether anyone treats this child or their caregiver any differently and, if so, how?

Group interaction (in local language):

- introductions of all present
- ice-breaker (“safe” topic designed to give everyone an opportunity to speak, eg: what do children in your community do when they are not in school?)
- invite four (five for children) participants to volunteer as rapporteurs (to avoid asking who is literate – rapporteurs do not have to share their writing with anyone, it is purely for their own reference), break into four sub -groups (minimum two persons in each, one of whom is a rapporteur) to discuss each of the research questions (10 mins).
- group feedback – begin with question 1, ask the sub -group to list their ideas and the whole group to add their own, moderator lists them on a chart (key words, on the floor?)
- check answers with the group (“does this affect children whose parents are not HIV-positive?” If so, that answer is eliminated, as it is not unique to children with positive parents)
- the group then chooses the three most important barriers on the list (using debate, not voting!) in descending order of importance<sup>30</sup>
- the group is then asked to qualify each of the three most important barriers in turn (“why is it a barrier, who is affected, who is responsible, how can it be overcome?”)
- briefly summarise the outcome of each question (the three most important barriers, in the group’s opinion, with the qualifiers) before moving onto the next question and repeating the process
- note that question 4 is important – leave enough time for it!
- be alert to and note down any distinction made by the group about barriers facing children with different profiles, eg: orphaned by AIDS vs. HIV -positive parents; girls vs boys; young children vs older children; children from very poor households vs middle-income households etc.

#### Conclusion:

- conclude the session by summarising the most important insights (on barriers, ways to overcome etc.) and by sharing useful contact information [nb: to be arranged and approved in-state before the field work begins ].
- try to end on a lighter note – especially with children – and to resolve any issues which you think may trouble them.
- do not make promises unless you know you can keep them!
- ensure that all respondents – particularly children – know how they are getting home, and that any obligations in terms of catering, travelling costs etc are met.

#### Questions

##### Adults and children

Here we have a child (draw, get fictional name from group) who has a parent living with HIV/AIDS, and here we have another child (draw, get fictional name from group) whose parent died of AIDS.

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<sup>30</sup> If necessary, the “most important” barriers can be defined as those which 1) affect the most children, 2) have the greatest impact on their lives and 3) are most difficult to overcome.

Everyone in the community knows that (child A) has a parent living with HIV/AIDS, and that a parent of (child B) died from AIDS. However, these children are not themselves HIV-positive – although the community may not know this, or believe it.

We want to know, from your own experience and observations (not your imagination!) how the status of that parent affects the life of these children – specifically whether they have difficulty accessing any kind of support or service which is available other children in their community in the following areas:

1. where that child lives, how s/he is raised
2. attending school
3. getting (non HIV) medical care (doctor, dentist etc.)

Adults only

4. getting other essential services ( name)

Children only

4. getting advice and emotional support (who do s/he turn to for help?)
5. having a say in decisions which affect him/her (can s/he decide...?)

## **Ethics**

Informed consent will be obtained from adult respondents, and from the legal guardian of minor respondents (aged less than 18), before their participation in focus groups is confirmed.

The attached consent form must be read by, or read to, and must be signed by each respondent or parent of a minor respondent. It is anticipated that this will be arranged by an intermediary such as a network of positive people or NGO.

In addition, at the time of the focus group meeting, the moderators will confirm that all adult respondents have signed the form and understood its contents.

As regards minor respondents, moderators will check that they have signed consent forms from the parents of all children, and the children will be interviewed individually before the focus group is held to confirm that they are:

- aware of the nature of the meeting (ie: that it concerns families affected by HIV/AIDS) but that they will NOT be asked to disclose anything about themselves or their own family (questions will relate to an imaginary family);
- willing to participate and express their point of view **about children who have HIV-positive parents, or children who may have been orphaned by AIDS**, in front of other boys and girls of their age, some or all of whom may be strangers;
- free to decline to participate, or to leave the session at any time (although they may not join, or re-join, once the session has started, unless they have left briefly to go to the toilet).

The child should also be asked individually if they have any questions or confusion about why they were chosen, and why they are there (and, if so, they should not be included in the FGD, but cared for separately until it is over).

## Annex 4: Informed consent form

The government of (state), the (state) AIDS -Control and UNICEF, are conducting a study to investigate whether children whose parents are living with HIV/AIDS, or have died of AIDS, face difficulties in accessing essential services which other children do not face.

We, \_\_\_\_\_ the positive network / NGO have been asked to approach families that have children who have a parent living with HIV/AIDS, or where a parent has died of AIDS, to find out whether members of that family would be willing to participate in group discussions to be held in \_\_\_\_\_ (place) on \_\_\_\_\_ (date & time).

The researchers are looking for four categories of people to participate in these discussions:

- boys and girls between the ages of 9–12 who have a parent who is HIV -positive, or who died of AIDS;
- teenagers between the ages of 14–17 who have a parent who is HIV -positive, or who died of AIDS;
- women who are the primary caregivers of children who have a parent who is HIV - positive, or who died of AIDS;
- men who are the head of a household which includes a child who has a parent who is HIV-positive, or who died of AIDS;

We cannot include more than one child from the same household in the same category – for example we cannot take two teenagers from the same household, but we can have one child under the age of 13, and one over the age of 13. Also, we cannot have caregivers and household heads from the same household participating in the study.

Participation is strictly voluntary. Nobody has to take part if they do not wish to. Adults and children who agree to participate will be in a group discussion and will be asked to give their views on the experience of children who have a parent living with HIV/AIDS, or a parent who died of AIDS. However, nobody will be asked to reveal their own HIV status, or to discuss their own families.

Nevertheless, it is essential that all children who participate in this research are aware that they have a parent living with HIV/AIDS, or that a parent died of AIDS, **and the child must have known about their parent's status for at least a month.** However, they will not be asked to share this information in the group discussion.

All responses will be recorded and written down for the purposes of the research, but the names of participants will not be used in any report, or made available to anyone outside the research team. Nobody is obliged to answer any question, and participants will be allowed to withdraw from the group if they wish.

It is not possible to provide any monetary compensation for participation, either by adults or children. However, participants can be assured that the knowledge gained from their participation will help many children across the state. We will also pay for transportation to and from the meeting venue, and provide lunch and refreshments.

You are free to ask questions before agreeing to participate in this research, and you can refuse to participate or allow your children to participate. However, if you agree to participate, or to allow any of your children to participate, it is necessary that you sign this form. If you have any questions during the course of the study, you may contact:

(name and phone number of lead researcher).

**Adult consent:**

I have read this entire consent form/it has been explained to me (delete as appropriate), and all my questions have been answered to my satisfaction. I agree to participate in a group discussion as described.

I am (delete as appropriate) the female caregiver of a child who has a parent living with HIV/AIDS, or a parent who had died of AIDS **OR** the male head of household which includes a child who has a parent living with HIV/AIDS, or a parent who died of AIDS.

Name of participant: \_\_\_\_\_ Age: \_\_\_\_\_ Sex: \_\_\_\_\_

Signature of participant: \_\_\_\_\_

**Guardian's consent for child** (to be completed by the adult responsible for the child):

I have read this entire consent form/it has been explained to me, and all my questions have been answered to my satisfaction.

I agree to allow the following child/ children, for whom I have legal responsibility, to participate in a group discussion on barriers to services for children who have a parent living with HIV/AIDS, or a parent who died of AIDS. I confirm that this child/these children have/had a parent who is/was living with HIV/AIDS, **and that they have been aware of this fact for at least a month.**

It has been explained to this child/these children that child participants in the group discussions will be asked for their views on the experience of other children who have a parent living with HIV/AIDS, or who have a parent who died of AIDS, but that they will not be asked to reveal their own HIV status **to the group** or to discuss their own family.

This child/these children have been made to understand that what they say will be recorded and written down, but that their names will not be used in any report, or made available to anyone outside the research team.

Name of child: \_\_\_\_\_ Age: \_\_\_\_\_ Sex: \_\_\_\_\_

Name of child: \_\_\_\_\_ Age: \_\_\_\_\_ Sex: \_\_\_\_\_

Name of parent or guardian: \_\_\_\_\_

Signature of parent or guardian: \_\_\_\_\_

**Investigator's statement (to be filled by representative of NGO / Network):**

I, the undersigned, have explained to the above subject in the language that he/she understands, the procedures to be followed in this study and the risks and benefits involved. He/she has agreed to participate in the study.

Name of investigator: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of investigator: \_\_\_\_\_

Note: two forms required per household – both to be completed and signed, one to be left behind.

## **Annex 5: Key informant interview guideline**

### **BACKGROUND**

The Key Informant Interviews (KIIs) are the second phase of the barriers study, building on the Focus Group Discussions (FGDs) during the first phase. The FGDs identified the most important barriers to services confronting children with positive parents, and children orphaned by AIDS. These children, and their caregivers and heads of household, are the “consumers” of services. The KIIs will verify whether the “providers” of those services are aware of these barriers, and what can be done to overcome them.

This guideline:

- provides an introduction to be used at the beginning of each interview
- identifies the barrier categories (ie: children’s wellbeing, education and health); the respondents to be interviewed on each barrier; the barriers to be described to each respondent; and the (standard) questions which must be asked about each barrier
- identifies a group of “cross-cutting” respondents who have an interest in all three categories, along with modified barriers to be used as the basis for their questions
- analyses the number and type of KIIs, to allow for scheduling
- provides hints and tips to deal with situations which may arise, and
- provides a form to be used by Research Associates (RA) during the interviews.

### **INTRODUCTION (to be used at interviews)**

Because many of the respondents will have limited time, the introduction given by the RA should be short. It must also be standardised across the six states, to reduce bias. The following should be used as a template:

Start with appropriate greetings, introductions and thanks. Ask how much time is available for the interview (this is important, because it will affect how you manage the interview). Advise that our protocol requires that all input by the respondents is “on the record” and that the interview will be audio-recorded (see hints and tips for more..). Then say..

*“We are conducting a study of barriers to services facing children who have HIV-positive parents, or who have been orphaned by AIDS, in the six high-prevalence states of India – Andhra Pradesh, Karnataka, Tamil Nadu, Maharashtra, Manipur and Nagaland.*

*“It is important to know that we are not focusing on children infected with HIV in this study, but on children who are not infected, but whose lives may be affected because their parent is HIV positive, or has died of AIDS.*

*“We have already conducted focus group discussions with about 1,000 children and 1,000 adults in the six states, asking them whether these children face barriers because of their parents’ status. We have identified the most common barriers in three areas: children’s well-being in their homes and neighbourhoods, general health care, and education.*

*“I would like to share the three most important barriers which they described in your area of expertise, and ask you whether you have observed them in your work, and what can be done to overcome these barriers. May I proceed?”*

The next step of the interview will be to collect personal data on the respondent (see the cover page of the interview form) followed by describing the barriers and asking the questions.

## BARRIER CATEGORY 1: CHILDREN'S WELLBEING

### RESPONDENTS:

From block/ village level [1 of each per district = 3 of each per state = 9 KIIs per state]

- Supervisor of Anganwadi worker/ ICDS workers/ Self Help Group
- Leader/ president Panchayat Samiti {village council in Nagaland}
- Member of peer group/ youth clubs/ Nehru Yuva Kendra/ students' federation

From district level [1 of each per district = 3 of each per state = 6 KIIs per state]

- Chief Executive Officer of Zilla Parishad {district council in Nagaland}
- District Social Welfare Officer or equivalent

State level [1 of each per state = 4 KIIs per state]

- Director [technical] DWCD
- Secretary [policy] DWCD
- Minister of Social Welfare/ Women and Child
- Senior person in NGO implementing programmes in that state with children's wellbeing, children's rights

### BARRIERS

1. Affect the quality of life of the child: family denied accommodation/ forced to relocate/ parents lose income/ employment/ paid less/ lose savings/ cannot borrow/ cannot get community certificate/ widow's pension/ life-health insurance/ impoverishment/ don't get full quota of supplementary food from Anganwadi Workers
2. Affect the social relationships and self esteem of the child: ostracised/ excluded/ refused services/ turned away within community/ neighbourhood/ extended family/ places of worship/ grocery store/ by own parents/ denied access to facilities/ perceive that they are less important/ have nobody to turn to/ nobody cares/ cannot confide in anyone
3. Affect the ability of the child to influence decisions which affect him/ her: not marriageable/ forced to marry earlier/ sent to live with relatives/ have less/ no say in decisions on marriage/ education/ career/ location

### QUESTIONS (note, the following questions are common to all barrier categories)

The RA should describe the first barrier as above. Say that this barrier has been identified across all six states, but you do not know if it applies in your respondents' domain. Do not add your own interpretation or insights from local FGDs – stick to the general (national) terms given above. Then ask about that barrier:

- *Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?* [At this point you should be very aware of the time you've been given, and guide your respondent so s/ he has time to respond to all three barriers]
- *What should be done to overcome this barrier? If it does not happen in your area, what advice would you give to people in areas where it does occur?*

## **BARRIER CATEGORY 2: EDUCATION**

### RESPONDENTS

From block/ village level [1 of each per district = 3 of each per state = 9 KIIs per state]

- School teacher [mix private and government..]
- School principal [not from same school as teacher]
- Inspector of schools/ member of education committee of Panchayat {village council in Nagaland}

From district level [1 of each per district = 3 of each per state = 6 KIIs per state]

- District Education Officer
- [Elected] chairman of education committee Zilla Parishad {district council in Naga land}

State level [1 of each per state = 5 KIIs per state]

- Secretary [policy] Department of Education
- Director [technical] Department of Education [primary education]
- Director [technical] Department of Education [secondary education]
- Minister of Education
- Senior person in NGO working in education/ advocacy

### BARRIERS

1. Affect the child's ability to get an education: principal/ school deny enrolment – other parents oppose enrolment, caregiver does not allow child to attend school through lack of money, ill health, children needed at home/ supplement income/
2. Affect the quality of education given to the child: teachers, ignore, separate, indifferent to attendance/ participation/ extra-curricular activities
3. Affect the self-esteem, socialisation of the child: classmates won't share lunch box, not play, bullying, taunting, not sharing class notes

### QUESTIONS

Same questions as in wellbeing category above

### **BARRIER CATEGORY 3: GENERAL HEALTH CARE**

#### RESPONDENTS:

From block/ village level [1 of each per district = 3 of each per state = 9 KIIs per state]

- Medical Officer in charge of Primary Health Centre/
- Para-medical staff [“gatekeeper”, first person to meet/ screen child at PHC]
- Private [non government, alternative] medical practitioner/ Registered Medical Practitioner

From district level [1 of each per district = 3 of each per state = 6 KIIs per state]

- Chief of hospital/ health care centre medical service (eg: Civil Surgeon)
- Elected member of Health Committee, Zilla Parishad

State level [1 of each per state = 4 KIIs per state]

- Indian/ State Medical Association [ethics officer]
- Secretary [policy] Department of Health [medical]
- Director [technical] Department of Health
- Minister of Health

#### BARRIERS:

1. Affect the child’s access to professional medical care: doctors/ para-medical staff refuse examination/ treatment/ first aid – refer to other facilities, won’t touch wounds;
2. Affect the child’s access to medical care at home: incapacity of parent/ lack of support from other family members/ neighbours to take children for health care/ provide first aid
3. Subject the child to stigma in a health care context: refusal of other patients to share waiting room/ ward/ facilities; mis-treatment by health care professionals and home caregivers.

#### QUESTIONS

Same questions as in wellbeing category above

## **BARRIER CATEGORY 4: CROSS-CUTTING**

The following respondents have an interest in all three barrier categories. Specific questions have been compiled for them:

### RESPONDENTS

From district level [1 of each per district = 3 of each per state = 6 KIIs per state]

- Collector: ensuring access to shared facilities
- Deputy Superintendent of Police: action in cases of discrimination

State level [1 of each per state = ± 4 KIIs per state]

- Project Director of SACS
- State network of positive people
- UNICEF (where applicable)
- S-GAP core group members (if not covered elsewhere)

### BARRIERS

The following are a compilation of barriers from each of the three areas above (wellbeing, education, health):

1. Affect the quality of life, social relationships and self esteem of the child: family denied accommodation/ forced to relocate/ parents lose income/ employment/ paid less/ lose savings/ cannot borrow/ cannot get community certificate/ widow's pension/ life -health insurance/ impoverishment/ don't get full quota of supplementary food from Anganwadi Workers; child ostracised/ excluded/ refused services/ turned away within community/ neighbourhood/ extended family/ places of worship/ grocery store/ by own parents/ denied access to facilities/ perceive that they are less important/ have nobody to turn to/ nobody cares/ cannot confide in anyone
2. Affect the child's ability to get an education, and the quality of that education : principal/ school deny enrolment – other parents oppose enrolment, caregiver does not allow child to attend school through lack of money, ill health, children needed at home/ supplement income/ teachers ignore/ separate from other students/ indifferent to attendance/ participation/ extra-curricular activities
3. Affect the child's ability to get professional medical care and medical care at home : doctors/ para-medical staff refuse examination/ treatment/ first aid – refer to other facilities, won't touch wounds; incapacity of parent/ lack of support from other family members/ neighbours to take children for health care / provide first aid

### QUESTIONS

Same questions as in wellbeing category above

## NUMBER OF KIIs

	<b>Wlbg</b>	<b>Educ</b>	<b>Hlth</b>	<b>X-ct</b>	<b>p/dist</b>	<b>p/state</b>	<b>6 state</b>
Block/local level respondents, per district	3	3*	3	–	9	27	162
District level respondents, per district	2	2	2	2	8	24	144
<b>Block/local and district respondents, per district</b>	5	5	5	2	17	51	306
State level respondents	4	4	5	± 4		± 17	± 102
Total KIIs						± 68	± 408

Wlbg = children's wellbeing; Educ = education; Hlth = health; X -ct = cross-cutting

\* ie: one teacher, one school principal, and one inspector of schools, in one district. These respondents need not be drawn from the same block or site, and the principal and teacher may not come from the same school.

## INTERVIEW FORMS

### Cover page:

*Please check the following data carefully with your respondent before beginning the interview:*

<b>Interview date:</b>		
<b>First name:</b>		
<b>Last name:</b>		
<b>Title (Dr., Sr., etc)</b>		
<b>Job title/position:</b>		
<b>Organisation:</b>		
<b>Physical address:</b>		
<b>Email address:</b>		
<b>Telephone:</b>	<b>Land:</b>	<b>Cell:</b>
<b>Interviewer:</b>		
<b>Site/block:</b>		<b>Hi/lo prev:</b>
<b>District:</b>		<b>Urb/rural:</b>
<b>State:</b>		<b>Rspndnt grp:<sup>31</sup></b>
<b>Info resources for bibliography?</b>		
<b>Useful contacts?</b>		
<b>Notes:</b>		

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<sup>31</sup> Wellbeing, education, health, cross-cutting

*Note to Lead Researchers – each of the following boxes should be expanded (by inserting carriage returns in the white space) to occupy a full page, and then printed out. RAs will therefore carry seven pages (a cover page, plus two pages for each barrier) into each interview. RAs should keep their (handwritten) notes within this space.*

**For “wellbeing” respondents**

*our FGDs in the six high-prevalence states have told us that many children with HIV-positive parents, or who have been orphaned by AIDS, face barriers to services which..*

<p>1. <u>Affect the quality of life of the child:</u> family denied accommodation/ forced to relocate/ parents lose income/ employment/ paid less/ lose savings/ cannot borrow/ cannot get community certificate/ widow’s pension/ life -health insurance/ impoverishment/ don’t get full quota of supplementary food from Anganwadi Workers</p> <p><i>Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?</i></p> <p><i>Page 1. Respondent: Date: RA:</i></p>
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<p>2. <u>Affect the social relationships and self esteem of the child:</u> ostracised/ excluded/ refused services/ turned away within community/ neighbourhood/ extended family/ places of worship/ grocery store/ by own parents/ denied access to facilities/ perceive that they are less important/ have nobody to turn to/ nobody cares/ cannot confide in anyone</p> <p><i>Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?</i></p> <p><i>Page 1. Respondent: Date: RA:</i></p>
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<p>3. <u>Affect the ability of the child to influence decisions which affect him/ her:</u> not marriageable/ forced to marry earlier/ sent to live with relatives/ have less/ no say in decisions on marriage/ education/ career/ location</p> <p><i>Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?</i></p> <p><i>Page 1. Respondent: Date: RA:</i></p>
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Standard second page for each question (expand the following to a full page)

<p><i>What should be done to overcome this barrier? If it does not happen in your area, what advice would you give to people in areas where it does occur?</i></p> <p><i>Page 2. Respondent: Date: RA:</i></p>
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**For education respondents:**

*our FGDs in the six high-prevalence states have told us that many children with HIV-positive parents, or who have been orphaned by AIDS, face barriers to services which..*

1. Affect the child's ability to get an education: principal/ school deny enrolment – other parents oppose enrolment, caregiver does not allow child to attend school through lack of money, ill health, children needed at home/ supplement income/

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*Page 1. Respondent: Date: RA:*

2. Affect the quality of education given to the child: teachers, ignore, separate, indifferent to attendance/ participation/ extra-curricular activities

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*Page 1. Respondent: Date: RA:*

3. Affect self-esteem, socialisation of the child: classmates won't share lunch box, not play, bullying, taunting, not sharing class notes

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*Page 1. Respondent: Date: RA:*

Standard second page for each question (expand the following to a full page)

*What should be done to overcome this barrier? If it does not happen in your area, what advice would you give to people in areas where it does occur?*

*Page 2. Respondent: Date: RA:*

**For health respondents:**

*our FGDs in the six high-prevalence states have told us that many children with HIV-positive parents, or who have been orphaned by AIDS, face barriers to services which..*

1. Affect the child's access to professional medical care : doctors/ para-medical staff refuse examination/ treatment/ first aid – refer to other facilities, won't touch wounds;

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*Page 1. Respondent: Date: RA:*

2. Affect the child's access to medical care at home : incapacity of parent/ lack of support from other family members/ neighbours to take children for health care/ provide first aid

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*Page 1. Respondent: Date: RA:*

3. Subjecting the child to stigma in a health care context: refusal of other patients to share waiting room/ ward/ facilities; mis-treatment by health care professionals and home caregivers.

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*Page 1. Respondent: Date: RA:*

Standard second page for each question (expand the following to a full page)

*What should be done to overcome this barrier? If it does not happen in your area, what advice would you give to people in areas where it does occur?*

*Page 2. Respondent: Date: RA:*

**For cross-cutting respondents:**

*our FGDs in the six high-prevalence states have told us that many children with HIV-positive parents, or who have been orphaned by AIDS, face barriers to services which..*

1. Affect the quality of life, social relationships and self esteem of the child : family denied accommodation/ forced to relocate/ parents lose income/ employment/ paid less/ lose savings/ cannot borrow/ cannot get community certificate/ widow's pension/ life-health insurance/ impoverishment/ don't get full quota of supplementary food from Anganwadi Workers; child ostracised/ excluded/ refused services/ turned away within community/ neighbourhood/ extended family/ places of worship/ grocery store/ by own parents/ denied access to facilities/ perceive that they are less important/ have nobody to turn to/ nobody cares/ cannot confide in anyone

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*Page 1. Respondent: Date: RA:*

2. Affect the child's ability to get an education, and the quality of that education : principal/ school deny enrolment – other parents oppose enrolment, caregiver does not allow child to attend school through lack of money, ill health, children needed at home/ supplement income/ teachers ignore/ separate from other students/ indifferent to attendance/ participation/ extra-curricular activities

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*Page 1. Respondent: Date: RA:*

3. Affect the child's ability to get professional medical care and medical care at home : doctors/ para-medical staff refuse examination/ treatment/ first aid – refer to other facilities, won't touch wounds; incapacity of parent/ lack of support from other family members/ neighbours to take children for health care/ provide first aid

*Is this your experience? Are you aware of anything like this here? If so, can you give an example? If not, why do you think it is different here?*

*Page 1. Respondent: Date: RA:*

Standard second page for each question (expand the following to a full page)

*What should be done to overcome this barrier? If it does not happen in your area, what advice would you give to people in areas where it does occur?*

*Page 2. Respondent: Date: RA:*