

ChildHope UK and The Railway Children

Developing Policy and Operational Responses to HIV/AIDS: Railway Children Federation of India

Report to CSCF, DFID East Kilbride

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1. Executive Summary

With an estimated total of 3.9 million people living with HIV/AIDS at the end of 2000, India is host to the largest epidemic in Asia¹. If infections continue to double every 2-3 years (a scenario currently entertained by many HIV-specialist agencies in the absence of significant intervention) by 2015 there will be between 100 and 120 million cases – or roughly one in ten of the population. According to a recent UNAIDS report: ‘Children and young people are at the centre of the HIV/AIDS epidemic. The extent to which their rights are protected, the services and information they receive, and the behaviour of young people can help determine the quality of life of millions. Young people are particularly susceptible to HIV infection and they carry the burden of caring for family members living with HIV/AIDS’ (UNAIDS, 2001). Under CRC health-care is a child’s right. In the case of HIV/AIDS, intervention is both a rights issue and a matter of India’s future development as a whole.

Indian NGOs report an increase in the number of children living and working on the streets with HIV/AIDS. Increasing numbers of HIV-affected street children are presenting themselves to projects and programmes for help. To date, however, on-the-ground experiences remain anecdotal. There is a need to understand better, quantitatively and qualitatively, the conditions of HIV among Indian street children as soon as possible, in order that appropriate policy can be developed.

Child-focused Indian NGOs share common and fundamental concern at the increase in numbers of children with social and medical needs as a consequence of their living with HIV/AIDS. Between these NGOs, however, there is an ongoing debate regarding the most appropriate and effective service for children and HIV. This debate can be summarised as a difference in approach between the community-based focus in interventions, and the complementary approach combining community action with residential care and/or hospice services. The arguments for purely community-based responses to HIV are countered by vigorous calls from several NGOs for specialist residential establishments that respond to the emotional and medical needs of street-children who – in a sense by definition – have lost or rejected links with a community that has in some respect already failed them. Such establishments would offer respite and palliative care, alongside and complementary to action-research on children, HIV and social exclusion, outreach support and community-based care whenever and as long as appropriate.

There are substantial indigenous resources of Indian experience and knowledge on the subject of HIV/AIDS, articulated within a clear and incisive professional development discourse. Weaknesses with respect to child-focused NGOs and HIV lie in the present fragmented state of organisational responses and a problematic relationship between the non-government sector and the Indian state, marked by frustration and often unconstructive cynicism. This undermines the extent to which knowledge and experience can be effectively applied to the task of combating HIV/AIDS in India and does not, consequently, serve children well.

¹ ‘With an adult prevalence rate of 0.7%, sentinel surveillance studies conducted in 1999 found HIV seroprevalence of greater than 1% in six of 32 states and territories. The epidemic is growing outside high-risk groups and is now found in the general population. It is also moving from urban to rural districts’ (USAID, 2001).

One of the major tasks identified for NGO sector actors is to identify and agree a framework within which the effectiveness of HIV knowledge and the energy and commitment of Indian NGOs to working for the welfare and rights of street children may be maximised. Such a framework should act as a clearing-house for learning, systematically collating and disseminating information and experience, seeking to enhance organisational and collective knowledge. The NGO sector has a duty to its donors and to its clients/beneficiaries to use resources as effectively as possible. It is therefore incumbent upon Indian NGOs that they avoid having to re-learn what has been learned before by others elsewhere, wasting valuable resources and perhaps offering an intervention that has been found elsewhere to be inappropriate.

HIV/AIDS touches every aspect of Indian development. In this regard, street children cannot be seen as a stand-alone issue, but within a context of social exclusion and marginalisation, and within broader parameters of poverty and health. Lessons learnt from working on HIV with street and working children should be able to influence work with other groups elsewhere. Conversely, lessons learnt about other groups of people living with HIV/AIDS should be studied in terms of their relevance to socially excluded/marginalized children.

The role of government is crucial. A lack of interest (real or assumed) can profoundly hinder the NGO sector's ability to work effectively, and presents a sizeable obstacle to the design and implementation of strategy and policy. By contrast, an engaged government has enormous potential to guide a national strategic response, to set the parameters within which different actors are allocated roles, supporting measurable quality interventions, and building an institutionalised infrastructure of HIV education, prevention and care. To this end, the NGO sector needs to define valid, agreed and effective advocacy strategies to engage with government (and donors) as partners.

Reflecting discussions over community-based and residential/palliative HIV interventions, Indian NGOs are engaged in a debate over donor relations. It is recognised that much contemporary developmental thinking with regard to HIV favours community-based and preventive project work. And it is recognised as a consequence that where hospices or other residential treatment and palliative care units are the preferred approach, they should be set in a context of community outreach and – crucially – research, in order to improve understanding of street children's own perceptions, attitudes, behaviours and options with respect to HIV, and the way in which Indian urban communities, street children, and HIV interact.

In this sense, the concept of 'community' must be revisited in the Indian context, and entertained as a matter of reality rather than a conceptual ideal. When working with marginalised children, especially street children, 'community' as a medium of support and care for HIV becomes problematic. Street children exist in many respects simultaneously within but also outside 'community'. As such, unaddressed by the conventional 'community' focus, street children may continue negatively to affect and be affected by the HIV epidemic in Indian cities. Indian NGOs are in a position to review the concept of 'community', to explore how real urban communities respond to street children affected by HIV, and how a productive relationship between community and such children might be built up. Freed from the conceptual determinations of 'community', Indian NGOs are working to free themselves from prescriptive responses to the needs of street children.

There is a need for action. Conferences such as this offer the opportunity to network and to learn. Gaps in knowledge or problems in the way knowledge is applied may be identified, and new learning acquired. However, while the conference has shown how much knowledge, experience, energy and commitment Indian NGOs have in their work with socially excluded street children with or at risk from HIV, it has also shown that the extent of that knowledge is provoking not a sense of satisfaction, but a keen and critical desire to do more.

2. Recommendations

a. Establishment of an RCFI Task Force

Conference agreed that an increase in the number of street and working children presenting with HIV/AIDS is happening and is likely to continue. However, it was felt that there is insufficient data to provide an accurate picture of the emerging situation vis-à-vis urban and socially excluded children. This lack of data hinders strategic planning, policy formulation and resource allocation at all levels – community, civil society, state and national government.

It was agreed that NGO groups such as the Railway Children Federation of India (RCFI) present themselves as valuable fora for collective action in pursuing appropriate responses to the needs of socially excluded children living with and/or affected by HIV/AIDS.

On that basis, Indian and international partner NGOs should together organise a task force mandated to:

- Collect and collate from the members of the RCFI and others statistical and diagnostic trends apparent in their work with children with HIV/AIDS, and disseminate these among civil-social and other organisations as widely as possible;
- Prepare a report on the responses of RCFI members and others to HIV among street children, detailing problems faced in terms of: finance, counselling, medical expertise, drugs and professional experience;
- Prepare – if necessary, *commission* – a qualitative study of health-related child needs as seen by children themselves;
- Review existing approaches to street and working children living with HIV/AIDS, paying particular attention to the benefits and disadvantages of community-based and residential-based care;
- Set up an e-mail group for the sharing of ideas and dissemination of information amongst members;
- Identify and agree common and systematised data collection procedures.

b. Develop the capacity of RCFI members

RCFI should consider the HIV/AIDS training needs of its membership and embark, where necessary, on a common capacity-building programme. Where

members are running in-house training, it is recommended that such training be offered free to other members.

It was recommended that ChildHope UK and the Railway Children (through the Task Force) conduct a Training Needs Analysis (TNA) and develop a capacity-building response to which all members would be invited. It was agreed that ChildHope and the Railway Children should take the lead on this in London.

c. Lobby and advocate for policy implementation

It was agreed that the RCFI is well placed to act as a voice for children or, preferably, as a forum through which children may articulate their own views to service providers and policy-makers. It was recommended that the RCFI works to develop its potential as a lobbying and advocacy forum, looking at influencing appropriate responses to children living with and affected by HIV/AIDS, and at preventive health education strategies.

d. Develop a model of best practice for voluntary counselling and testing (VCT) capable of replication throughout India, and proposed for funding

Divergent models of care based on philosophical differences to development principle may overlook the needs of children with HIV/AIDS. It was recommended that ChildHope UK and the RCFI develop a model of care that includes the following main features:

- A central '*hamara ghar*' (Hindi for 'our home') offering testing, diagnosis, medication, counselling, respite and palliative care and accommodation for children during their final days.
- Identification through research of 'satellite communities' to be served by the central *ghar*. 'Community' is defined as those places habitually frequented by children, and may range from the family home or extended family homes to clinics, NGO drop-in centres, and/or shelters, and the street itself.
- Outreach awareness and support to satellite communities by key personnel from the *hamara ghar* to respond to the needs of children, their families and carers, living – and dying – with HIV/AIDS.

The salient feature of this approach would be to maintain community care for as long as appropriate and possible, whilst enabling professional and cost-effective treatment of opportunistic infections (OI) and allowing for the child and community to work together on awareness, care and end-stage preparations.

- The community (in its various forms) would be supported by educational/ awareness-raising campaigns around the issues of HIV/AIDS (acceptance/ acknowledgement, prevention and care).
- The community would be supported to care for its children until such time as they required intensive medical care. At this time, the child would be admitted to the *hamara ghar*.

- Action-based research would be an ongoing theme. It would look at ‘factors that influence changes in the high-risk behaviour in relation to HIV/AIDS’, and ‘Community responses to children with HIV/AIDS’.

3. Background to the Conference

This two-day conference is the result of the efforts of a number of Indian NGOs working with socially excluded and marginalised children, in particular street and working children. They are members of the Railway Children Federation of India, NGOs working with the Railway Children UK, a British registered charity.

There are 19 members of the Railway Children Federation of India (RCFI) working in 36 locations across India, linked by their work with disadvantaged children and their association with Railway Children UK. The purpose of the RCFI is to provide a forum to support the professional development of member organisations. It does this through shared learning and exchange of information, and through the development of policy and practice that best meet the needs of children in the context of commonly identified development issues.

The collective experience of the RCFI is of an increase in the number of Indian street children testing positive for HIV and becoming HIV symptomatic. In the face of this reality, RCFI members are united further by a sense of urgency to determine an appropriate response to the situation, taking into account on one hand the lack of family and community support that marks the lives of many of these children, and on the other a disinclination among many development agencies to focus on residential-based service provision interventions.

The rate of increase in HIV positive cases in India points to a time when it will be home to the largest number of such people in any one country. HIV/AIDS is a development issue and, if not dealt with appropriately, has the potential to destroy communities and undermine national development initiatives through reduced production and an increased call on precious national resources that may need to be diverted from other needy sectors such as poverty reduction initiatives, primary health and education. It has a disproportionate affect on the poor and is exacerbated by poverty.

A proposal was made by ChildHope UK and The Railway Children to DfID to arrange a conference of members of the Railway Children Federation of India, and other actors, to examine these issues and explore possible communal responses.

4. HIV/AIDS in India and among Marginalised Children

Apart from a relatively modest spread of notable documents (e.g. Save the Children vulnerability impact²), too little still is known about the conditions in which vulnerable and marginalized children in India live. RCFI members all work with such children – specifically urban street children – whilst recognising that street-living and -working emerge out of, and need to be understood in relation to, extreme poverty, discrimination,

² HIV/AIDS & Children: Vulnerability and Impact. Save the Children UK, India Office, August 2000)

alienation, and a breakdown of social and community links and the rights such links should reinsure.

RCFI and ChildHope, equally, believe excluded or marginalized children to be at significant and special risk of HIV through their often extreme vulnerability, their lack of access to information, resources, health-care, and to constitute – at the same time – a significant and hard-to-reach medium by which the disease continues to spread. Their very exclusion from many forms of community interaction, and the abuses they suffer, make HIV-safe behaviour and behaviour change considerably less compelling issues from the street child's perspective. Thus, just as street children cannot be seen or engaged with as an isolated social phenomenon, so agencies' work cannot deal with HIV/AIDS outside of a context of poverty, gender, access to power, and rights.

Through initial discussions, Conference explored factors contributing to street children's special vulnerability to HIV, agreeing the following key conditions:

Factors that increase vulnerability of marginalised children to HIV/AIDS

- *Poverty (ending education, going to work);*
- *Gender: though girls and boys are abused, girls may be forced into long-term sex working as an economic activity;*
- *The lack of a stable 'community' to turn to;*
- *Inability or unwillingness (in cost-benefit analysis) to relate to HIV risk; day-to-day pressures of survival outweighing more 'distant' considerations of future well-being;*
- *The belief that sex is safe so long as it's not with a sex worker;*
- *Lack of condom use: cost; 'opportunistic' sex, and personal dislike;*

Existing responses

Conference believed that despite the vast number of organisations and projects working on HIV/AIDS in India, the lack of a centrally-coordinated national plan meant that work was not being systematically tested, nor was success being adequately measured or strategy defined. Though much individual work was agreed to be good, undoubtedly improving lives, it was felt that this would not 'keep up' with the growth of HIV, nor make a sustainable difference to the spread of HIV/AIDS and its impact on individuals, communities and national development.

In the absence of coordinated national strategies for HIV/AIDS prevention, NGOs working with particularly vulnerable children are likely to face increasing numbers of children living with HIV and dying from AIDS. Where 'community' is idealised, and alternative care models are rejected without contextualised consideration, marginalized children may be failed. An unwillingness to explore the widest range of possible interventions for children was considered unacceptable.

Conference did not accept the 'either/or' approach, choosing exclusively between community-based and residential-based preventive and palliative approaches to those respectively at risk and those already infected/affected. It questioned the understanding

of the term 'community' and its relevance to the lives of street and other marginalised children, asking for further exploratory and pilot project work on the dynamics of street-living and -working, HIV/AIDS and community.

5. Conference Terms of Reference

5.1. Objectives

In view of the growing impact of HIV/AIDS on poor people in India and the civil-social organisations working with them, a meeting of the child-focused Federation of 19 Indian NGOs (RCFI) is convened to generate qualified intellectual material with the objectives of:

5.2. Expected results

- a. Designing a strategy to respond to the impact of HIV/AIDS on the Federation's target groups;
- b. Establishing procedures for monitoring this impact and learning from responses to develop the capacity of the Federation and others.

6. Summary of Issues Arising, Day 1

6.1 Why are street children vulnerable to HIV/AIDS?

- Street and working children like other people require and benefit from love and care. When asked, some children expressed this as one of the reasons they engage in sexual activity. In the context of their vulnerability, however, this leaves them prone to the abuse of adults and to illness and disease.
- Children sell sex as a means of survival. It is an income activity and earning an income is an urgent and immediate need. In situations of poverty, long-term and behavioural planning gives way to satisfying immediate needs.
- Economic imperatives may therefore undermine preventive health work of NGOs and others.
- Sexual activity is frequently high-risk: drug and solvent abuse may increase the risk of sexual abuse (or make it more tolerable): condoms are unlikely to be used.
- Drug use is itself a high-risk behaviour.
- Street and working children suffer a greater exposure to the rape and sexual abuse of other street-dwellers.
- Street and working children are freer to engage in sexual activity, and begin sexual activity at an earlier age.
- Street children often experience higher levels of illiteracy, work at an earlier age and thus have less education, and have reduced access to information on HIV and health services.
- Access to hospital and health-care is difficult and may be entirely denied. Bribes are often needed to gain access to hospital treatment – street children cannot afford this.
- Hospital staff may not wish to treat people with HIV and AIDS, or may be fearful because of their ignorance.

Street girls and boys are in particularly vulnerable situations due to continuous exposure in the street environment. Health-care services rarely understand the circumstances and specific needs of street children and their access to health services – particularly those related to drug abuse and HIV/AIDS – is severely restricted.

RCFI Workshop, 2002

Younger children under the influence of a substance are very often forced to have sex with older boys.

RCFI Workshop, 2002

Many street children turn to drugs to escape degradation, guilt and misery. Health risks related to glue sniffing, tobacco abuse, cannabis and heroin are further complicated by malnourishment and risks associated with HIV/AIDS. Besides needle-sharing by heroin users, unsafe practices under the influence of drugs increase the risk of contracting STDs and consequently HIV.

RCFI Workshop, 2002

- There is a shortage of anti-retrovirals (ARV) that can prolong life, and of drugs for secondary illnesses such as tuberculosis.
- Poverty and social exclusion may hinder and prevent children from even asking relevant questions about services they are offered, even when they are fully armed with all relevant information. For example, they may not ask if a needle has previously been used for injection at a medical centre.

- Reliance on unregistered medical professionals provides the child with limited and sometimes counterproductive support.
- Communities frequently refuse to acknowledge existence, conditions and/or extent of HIV impact and need to develop greater knowledge of HIV/AIDS. NGOs should work at community level to overcome taboo resistance to discussion of the issues.
- HIV/AIDS awareness is often low among secondary stakeholders. NGOs should work to raise such awareness, in particular breaking down resistance to explicit information.

6.2. Responding to the needs and rights of street and working children.

Macro-level:

- Globally, 50% of new infections are of people between the ages of 10 and 24.
- India is home to the largest number of HIV infected people in the world.
- HIV/AIDS is located and must be recognised within the wider development context. HIV is a development issue, enhanced in its spread by poverty, ignorance and social exclusion, and with the power to undermine family structure, social organisation and community cohesion. It exerts substantial pressure on scarce and urgently needed national health resources.

The vast majority of HIV/AIDS interventions are community-based. For those who lead an itinerant lifestyle the paradigm of care undergoes a shift
RCFI Workshop, 2002

- 'Street children' are not a stand-alone phenomenon, but must be seen in context of social exclusion and marginalisation, and understood within a range of causal factors that include poverty, disease and conflict. India needs a geographical information system (GIS) to track and record the disease and its spread.

Government should develop an information, education and communication (IEC) methodology that identifies work that is being done, by whom, where, and with what success.

- Government should commit to tackling poverty, with inter-organisational networking (joined-up government) which recognises NGOs as interlocutors between wider society and street and working children.
- The HIV/AIDS pandemic requires partnership among NGOs, and between NGOs and the government.
- NGOs must talk, share information and map their work. A national code of best practice is needed. We require a dialogue with government, to increase the sharing of information. Government 'ownership' and overall responsibility for disparate interventions is required.
- The needs of children must be contextualised within a rights-based approach to development.
- Street corner epidemiology may be an appropriate tool for the collection of relevant data and coordination by NGOs. Findings should be shared; NGOs need to accept this as an ethical and professional requirement.

Street children are amongst those at greatest risk. Many millions of children and adolescents in the world are working or living on the streets, often in violent and dangerous situations.
UNAIDS position paper

- Actors should review the development orthodoxy that insists on community-based care systems and which may not be relevant or accessible to street and working children becoming infected or symptomatic with HIV.
- The NGO sector must articulate the need, and push for the provision of a package of responses that does not as a matter of principle exclude a care element.

Micro – NGO level

- Direct services and ‘rights’ are not mutually exclusive, and may constitute integral components of programmes for street children. Needs must be addressed – shelter, food, health, education services and testing/counselling – though they should be expressed in terms of a rights-based agenda.
- Programmes need to be holistic. HIV/AIDS should be integrated into the broader package of services and the wider goal of civil-social empowerment.
- The capacity of NGOs should be developed, in particular staff trained in specialised community outreach, research, data-gathering and analysis and palliative care services.
- A good rapport and working relationship is necessary between NGOs and other services (local government/state services, etc).
- An increase is necessary in social knowledge and awareness, and a reduction in HIV taboos, stigma and denial.

Child appropriate approaches

- A holistic primary health-care approach should address both psychological and physical health, emphasising both preventive strategies and the caring and treatment needs of those already or becoming infected.
- Building institutional responses to HIV among street and excluded children requires a better understanding of child-community relationships both with regard to awareness of HIV as risk, and acknowledgement of HIV as condition.
- Interventions should acknowledge the reality of the lives of street and working children, without judging, moralising or blaming children for their situation.
- Education materials should be child-appropriate – appealing and attractive to them and using their language – and preferably developed with them. Children should be involved in the design and implementation of programmes.
- Programmes should include support for vocational training and work, with education and with medicine.
- Peer education works – NGOs should use and build upon it.
- Programmes should help to develop positive human relationships. NGOs should be careful to avoid risks implicit in warning about the motives of adults, the dangers of exploitation, etc.
- Programmes should focus on enlarging and enhancing access to information about the dangers of HIV/AIDS and other STDs and knowledge about how best to avoid them.
- Guides to ethical HIV testing should be standardised, disseminated and followed.

7. Findings from Group Discussions, Day 1

Group 1: Counselling:

- Don't advise against sex: advise on safe sex, whatever sexual preference.
- Free condoms. Children won't buy them (too shy, or lack of money). Agencies should have the facility to provide them.
- Advise alternatives to penetration – safe sex practices.
- Help children locate sex within wider role of social relations.
- Teach children how to use condoms.

Life on New Delhi Railway Station

'Gradually sex is seen as a means for survival around the station, the boys make it difficult for the girls to work around the station after they have reached puberty. Some of the new girls who come to the station become part of a gang in order to survive: they have to provide sexual favours to the older boys. The older boys have sex with the younger boys, girls living at the station and with sex workers in the red light area and also with the eunuchs. There is no sexual preference for boys or girls; sex depends on whom they get'.

SCF 2000

- Organisations should explore the possibility of appointing a staff well-being officer.
- NGOs should monitor the resources and professional approach of other organisations to whom their street children clients may be referred.
- Conference wished to explore further the need for HIV/AIDS 'Home Centres' for kids with HIV/AIDS.
- Conference felt that the word 'counselling' can be misused. Conference understands it to mean, in this instance, 'talking and listening to'.
- When a child is traumatised, psychological counselling may help. Counselling should always be founded in an understanding of street children's lives.
- Counsellors should be professional – qualified and appropriately experienced.

Group 2: Ethical issues in HIV testing

Conference addressed the question: In what circumstances should children be HIV tested? The group listed a number of situations in which a child might be tested, and then discussed each one for clarification of group opinion. The group then discussed the possible implications of HIV testing on a child, and, conversely, the possible policy implications of no tests being available to the state. The group determined four situations:

- **Mandatory:**

The group believed that no circumstance warranted this.

- **Voluntary:**

This would be possible, for example with children with other STDs, or where a close relative or friend had died and the child wished to be tested. Counselling would be

provided for child, and family and guidelines on voluntary counselling and testing followed.

- **Research:**

The group accepted the need for random, anonymous research, mandated by government for the purposes of policy. The community would be informed of the purpose and agreement to test would remain voluntary. Full individual confidence would be guaranteed, but research would be made available for publication.

- **Diagnostic:**

Testing for AIDS was recommended when predatory/opportunistic symptoms were evident, and/or when cause of illness could not be otherwise determined. It was recognised that this is entirely confidential.

Group 3: Capacity building

Capacity-building is dependent on the recipient wishing to learn/seeing the value in learning. Two main issues arose:

- Insufficient training;
- Lack of networking on the issues.

The group asked: 'Whose capacity is being addressed...children's? NGOs'? It noted there is little follow up to much capacity-building. One to one, the group found that much work had been done, but that the weakest area was lack of research. NGOs, the group felt, did not measure the effect of their interventions.

Capacity-building should not be carried out 'in isolation'. Capacity building should be seen as a broader, multi-pronged approach. It is a process, and not just piecemeal periodic interactions. It is continuous, bringing an immediate need for improved and modified methods of monitoring and evaluation systems. The group tried to assess capacity building in terms of its effectiveness for affecting attitudinal change. The importance of quality documentation was stressed, if it was to be useful in advocacy.

Group 4: Networking Recommendations

- A resource directory of NGOs and others who are working in the sector is needed. It should detail who is working on what, and where, and should be updated.
- There is a need to know about action-oriented fora.
- Donor agency networking is needed in order that the interests of donors can be determined and influence applied according to changing needs.
- The NGO sector should avoid duplication in order to ensure optimum use of resources.

8. Summary of presentations, Day 2

The nature of the problem facing street children

There is strong anecdotal evidence of a rise in the number of street and working children with HIV/AIDS. However, quantifiable evidence is difficult, due to factors including:

- NGOs ill-equipped to test;
- NGOs need policy guidelines about whom to test, in what circumstances. NGOs may not have a clear idea of who is at risk;
- Children unwilling to be tested;
- The question of a 'right' to test and a lack of common guidelines;
- The ethical responsibility of caring/supporting a child post-test;
- The child's fear of being further rejected by community (or by street 'community') if the test is positive;
- The reality of being rejected by one's community;
- The child's sense that there are other, more pressing, urgencies (food, shelter, etc);
- The unwillingness of children to change behaviour, and the added burden of responsibility that a positive test might mean.

What sort of response?

There were differences in delegates' opinions regarding the most appropriate sort of response. Conference Report presents a summary of the views:

- The shift, over some years, away from residential care to care in the community presents the best model still, representing:
 - Maintained links with family
 - Cost effectiveness
 - Community responsibility for a community problem
 - Sustainability
- Care in the 'community' may not always be most appropriate for street and working children because:
 - They have left their communities and may not be able to return to them
 - They may not want to return to their communities – their communities may have changed, or may not want them
 - The nature of their illness may stigmatise them
 - The risk of being shunned by the community may deter a child from returning
 - The community may not have access to medicine, or may find the costs too burdensome
 - The community may be afraid of the risk of infection (levels of knowledge of the community)

On the basis of this divergence of view/approach, delegates debated the pros and cons of a residential establishment/model of care:

Pros

- Children can be given holistic and integrated care (medical, psychological, 'whole child');
- Provides a substitute 'community' when alternatives do not exist;
- Palliative care (including drugs procurement and administration) is more realistically possible within residential establishment;
- Antiretroviral therapies may be made more available for children;
- Residential establishment may double as a centre of research and excellence, and may train other NGOs.

Cons

- Residential establishment will soon fill up, offering high-cost, low-numbers care impact;
- Does not, consequently, answer the problem of large numbers, of key significance with current HIV-demographic trends;
- Will inevitably be elitist (the 'chosen few');
- Is very expensive;
- Is not sustainable.

9. Summary of Findings from Group Discussions, Day 2

Working groups 1-4:

1. Strategies we shall take for strengthening the Railway Children Federation of India and for networking with other forums.
2. Strategies we shall take to learn from our children and from one another, and for the dissemination of our learning.
3. Practical steps we shall take for the appropriate care of street and working children with HIV/AIDS.
4. Strategies we shall adopt for advocacy and enabling policy implementation and/or change at the policy level.

Findings from working groups

Group 1: Strategies for strengthening the Railway Children Federation of India.

- Sharing of information about members – what we learn;
- Problems faced;
- Networking – access of information about each member;
- Developing a common advocacy agenda;
- Develop an associate membership;
- Write up a code of conduct, membership criteria, etc.;
- An information exchange mechanism to be established – central source of information;

- National meetings to be held. Regional level meetings to be held. Street educators and children to attend;
- Common training needs identified and capacity building strategy developed and applied;
- Learning exchange visits can be made to one another's organisations;
- The RCFI should set up a task force to identify and progress common issues;
- Commit to an open and transparent organisation.

Group 2: Learning Strategies

- Put in place a policy of learning from street children. This can be done via an interactive workshop with children. Accepted by all members;
- Exposure visits should be institutionalised (learning exchange visits), as well as sharing of policies, etc.;
- The national and international experiences of street children's programmes should be compared and published;
- Enrich the website of RCFI.

Group 3: Care and support services

- Commit to making contact via the entry points into the city;
- Children will be given a basic health check up. The person responsible will be familiar with signs of HIV/AIDS, an understanding of the lifestyle of the child that might illustrate/indicate risk;
- In the night shelter, there will be ongoing counselling on HIV/AIDS/STDs, sexuality, etc.;
- Children will be tested according to guidelines of ethical policy. May be encouraged to move to a care home where care can be provided;
- When a child develops symptomatic HIV, the need for residential care (hospice/home/village/centre) is recognised. Conference felt that the residential approach was a necessary element;
- A regional home should be set up for children with HIV who will move there when they contract symptomatic HIV;
- Referrals to agencies or homes shall be made by those organisations that do not have them;
- Networking should be conducted to discuss this proposal;
- Treatment strategies for opportunistic/predatory illnesses should be developed;
- Provision of free anti-retroviral treatment should be promoted.

Group 4: Advocacy

- Government is not responding in a way that helps NGOs;
- There are areas of mistrust between the sectors;
- There is a clear need to advocate:
 - Make lobbying apolitical;
 - Strengthen pressure groups – join them up, enable them;
 - Identify what is needed by NGOs;
 - Identify what we can offer one another;

- Be realistic about sustainability of projects; understand and promote development as a joint, long-term partnership;
- Set up a Task Force to:
 - Conduct Needs Assessment;
 - Offer avenues of work to strengthen the GO sector;
 - Identify and formalise what works now;
 - At the Principle Secretary Level: increase membership from NGOs and GOs;
 - Enhance replicability of successful work in certain states;
 - Increase organisational focus on HIV/AIDS;
 - Re-examine existing policies to see which are appropriate and which are not.

Appendix 1: Conference Agenda

Day 1, 24th January 02

- 9.0 Registration
- 9.30 Welcome
- 9.35 Inauguration Chief Guest: Mr. Ravi Kant, Special Secretary, WBHSDP
- 9.50 Objectives of the Conference. Mr. David Maidment, Chairman, Railway Children
- 10.0 Access to health care as a child's right
- 10.15 Concerns of the Railway Federation of India, (RCFI), Mr. Manihara Norton, President RCFI
- 10.30 Tea break

Working Session

10.45 – 12.45 **HIV/AIDS Awareness and Prevention, Issues faced and experiences gained**

Speakers:

- a. Dr. Atanu Majumder, CINI ASHA
- b. Dr. Shankar Chowdhury, UNESCO
- c. Dr. Tarun Roy, Consultant
- d. Dr. Bitra George, Salaam Baalak Trust

12.45 Lunch

1.30 – 3.00 **Issues faced and experiences gained**

Speakers:

- a. Sujata Ganega, Support.
- b. Father Robinson, Bosco
- c. Mr. Bhadra, Head, Community Medicine.

3.00 Tea break

- 3.15 Group discussion
- 4.0 Presentations
- 4.45 Conclusions from Day 1
- 5.0 Sketch by children of 'Shristi', cultural wing of CINI ASHA.

Day 2, 25th January 02

9.30 Care and support for street children with HIV/AIDS

Speakers:

- a. Mr. Eliazar Rose, New Hope
- b. Dr. Lal Thangsing, NAZ Foundation
- c. Dr. Asha Rao, HIV/AIDS Alliance

11.0 Tea break

11.15 Care and support for street children with HIV/AIDS (cont.)

Speaker

- d. Mr. Ashok Rau, Freedom Foundation

11.45 Group discussions

12.30 Presentations

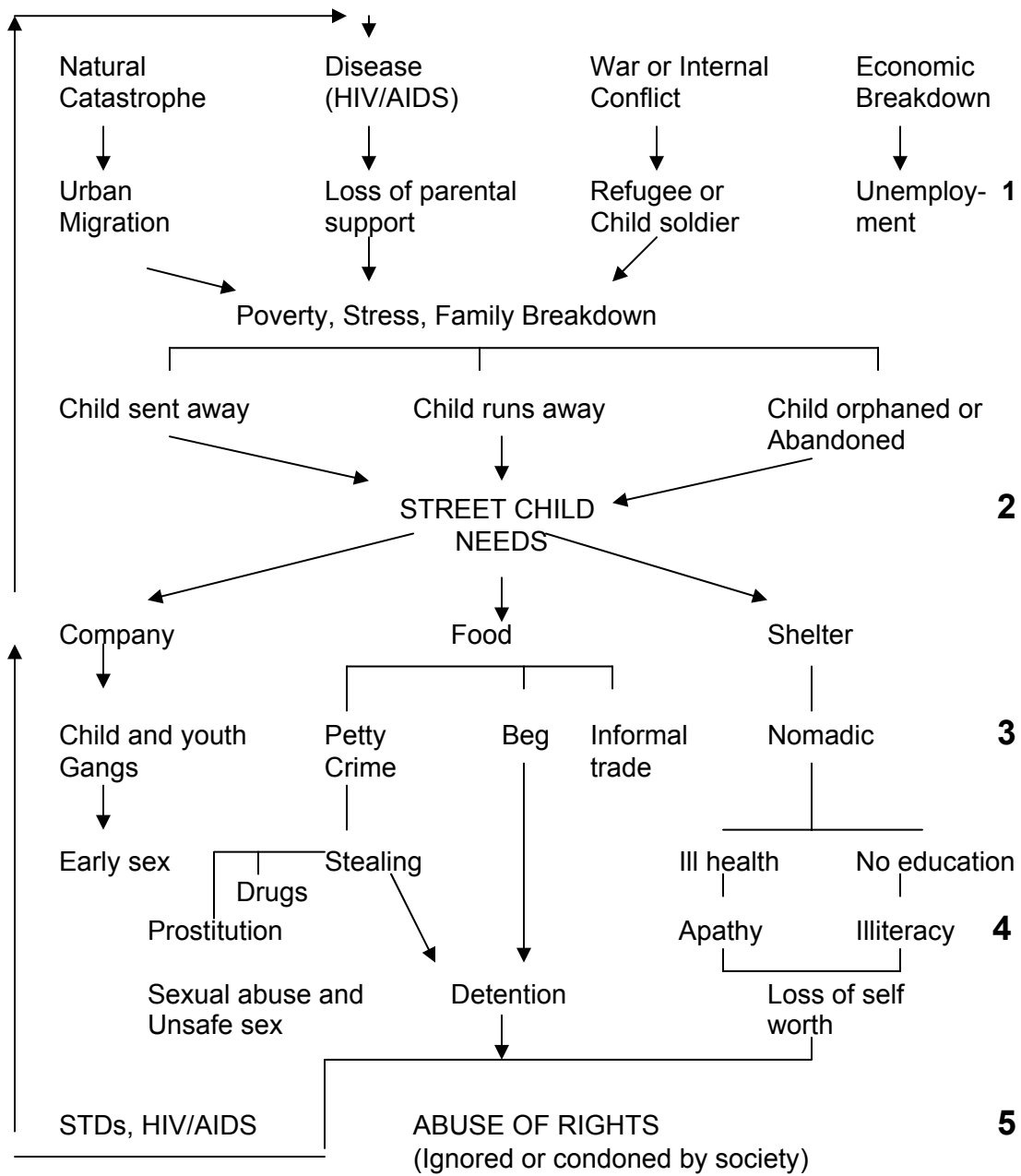
1.15 Lunch break

2.15 Plenary: Emerging key issues from the Conference

3.15	Tea break
3.30	Conclusions
4.0	Vote of thanks

Appendix 2: Street Child Risk Assessment (Copyright Railway Children)

Fault Tree (Cause) and Event Tree (Consequence)



1. Community Health - Education Programmes
2. Early intervention
3. 'Rescue' from the street
4. Rehabilitation
5. Rights abuse advocacy and legal interventions

Appendix 3: Participants

No.	Name	Org	Email address	Telephone
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