

Growing up together:

Experiences of care and support for children affected by HIV/AIDS in India



The International HIV/AIDS Alliance

The International HIV/AIDS Alliance (the Alliance) is an international non-governmental organisation that supports communities in developing countries to make a significant impact to HIV prevention, AIDS care, and to the provision of support to children affected by the epidemic. Since its establishment in 1993, the Alliance has provided financial and technical support to NGOs and community-based organisations from more than 40 countries.

The India HIV/AIDS Alliance

The India HIV/AIDS Alliance (Alliance India) is part of the International HIV/AIDS Alliance and its strategic goal is to increase community action for, and access to, prevention, care and impact mitigation efforts in India. We achieve this through improving coverage of effective community-focused AIDS efforts; strengthening leadership and capacity of civil society to respond to AIDS; and, improving institutional, organisational and policy environments for community AIDS responses.

Strategic priorities include home- and community-based care and support, children affected by AIDS, positive and meaningful involvement of People Living with HIV/AIDS, focused prevention with population groups key to the epidemic, and community mobilisation to facilitate ownership and sustainability of HIV/AIDS efforts. This work is supported by Abbott Laboratories Fund, The Bill and Melinda Gates Foundation and the European Union.

Alliance India provides technical, programmatic, organisational development and financial support to four Lead Partner organisations and more than 50 NGOs in the states of Delhi, Andhra Pradesh and Tamil Nadu. Our Lead Partners are Vasavya Mahila Mandali (VMM), MAMTA, Palmyrah Workers Development Society (PWDS) and LEPRO India. Alliance India has offices in Delhi and Hyderabad.

Alliance India and its partners work in support of the National AIDS Control Programme in India and in collaboration with the National AIDS Control Organisation (NACO), the State AIDS Control Societies and other key stakeholders.

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Cover image: Children affected by HIV/AIDS in Tamil Nadu learn to knit in an activity run by the Center for Social Reconstruction, which also encourages the children to share their concerns and build relationships.

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1. Executive summary

This report draws on the learning of over 90 participants from across India and South East Asia, who attended a meeting in December 2002 entitled 'Working with Children Affected by HIV/AIDS', hosted by the International HIV/AIDS Alliance and the India HIV/AIDS Alliance (Alliance India). Participants came from a range of backgrounds – local and international, governmental, non-governmental and community-based organisations.

The International HIV/AIDS Alliance and Alliance India have pioneered an integrated community- and home-based care and support programme in the states of Tamil Nadu, Andhra Pradesh and Delhi. Programme activities strive to create an enabling environment to address and challenge stigma and discrimination against HIV/AIDS-affected families. In addition, projects in the three states encourage, and advocate, the participation of children affected by HIV/AIDS at all levels of programme development, planning and implementation.

Over the past three years of programme implementation, we have learned that the best way to respond to the diverse care and support needs of children affected by HIV/AIDS in a locally appropriate and sustainable way is through an **integrated** approach. Mainstreaming the response to children and families at the community level helps to overcome stigma and discrimination. In addition, it is important to address the specific needs of children affected by HIV/AIDS as different from those of adults. It is also vital to acknowledge that children have different needs based on their age and the contexts in which they live. It is therefore important to be child-centred in the planning and implementation of services by involving and working with children. Moreover, integrating prevention with care and support services to children affected by HIV/AIDS can reduce their vulnerability. Participation of older children in the implementation of care and support services is a very effective prevention approach within the community.

We need to recognise that children's needs are diverse and that multi-sectoral responses are required, at both community and government levels. Collaboration and partnerships are needed to provide choices and comprehensive services.

The report is divided into sections. It begins with an introduction to the background of this report and the meeting, considering lessons learned from programmes that support children affected by HIV/AIDS in the region. This is followed by a discussion of what it means to use a rights-based approach, with a focus on children's participation. The next three sections consider the impact on children at different ages (0–5, 6–12 and 13–18 years) and their consequent needs. Finally, the report considers some lessons learned from field experience, with some case study examples of the work of one of Alliance India's Lead Partners. Appendices provide a list of useful resources and websites, as well as the draft policy paper that was developed during the meeting.

2. Introduction

There is an urgent need to address the diverse care and support needs of children affected by HIV/AIDS and their families. The International HIV/AIDS Alliance and Alliance India have pioneered an integrated community- and home-based care and support programme in the states of Tamil Nadu, Andhra Pradesh and Delhi with support from the European Union, the Step Forward Initiative and the Allan and Nesta Ferguson Trust. Since 2000, the programme has provided programmatic and organisational technical support and financial support to 37 implementing NGOs, through three Lead Partners. Currently, a total of 37 implementing NGOs are being supported to implement:

- 20 projects in 14 districts of Southern and Central Tamil Nadu
- 10 projects in 7 coastal districts of Andhra Pradesh
- 7 projects in urban Delhi.

The projects focus on the delivery of child-centred services. They may give direct support, or they make referrals to existing public and private sector health care services. The aim of their work is to build supportive and enabling environments with the active participation of community leaders. Projects work with religious leaders, schoolteachers, local youth groups and local philanthropists. Project activities strive to promote an enabling environment that addresses and challenges stigma and discrimination against HIV/AIDS-affected families. In addition, the projects encourage, and advocate for, the participation of children affected by HIV/AIDS at all levels of programme development and implementation.

Community – and home-based care and support services provided to children affected by HIV/AIDS include:

- basic medical care
- psychosocial support
- training to family members on home care, covering nutrition needs and diets, consumer information on basic medicines, and access and utilisation of referral services
- educating parents and other family members in planning for the future of their children, providing specific interventions for children who are orphaned, such as community-based foster care

- support for income generation activities
- support for affected children to remain in school through subsidised school fees, provision of school uniforms and notebooks, and vocational skills training.

Over the past three years of programme implementation, we have learned that the best way to respond to the diverse care and support needs of children affected by HIV/AIDS in a locally appropriate and sustainable way is through an **integrated** approach. Mainstreaming the care and support needs of children affected by HIV/AIDS and their families at the community level helps to overcome stigma and discrimination. In addition, it is important to address the specific needs of children affected by HIV/AIDS as different from those of adults. It is also vital to acknowledge that children have different needs based on their age and the contexts in which they live. Programmes need to be child-centred in the planning and implementation of activities by involving and working with children. Moreover, integrating prevention with care and support services to children affected by HIV/AIDS can reduce their vulnerability. Participation of older children in the implementation of care and support services is a very effective prevention approach within the community.

In continuation of Alliance India's commitment to prioritising work with children affected by HIV/AIDS as a national priority, Alliance India hosted a three-day meeting entitled 'Working with Children Affected by AIDS' between 17 and 19 December 2002, at the India Habitat Centre, New Delhi. The aims of this meeting were:

- to influence national policies on children affected by HIV/AIDS in India by drafting a policy paper
- to influence how we work with children affected by HIV/AIDS by sharing the values we uphold in our programmes as well as sharing lessons learned and reflecting on achievements and challenges
- to provide skills-building training to participants working with children affected by HIV/AIDS.

A total of 150 participants were invited to the meeting. They included: representatives from the Indian Central and State governments; multilateral and bilateral agencies; Alliance donors; international and local NGOs including current Alliance partners in India and the Asia

2. Introduction

and Eastern Europe region; and other NGOs with considerable experience in working with children in health and development.

The meeting commenced with an inauguration ceremony and keynote addresses from the Vice President of India, the Alliance and speakers from Kenya, Uganda and Cambodia with extensive experience of working with children affected by HIV/AIDS. A 'market-place' session was held in which partner NGOs shared their experiences of working with children affected by HIV/AIDS with a reflection on lessons learned through posters, children's skits and role-plays.

There were also skills-building sessions on working with children affected by HIV/AIDS according to a child's life cycle. The sessions were split into three age groups:

0–5: early childhood development

6–12: pre-adolescence

13–18: adolescence.

All market-place and skills-building sessions were conducted in three language tracks – English, Telugu and Tamil. Rapporteurs attended and documented key issues that emerged from the different language tracks from the sessions. The meeting ended with a plenary session where the rapporteurs presented an overview of the key themes and issues that emerged over the three-day meeting. These key points were documented as the draft policy paper.

This policy paper aims to bring in a common understanding of the definition of a child affected by HIV/AIDS as well as to introduce the principles of a child-centred approach when working with children affected by HIV/AIDS. A child-centred approach involves prioritising and responding to the specific needs of children affected by HIV/AIDS within a continuum of care and support, including prevention. It includes upholding the rights of children, and working with children, by actively encouraging their participation in assessing their needs, and the development and implementation of services and programmes. See Appendix 4 for the draft policy paper.



Participants were involved in lively discussions

3. Understanding a rights-based approach to working with children infected and affected by HIV/AIDS

The Alliance promotes a child-centred and participatory approach in its work with children affected by HIV/AIDS.

Children are valuable members of the community and the Alliance advocates for their participation in programmes that aim to improve their lives. This section outlines the key elements of a rights-based approach and illustrates its benefits and importance in HIV/AIDS programming.

Traditionally, policies and programming of development work have emphasised children's *needs* rather than their *rights*, and as a result children have been passive beneficiaries of what adults decide they should receive.

The table below outlines the benefits of using a 'rights-based approach' rather than a 'needs-based approach'.

The United Nations Convention on the Rights of the Child outlines a set of universal principles devised for the protection of children. It is the most widely accepted instrument of human rights law and has at its core respect for the dignity of children. The key principles are a child's rights to survival, development, protection

and participation. Countries that are signatories to the convention have an obligation and a duty to articulate these principles in their domestic laws.

The right to survival and development

Children have a right to survival and to information and experiences that could help them develop their potential and their life skills. They have a right to education and to play, to freedom of thought, conscience and religion. Children have a right to be able to protect themselves from the impact of HIV/AIDS. They have a right to prevention education and the skills to negotiate safer sex practices. They also have a right to be protected from the impact HIV/AIDS can have on their lives, such as caring for ill relatives, becoming the head of the household and becoming an orphan.

The right to protection

Children have a right to be protected from discrimination and exploitation. They should not be subjected to discrimination on the basis of either their own HIV status

Rights-based approach	Needs-based approach
<ul style="list-style-type: none">• Beneficiaries are active participants• Beneficiaries are legally entitled to their rights• Government is legally obliged to fulfil these rights• All people's rights need to be fulfilled• All people play a role in achieving rights• Considers process as well as outcome• Rights are realised through the help of a variety of key players• Interventions are long-term and sustainable• People have a sense of ownership over the action being taken 'with us not just for us'	<ul style="list-style-type: none">• Beneficiaries are passive participants• Beneficiaries need or 'deserve' a thing• Government 'can if it wants to'• Given that resources are scarce, only some people will benefit• Only some people with technical expertise will help• Looks at outcome• Works in isolation, addressing only the need• Short-term and not sustainable• Creates dependence

3. Understanding a rights-based approach to working with children infected and affected by HIV/AIDS

or that of a family member. They have a right to access health and social services, and it is especially important to ensure that orphans and vulnerable children receive adequate support from health and social services.

Children living in households affected by HIV continue to experience discrimination, exploitation and abuse in many countries. Violating children's rights in this way, because of either real or perceived HIV status of the child or their family members, adds yet another load to the tremendous burden these children already carry.

The right to participate

The Convention on the Rights of the Child includes the principle of child participation. This states that children and young people should have the right to be involved in all decisions concerning them, to freedom of expression, freedom of thought, conscience and religion, and to freedom of association. It is essential that children who are participating have the right to privacy and have access to information.

But what constitutes children's participation?

The Alliance uses participatory methods in its work with children affected by HIV/AIDS. By exercising their right to participate in programmes addressing issues that concern them, both children and their communities can benefit.

Respecting and fulfilling a child's right to participate is different from working with adults. Their participation is always dependent on the opportunities provided by adults. They should be given the freedom to participate on their own terms as much as possible and their views must be respected. Children can participate in many ways, by simply voicing their thoughts and feelings, or by being involved in the planning, implementation and assessment of programmes. Their participation must take into account a child's age, maturity, the context in which they live, as well as the child's abilities, needs and interests. They can be involved in decision making according to their maturity and capacity. For the child to receive most benefit, their participation should be viewed as a long-term process of empowerment rather than a single event. Using a child-centred approach implies working *with children* rather than *for children*. It means realistically

assessing children's abilities and ensuring their participation in planning, implementing and evaluating programmes. Children, including those living with HIV/AIDS, have knowledge, skills and abilities, which need to be respected and built upon. We need to be aware of their emotional needs and acknowledge that developing their self-esteem is as important as providing for their basic needs.

Why should children and young people participate?

It is only the children and young people themselves who can tell us what it means for them to live in a world affected by HIV/AIDS. Their contribution and insight is necessary to ensure a child-centred approach in programmes.

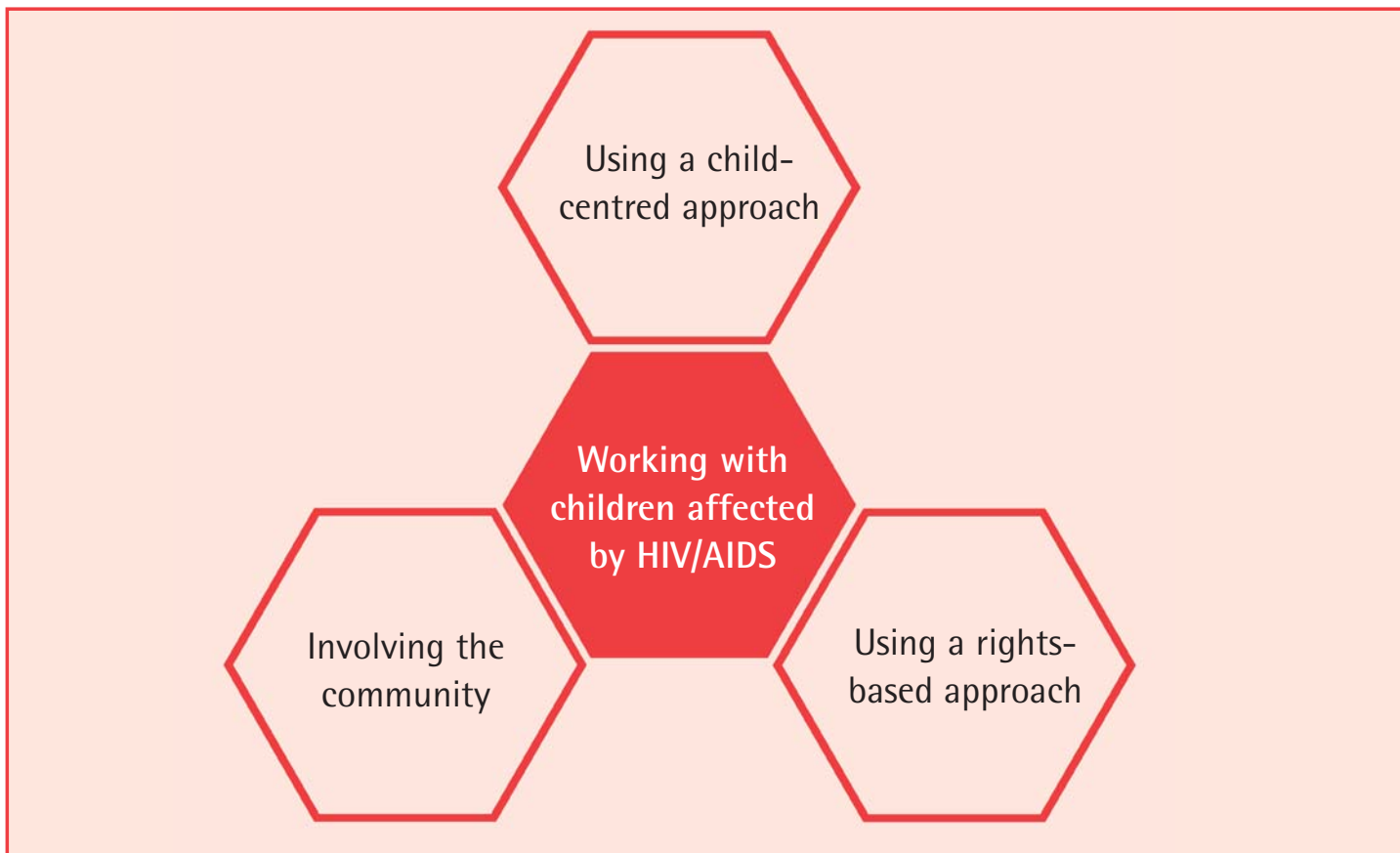
By being involved in HIV/AIDS programmes, children and young people also have the opportunity to develop skills and confidence in areas that will benefit them and their communities. For example, they may learn about co-operation and social responsibility. They may become more informed and equipped with new skills in communication and in thinking, which will prepare them for adult life. With the benefit of information, they are in a position to make well-informed decisions about their lives.

Another important advantage to participation is that it can provide an opportunity to meet others who are facing similar situations. The knowledge that they are not alone can provide strength, and their peers can provide important emotional and social support. When children gain more control over their lives, they develop hope for the future, increasing the likelihood that they will choose behaviours that help them to avoid HIV infection.

Involving the community

The Alliance promotes the need for care and support of children within their families and communities. In India, children who become orphans are often placed in institutions. Generally, children are best cared for in their own homes and communities through a collective, multi-sectoral community response. The work of the Alliance expands and strengthens community-based responses for children affected by HIV/AIDS so that institutionalisation becomes a last resort. Alliance partner organisations work with families, community leaders (including religious

3. Understanding a rights-based approach to working with children infected and affected by HIV/AIDS



A diagram to show the Alliance India's principles for work with children affected by HIV/AIDS

leaders), schoolteachers, local youth groups and local philanthropists to strengthen community-based responses to supporting children affected by HIV/AIDS.

Work with children infected and affected by HIV/AIDS should use a child-centred and rights-based approach and involve the community. It should also:

- respect
- recognise
- realise.

Respect	Recognise	Realise
<ul style="list-style-type: none"> • children's knowledge, skills and abilities, building upon them • children's emotional needs and developing their self-esteem 	<ul style="list-style-type: none"> • children of different backgrounds, age groups and gender, have separate and specific needs • children have the right to basic services that will improve the quality of their lives 	<ul style="list-style-type: none"> • children are best cared for in their own homes and communities through a collective multi-sectoral community response • children face stigma and discrimination at all levels, which should be challenged to create an enabling environment

4. The first five years

Overview

The first five years are probably the most important in a child's life. Growth and learning is very rapid, and most brain development happens during this period. Children at this age are vulnerable, impressionable and highly dependent on adult support. Experiences during early childhood will have a great impact on the adult personality – this is why this period is often referred to as 'the formative years'.

Many programmes that support people living with HIV/AIDS do not consider all the needs of any babies and young children in the family. Sometimes support only focuses on physical needs, and does not give equal importance to children's other needs – mental, emotional and social.

Young children need attention, love and mental stimulation, through social interaction and play. They need a stable and predictable home environment, ideally with one or two 'primary caregivers' – adults who are a relatively constant presence in children's lives. The relationship between the young child and their caregivers has a great influence on their personality and development.

Parents and caregivers can provide an environment that supports and stimulates growth and development. This will ensure that children grow up into healthy and well-adjusted adults, able to cope with the challenges of life.

Communicating with children

Much of a child's communication at this age will be non-verbal – it will be expressed through body language, facial expressions, gestures and tone of voice, rather than through words. It is important for adults working with children to understand effective ways of communicating with this age group.

What children need

Children at this age need to feel that someone is listening to their needs and paying attention. They need to be able to find their own way of expressing themselves, and often take time to do this. Children who are suffering fear and anxiety need someone they can trust, who can help them relieve their emotional tension and take care of them.

What adults can offer

- **sensitivity and understanding:** especially of how children react to loss and other upsetting events in the house
- **patience:** since children may be shy and take a long time to open up
- **active listening:** concentrating when the child is talking – taking the child seriously, paying attention to her, and making it clear you are listening through non-verbal gestures such as eye contact and posture
- **observation:** of facial expressions and body language – understanding of children's communication can be enhanced by observing non-verbal gestures
- **acceptance of children's feelings:** adults can act as a safe holder of children's feelings so that children can release their emotional tension
- **empathy:** understanding the child's experience 'through their eyes' can help adults to plan appropriate interventions for children and their families
- **love:** children need adults who are kind and empathetic, and who can be trusted to love the child unconditionally.



An adult comforts a young girl

Understanding children's behaviour when they are traumatised

Example: scenario 1

A child of about five years of age walks into your room. She is unkempt, and looks drowsy and tired. You ask her what the problem is, and she starts crying. You reach out to soothe her, but she responds by shrugging her shoulders. For some minutes you don't know what to say because you want her to say something. She stops crying, but she keeps quiet.

4. The first five years

This child is clearly deeply troubled. Other non-verbal signs of distress may include: not establishing eye contact, head hanging downward, being overactive, twisting fingers or playing repetitively with an object, biting fingernails or scratching hands.

Communicating with a child in these circumstances is challenging, and requires many of the skills and attitudes mentioned above. Building a rapport with her would help her overcome her initial fear and anxiety of being with an adult she does not know well. To communicate with this child, we could use the following methods:

- smiling, talking gently, touching and hugging (as long as the child is not further distressed by physical contact)
- using toys, play, stories and songs
- asking the child to express herself through drawings, modelling with Plasticine or clay, playing in sand, etc.

Effective communication with this child could lead to the child's tension being relieved – she will feel that someone has listened to her, and will feel less alone. The child will have a new starting ground, and will begin to establish trust with the adult who has listened to her.

Example: scenario 2

Jane, who is 4 years old, lost her mother to HIV/AIDS. In the following month she refuses to leave the house and to play with other children. She has become shy and can no longer talk fluently. She starts bedwetting, and clinging to her older sister.

This child is suffering from trauma. She is sad and grieving her loss. Bedwetting and clinging are signs of insecure children dealing with stress. Missing the security provided by her mother, Jane is withdrawing from social contact and does not feel the need for speech, which is why she is no longer talking so fluently. Other signs of trauma include nightmares or night terrors, temper tantrums and loss of appetite.

To support this child, community workers should suggest that the family:

- provides a predictable routine to each day, with Jane being cared for by the same adults most of the time – including her sister

- provides loving care and attention, including hugging, listening and talking to Jane
- does not punish Jane when she wets the bed, but reassures her that she is still loved and cared for.

Care and attention such as this will enable Jane to develop new relationships with trusted adults, and to continue to develop her social skills and sense of self-worth.

Questions for adults to ask themselves

- Do you have enough patience to listen without interrupting?
- Are you able to listen to a child telling you about their pain without interrupting them and telling them what to do?
- Are you able to deal with a child crying in a natural way, without embarrassment?
- Can you take children seriously and accept that they have their own feelings and ideas about the things that they have experienced?
- Do you like children? Do you feel comfortable when talking and being with them?
- Are you able to consider the world from a child's point of view?
- Are you judgemental about situations?



Jane being held by her elder sister

4. The first five years

The impact of HIV/AIDS from birth to 5 years¹

Milestones	Children affected by HIV	Children living with HIV
<p>0-1 year Consistency and continuity Babies cry when they are distressed, they need physical contact, to be spoken to with eye contact and to be taken out every day. Babies over six months old begin to recognise people and bond with caregivers.</p>	<ul style="list-style-type: none"> • Mothers living with HIV may not breastfeed, which could result in reduced immunity for the baby and reduced opportunity for bonding. • If a parent/caregiver is ill, a baby could receive inadequate attention and their physical needs may not be met. • Although they don't understand death, babies still miss their parent's voice, touch and smell. They may display subtle signs of this in the form of changes in sleeping or eating. • Constant changes in the infant's environment can lead the infant to mistrust their world. 	<ul style="list-style-type: none"> • The HIV status of babies can first be identified at 18 months old. The anxiety of parents as to whether the child has the virus or not can affect the baby. • Stigma and discrimination related to HIV infection could result in people not wanting to touch the baby. • Babies with HIV have more illnesses and develop more slowly. • Overprotection of the baby living with HIV (to avoid contracting opportunistic infections) could also lead to reduced exposure to external stimuli, which in turn could retard the baby's development.
<p>1-3 years Encouragement, enthusiasm and independence At this age, toddlers will learn to walk, feed themselves and talk. They will begin 'holding on and letting go' and 'putting in and taking out' things, as their muscles mature. They are self-conscious and can feel shame and pride. They feel self-doubt and this can remain if parents/caregivers shame them often. Parents/caregivers must be active listeners. Show enthusiasm, take time to answer questions and encourage curiosity.</p>	<ul style="list-style-type: none"> • When dealing with death, toddlers may show signs of irritability and be difficult to pacify while crying. • They may forget or be unable to repeat milestones they have already achieved (standing, walking, talking, etc.). • At this age, children are immediately aware of changes in the way they are cared for, and if they lose a primary caregiver they will grieve intensely, even though they do not understand that death means 'my parent will never come back'. 	<ul style="list-style-type: none"> • HIV-positive children may show signs of motor skills deficits and slow social development. • The impact of HIV becomes more evident after the age of 2 years, as everything (including school, family, social and psychological adjustment) may be affected. • Communities often isolate and ostracize the child, which could result in inadequate love and attention.

¹ Many of the development milestones in this table and the other two tables (see pages 14 and 18) have been taken from Erikson, 1987.

4. The first five years

3-5 years

Initiative and inspiration

Children need to participate in activities and learn to use language effectively. Caregivers can support children by reacting positively when children take the initiative. At this age, goals are important to children and guilt or anger can arise if they do not achieve those goals. They begin to feel competitive and sibling rivalry is common. They begin to mimic the adult world, and caregivers are the primary role models. This is their first step to discovering their own identity.

- Signs of distress and regression are common. Some children start bedwetting or sleepwalking. Others may crave attention and throw tantrums.
- Impatience or over-protectiveness from the caregiver may cause feelings of self-doubt or over-dependency.
- Positive memories from childhood are important, and not having a sense of history could adversely affect a child.
- Orphans often move home to be cared for by relatives. This loss of familiar environment could be very stressful. The company and support of siblings is important.
- Losing family members means losing role models and this could affect the child's sense of self-worth.

- Constant medical problems could affect the child's normal activities. Perhaps the child would not be able to attend school and this would affect their normal development.
- Children can begin to understand more about their illness and the need to take their medicines.
- Caregivers are encouraged to talk openly and honestly with children about their health.

5. Children between 6 and 12 years old

Issues

This is a period in a child's life when they begin to be less dependent on adults. Their reasoning develops, they ask a lot of questions and begin to enjoy problem solving. They learn the importance of rules, and can appreciate their value, both in games and in daily life.

Children at this age need appreciation for their growing skills, and a reasonable amount of trust that they can make appropriate choices in their lives. They should begin to take responsibility for their own actions and the consequences thereof, while being supported in a loving environment. Adults can provide stable and predictable boundaries or 'rules' which give children a sense of security.

As children approach puberty, physical changes begin to take place, and these influence changes in children's attitudes, values and behaviour. Children begin to be more challenging, of themselves and others, and often ask questions which adults may find difficult to answer. This includes questions about HIV/AIDS, which raise concerns about sex and death. Adults should not avoid answering a child's questions, but provide correct and consistent information.

Belonging to a peer group is extremely important to this age group – they like to spend time with friends of the same age and sex. This is a chance for them to learn about life outside the family home, and to develop important social skills. Going to school is a chance not only to learn and develop their intelligence, but also to build social networks and support groups.

Communicating with children

Children are still learning to deal with their emotions during this phase of growing up. Unlike children under 5, who may not understand the concept of death, children in this age group are old enough to know what it means. However, the impact of losing a parent or loved one will be hard to comprehend at this age, which means it will also be hard for children to come to terms with their grief and bereavement. In addition, the other parent or caregiver in the family may also be grieving deeply, and not be able to support the child. The support of a wider network of adults and peers is essential.

As well as grief, children also experience insecurity – they realise that the family has lost a breadwinner or provider, and they worry about their future. They may experience mixed emotions of anger: *Why did this happen to me?*; low self-esteem: *I didn't deserve any better*; or self-blame: *I did something wrong so I lost my parents*.

What children need

Some children at this age will express their emotions freely, while others will keep their thoughts and feelings to themselves. Bottled emotions may cause further physical and psychological problems, and may be expressed as anger or destructiveness.

Children need someone who can help them understand their feelings, to listen to them and to answer their questions honestly. Children still need 'rules' and consistency in their lives, such as continued opportunities to be with their friends and peers.

What adults can offer

Adults working with children who have experienced loss need to be able to reach out to them, to listen to them, and to help them express themselves. There are many creative ways in which adults can reach out to children and allow them, at their own pace, to tell their story or express their feelings and worries in a safe environment. Play therapy, theatre, art, craft, music and dance are some ways. Materials such as paper, sand, plasticine or clay can all be used with positive results.

Helping children cope in traumatic situations

Example activity: modelling with clay

Sitting together and making models from clay is a good activity to use to help communication with traumatised children. It enables the adult to:

- **Build a relationship with the child** – an activity such as modelling with clay allows the child to be creative, and helps the adult get to know the child and overcome barriers in communication.



Participants practised clay modelling

5. Children between 6 and 12 years old

- **Learn more about the child and their particular interests** – by carefully observing what the child chooses to make, and by asking the child to share why they have made the shape they have, the adult could learn more about the child's interests and what they are thinking about.
- **Help them express themselves** – listening to the child, being non-judgemental and appreciating the child's efforts would all help in letting the child loosen their guard and open up.
- **Have a healing effect** – kneading clay, or building and destroying sand objects has a soothing healing effect on children. Making shapes which they can change or mould also helps them to understand that they can take control of their circumstances.

An increasing body of research from the fields of psychology, psychiatry and sociology is showing that most people – including young people – can bounce back from risks, stress, crises, and trauma, and experience life success. A resilient child can cope more positively than others in the face of the devastating impact of HIV/AIDS in their lives. Resilient children are those that bend rather than break in the storm. There are a range of personality traits and skills associated with resilience, which include: problem-solving skills, a strong sense of self-worth, optimism, the ability to communicate, empathy with others including adults, older siblings and peers, confidence and the ability to ask for help, the ability to regulate emotion and self-awareness.

Example activity: understanding resilience

Participants were invited to stand in a circle. They were asked to imagine they had characteristics of any tree of their choice. The facilitator led the group in imagining they were experiencing a fierce storm, and as trees they were to sway, bend as far as they could, and even fall. While some trees were able to bounce back and remain standing, others did not. Participants were asked to describe the characteristics of trees that withstood the storm and those that did not. They were to relate this characteristic to the skills and qualities that children need to withstand the potentially devastating effects of HIV/AIDS in their lives.

Participants were asked to repeat the storm exercise, but this time hold hands and stand very close to each other. They were asked to discuss what contributed to the strength and weakness of the types of trees in the circle.

This exercise helps to understand the qualities of resilience in children. Resilience is the ability to spring back from, and successfully adapt to, adversity. This definition of resilience was taken from the website Resiliency in Action: www.resiliency.com.



Participants take part in the trees in the storm exercise

5. Children between 6 and 12 years old

The impact of HIV/AIDS on children from 6 to 12 years old

Milestones	Children affected by HIV	Children living with HIV
<p>Cognitive development</p> <ul style="list-style-type: none"> • Learns the importance of rules and begins using scientific reasoning. • Begins to develop the ability to think abstractly and to understand symbols and principles. • Can form hypotheses about life and try to prove and disprove them (hypothetical-deductive reasoning). • Can reason on the basis of possibilities instead of being restricted to experience. • Develops the ability to think reflectively, e.g. about one's own thought. • Varies within their own cognitive growth so that it is normal for a young adolescent to think abstractly in one area but be tied to concrete thinking in another. 	<ul style="list-style-type: none"> • Witnessing or nursing parents as they go through a long illness and eventually death would be a traumatic experience for this age group, particularly if the family faces stigma and discrimination. This could also result in the child assuming maladaptive behaviour such as resorting to risky practices. • Lack of a peer group (who may reflect the stigma shown by their elders) may result in isolation and children losing an important support system. • Losing an earning member or increased household expenses (constant medical treatment) could mean the child having to take financial responsibility – perhaps having to earn to support the family. • With ill parents – the responsibility of looking after younger siblings and ill parents could be an added burden on the child. Children could also feel resentment and blame their parents for the situation. • Children affected by HIV/AIDS are vulnerable to becoming orphans, suffering from abuse, running away from home and taking to the streets. • Economic stress could result in the child having to work. Abuse and exploitation could become possible. 	<ul style="list-style-type: none"> • For children living with HIV, medical problems could result in slower physical and mental development. There could be questioning (<i>Why has this happened to me?</i>) and isolation, leading to further stress. • HIV-positive children could be shunned by their friends, which would be especially traumatic for them considering the significance of peer groups in their lives. Children could face discrimination from other quarters as well, and in some extreme cases could even be abandoned by their family. • An underlying issue would be the emotional and psychological problems that they may experience because of the condition having social as well as medical implications.
<p>Psychosocial development</p> <ul style="list-style-type: none"> • Comparison of self with others: begin assessing self as superior or inferior. • Learn to co-operate with others when carrying out tasks. 		
<p>Needs</p> <ul style="list-style-type: none"> • Unconditional acceptance and love. • Constant encouragement as they learn. 		

5. Children between 6 and 12 years old

- Reasonable amount of trust to make choices about their life's issues.
- Responsibility for own actions and their consequences.
- Build capacity to promote initiative.
- To develop the ability for personal organisation and respect of rule (home, schools and wider society).
- Exposure to challenging tasks that develop self-worth and competence.
- Freedom to build meaningful peer social networks.
- Share challenges of peer interactions
- Participate in home, school or group accomplishments.

6. Young people between 13 and 18 years old

Issues

This is a period of change, when a young person is neither a child nor an adult. Rapid physical and mental changes, and the search for identity, all make this period very unsettling. Young people at this age become egocentric (focused on themselves) and preoccupied with self-appearance. This is also a time when children become more sexually aware and begin to form friendships beyond their existing peer groups.

Teenagers prefer to be with their peer groups, and are often dependent on them for emotional and social support, although their family remains a reference point. They learn more sophisticated social skills such as leadership and decision making. Their reasoning power increases, and they are not satisfied with 'rules' established by others – they want to work things out for themselves. They like to experiment and to try and prove their theories.

However, children at this age are still developing emotionally, and need support to cope with trauma in their lives. Adults can be both a source of stress and conflict as well as of support and strength in young people's lives, and relationships will often shift between these roles. Young people's egocentricity may mean that they blame themselves for anything bad that happens in their lives. When a parent dies, children of this age may believe very strongly that it was their fault and that they could have prevented it. This sense of guilt adds to their bereavement and grief.

Young people in families affected by HIV/AIDS will often take on a lot of responsibility. However, children at this age still need a lot of support – mainly psychological and emotional, rather than simply physical.

Communicating with young people

During this period young people are trying to decide what they want to do or be. They need accurate information to help them make important decisions affecting their lives. This includes information on their education and careers, about their bodies, about sex and love, and about addictions and substance abuse. They also

need access to adolescent-friendly services related to health, family support, counselling and education. Most importantly, they need the space and privacy to explore their own feelings.

What young people need

The emotional turmoil that is normal at this age may get magnified when the young person tries to come to terms with their (or their family's) HIV status. Children may become depressed or even suicidal, and need careful monitoring and support.

The fact that young people may be egocentric at this age may mean that they become very sensitive to media images and reports, perceiving the messages as directed solely at them. Prevention messages will often carry very negative images about HIV, promoting stigma, discrimination and fear. This will have a very powerful effect on young people, concerned with their image and the opinion of their peers. Children need balanced and reassuring messages.

Adolescents also have to deal with the frustration of coping with their sexual maturity, but having to lead a restrained sexual life as they are not yet considered adults.

What adults can offer

Many of the skills and attitudes that have been described above remain important for this age group. Although adolescents may be as articulate as adults, they are still developing emotionally – reading non-verbal cues such as body language can help an adult understand what a child is feeling.

Adults can take the time to understand a situation from the adolescent's point of view, to be non-judgemental yet also able to offer helpful advice and information when it is asked for, making sure that it is kept confidential when this is requested.

Adults can also make sure that adolescents have privacy and time with their peer group. Adolescents can also be given the opportunity to organise their lives, and appreciation and praise when they do things well.

6. Young people between 13 and 18 years old

Helping adolescents understand and cope with trauma

Example activity: scenario 1

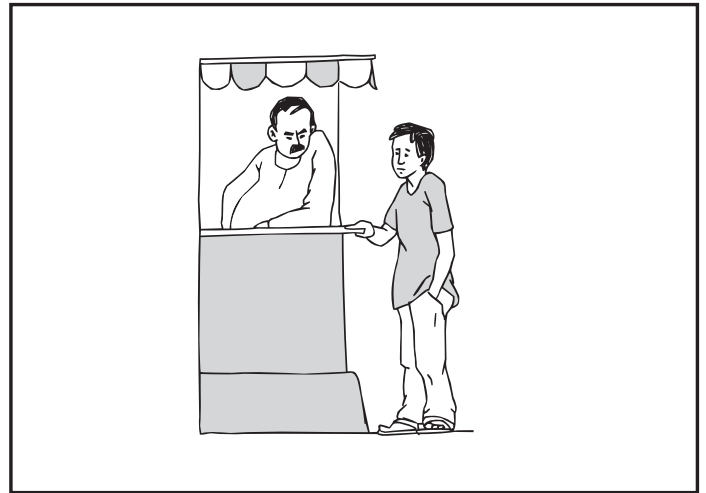
Participants took part in a role-play to understand how adults often judge young people very differently from adults. They were given a situation where a shopkeeper notices a theft taking place in his shop, and were asked to consider how the shopkeeper would react if it was an adult stealing, or an adolescent.

This role-play allowed people to explore the different ways adults interpret adolescents' behaviour and sense of responsibility, and how adults often treat adolescents very differently from adults. They were also able to consider the situation from the young person's point of view.

Example activity: scenario 2

Participants performed a drama for the group, depicting a family with a 13 year-old girl who has just lost her parents to HIV/AIDS, exploring the roles of her grandmother, uncle, neighbour and a community development worker. The drama was stopped at certain points, and participants were invited to take up the role of one of the characters and show what they would say or do in that situation.

The drama showed participants the differing and complex motivations in the family and community, and invited them to consider the impact of these on the young woman. They were also encouraged to see things from her point of view, bearing in mind what they had just learned about the particular needs of this age group. They saw how HIV/AIDS can lead to young people being forced into taking on adult roles, and making difficult decisions, and how adults can play a supportive role as they face this new challenge.



The shopkeeper with an adolescent



The shopkeeper with an adult



Participants take part in the drama

6. Young people between 13 and 18 years old

The impact of HIV/AIDS on young people from 13 to 18 years old

Milestones	Children affected by HIV	Children living with HIV
<p>15–18 years Identity</p> <p>The discovery of self-identity and independence from parents dominates this stage of development. If guilt or anxiety have been experienced heavily in earlier years, this time will be difficult for the teenager. Feelings of shyness, uncertainty and being unloved may be common.</p> <p>Characteristics</p> <ul style="list-style-type: none"> • Rapid physical changes. • Developing sexual awareness, wondering what to do, needs right information, etc. • A time of experimentation and risk-taking. • Egocentric – feel very powerful, think that adults have never been adolescents. • Self-conscious – who they are and what they should be. • Peer group is very strong in opinion-forming. • Family has become a reference point only. • Have their own language and codes. • Feel the stress of parental pressures. • Swing between two personalities – transient (which we see) and the real (that is developing). • Consolidating their values: <i>'I can fix it and do it myself.'</i> 	<ul style="list-style-type: none"> • The emotional turmoil that is normal at this age only gets magnified when the young person tries to come to terms with the family's situation. They may experience anger or feel depressed and suicidal. The future may seem bleak and pointless. Turning to self-destructive risk behaviours becomes an option for such young people. • It is important for young people to belong to a peer group; rejection from peers becomes all the more difficult to accept. • However, if young people have a supportive peer group, this can make an enormous difference at this age. • Young people at this age are able to fully understand illness and death, and will feel grief and bereavement like an adult. • Young people in families affected by HIV/AIDS are likely to feel very depressed and anxious about the future. • Young people's egocentricity may mean that they feel very personally affected, and even responsible, for the HIV/AIDS situation in their family. • Young people need to deal with their own developing sexual maturity. 	<ul style="list-style-type: none"> • Young people living with HIV have to deal with their own developing sexual maturity and the implications of HIV on their sexual behaviour. Clear information and prevention education is vital. • Young people living with HIV will see TV and newspapers carrying messages on HIV/AIDS that focus on prevention, and therefore are sometimes insensitive to people living with HIV. Young people living with HIV are particularly influenced by these negative reports and images as they may be unable to see themselves as separate from their HIV-positive identity. • Young people living with HIV will be able to fully understand the implications of their illness, and can consider what it means for their future.

6. Young people between 13 and 18 years old

- Reasoning increases – information from past, prove and disprove, think of future.
- Ability to reason is high but emotionally not developed.
- Look for collective solution from peers.

Needs

- Empathy.
- Unconditional love.
- Information.
- Freedom to make decisions.
- Guided from distance by parents.
- Privacy.
- Time with peer group.
- Chance to organise their life.
- Confidentiality.
- Appreciation.
- Praise.

7. Learning from the field

Introduction

This section considers how the principles of rights-based approaches translate into programmes, based on the experience of the Palmyrah Workers Development Society (PWDS) and three of their partner organisations (SEDCO, AIRD and WORD) in Tamil Nadu. The work of these organisations involves promoting and protecting children's rights to life and development, and their right to participate in situations and matters that affect them. PWDS aims to address situations in which children may be vulnerable to exploitation or neglect due to the stigma that is associated with HIV/AIDS.

Background

In Tamil Nadu, the relationship between poverty and HIV/AIDS is obvious and has many facets. Tuticorin, in southern Tamil Nadu, is a drought-prone area where employment is scarce and poorly paid. As a result, Tuticorin has a very high migration rate, especially amongst young men. Also, many families migrate to Mumbai hoping to find work, but are soon faced with the harsh reality of low wages and little job security. Such families live in extreme poverty, which is made worse if parents are unable to work due to illnesses related to HIV/AIDS. Typically, those who discover they are HIV positive return to the village. However, it is often the case that the extended family does not offer support, as a result of the stigma associated with the virus. This can leave children, who may soon be orphaned, without food, shelter, education and emotional support.

Programmes

SEDCO, AIRD and WORD address the problems faced by children affected by HIV/AIDS using a number of approaches. The most urgent needs of these children can be alleviated by economic and material support. SEDCO, AIRD and WORD all rely on the local community to provide this support. Community members provide shelter, food, clothing, school fees and sometimes also the important emotional and physical support that would have been provided by a parent. It is also important to recognise that children affected by HIV/AIDS may be traumatised and feeling a range of emotions such as anger, confusion and even guilt. Both material and

emotional support is necessary for a child's well-being. In some cases, this support can come in the form of adoption. For example, SEDCO have helped to arrange for two members of a local self-help group, Chitra and Sivasundaravadini, to adopt Anitha, a 12 year-old girl, who lost both her parents to AIDS. Although Anitha had a large extended family, they refused to take care of her when her parents died.

However, the stigma surrounding HIV/AIDS can make it difficult to encourage community support although increased access to treatment may help reduce it. However, people often transfer the stigma of HIV/AIDS to children from affected households. One method of reducing stigma is raising the community's awareness and educating them about the transmission and prevention of the virus. A method of reducing stigma employed by SEDCO, AIRD and WORD is to involve key community figures, such as Panchayat members, and the local church in their work. When respected members of the community become associated with HIV/AIDS, it can send a message to the rest of the community that it is acceptable to get involved. Involving key stakeholders and influential figures in the work of PWDS's partners has proved a useful strategy in increasing community involvement. AIRD has involved an ex-magistrate and respected member of the community. The church has also played an important role in raising awareness of HIV/AIDS in the congregation.

Those who lose the main wage earner in the family will often be left with no means of income. When 32 year-old Neela lost her husband to AIDS in 2001, she tried to make a claim from the Life Insurance Corporation (LIC). Without her husband, Neela had no income to provide for herself and her son. But the LIC insisted, that since Neela's husband Palam had been suffering from a 'chronic disease', he was not eligible for life insurance. Following a year of campaigning (assisted by AIRD), Neela was paid Rs 26,175 (US\$584). This case also resulted in a Supreme Court judgement, recognising that state run insurance companies should provide life insurance for people living with HIV.

The following case studies highlight some of the issues faced by children affected by HIV/AIDS and the ways in which SEDCO, AIRD and WORD have begun to address these issues.

7. Learning from the field

Robert's story

Robert is 14 years old and is the eldest son of Anthony and Amalli. Anthony died of AIDS and Amalli is HIV positive. Robert now lives with his mother, maternal grandparents and sisters Raveena and Sadhana. When Anthony died, the relatives refused to attend the funeral because they knew that AIDS was the cause of his death. Amalli is extremely worried about the future of her family and suffers periods of depression.

Robert's grandfather can no longer work. They now rely heavily on the material support provided by AIRD in collaboration with the local church. The family is given ten kilograms of rice and Rs 200 (US\$4.5) every month. AIRD had also arranged and paid for Robert and his sisters to continue with their education.

Conclusion

The work of PWDS's partners relies heavily on community involvement in reducing stigma and discrimination and interventions to promote and protect the rights of children affected by HIV/AIDS. Staff members at these organisations believe that the HIV incidence is increasing in Tamil Nadu, so it is essential that support is drawn from all sectors. Involving the community can also increase knowledge about the prevention of HIV and ensures a sustained response for children.

Kanaka's story

Fourteen-year-old Kanaka's parents had migrated to Mumbai for work but returned to their village once they were diagnosed HIV positive. Kanaka and the other children enrolled at a local school where their lessons were taught in Tamil. Kanaka found this transition difficult, as her education so far had been given in English. When Kanaka's mother became too weak to care for her ill husband and her children, Kanaka left school to help take care of her siblings. A year ago both Kanaka's parents died from AIDS and she is now bringing up her two sisters and brother. Kanaka's grandparents and aunt provide a small income.

Facilitated by SEDCO, a member of a local self-help group, who is also a neighbour and a Panchayat member, now makes regular deposits into a bank account for Kanaka and her siblings. SEDCO also provides emotional support to Kanaka and her family.

Appendix 1: List of participants

Skills Building Sessions

National Thematic Meeting and Workshop on 'Working with Children Affected by AIDS'

17–19th December 2002

Name	Organisation	Location
Minaxi Shukla	CHETNA	Ahmedabad
Bhavani Shankar	VMM	Andhra Pradesh
Dr. Davidson Solomon	Shadows Solomon Hospital Complex	Andhra Pradesh
Dr. G. Prabhakar	Green Vision	Andhra Pradesh
Easwar Prasad	Needs	Andhra Pradesh
G. Rashmi	VMM	Andhra Pradesh
K. Narasimha Murty	St. Paul's Trust	Andhra Pradesh
K. Vani	Sanghamitra Social	Andhra Pradesh
Koteswar Rao	VMM	Andhra Pradesh
Mohamed Nazeem	VMM	Andhra Pradesh
Y. Sambasiva Rao	AIRTDS	Andhra Pradesh
Musala Mallikarjuna	AIRTDS	Andhra Pradesh
Y. Padmavati	South Zone Office Save the Children UK	Andhra Pradesh
A. H. Taufique Ahmed	HASAB	Bangladesh
Ros Monichoth	Khmer Buddhist Association	Cambodia
Pen Siphon	Sacrifice Family Orphans Development Association (SFODA)	Cambodia
Ma Kol Chenda	Khmer HIV/AIDS NGO Alliance (KHANA)	Cambodia
David Harding	Friends-Mith Samlanh	Cambodia
Dushyanta Mehar	Salam Balak Trust	Delhi
Gopinath Bhupinder Parekh	Sharan	Delhi
Lusy Nesley	Sharan	Delhi
Priyanka Prabhat	Society for Promotion of Youth and Masses (SPYM)	Delhi
Ratna Gaikewad	Prayatn	Delhi
Sharmil Dubey	Prayatn	Delhi
S. Sweecharan	Navjeevan Seva Mandal	Delhi
Shariq Khan	Navjyoti	Delhi
Manju Shah	Naz Foundation India Trust	Delhi
Jaya Tiwari	Naz Foundation India Trust	Delhi
Praveen Kumar Jha	Salam Balak Trust	Delhi
Sidharth Singh	Sharan	Delhi
Shantanu Choudhury	Sahara	Delhi

Appendix 1: List of participants

Name	Organisation	Location
Bipin Kumar	Child Survival India	Delhi
Sheela Mann	Child Survival India	Delhi
Dr. Kumudha Aruldas	Plan India	Delhi
Dr. Suzie Poddar	Plan India	Delhi
Dr. Anand	Delhi Samata Vikas	Delhi
Tara Manchin Hangzo	India HIV/AIDS Alliance	Delhi
Bitra George	Family Health International	Delhi
Rajesh Kumar	SPYM	Delhi
Vaishali Sharma Mahendra	Population Council	Delhi
Dr. Subhadra Menon	International Vaccine Initiative	Delhi
Chris Mary Kurian	Centre for Social Medicine and Community Health	Delhi
Rangaian Gurumurthy	Population Council	Delhi
Anandi Yuvaraj	India HIV/AIDS Alliance	Delhi
Anand Kurup	India HIV/AIDS Alliance	Delhi
Dr. Ritu Priya	Associate Professor, Centre for Social Medicine and Community Health	Delhi
Malundra	Sangram	Maharashtra
Sheetal Bhosle	Salvation Army	Maharashtra
Madhavi Shinde	Committed Communities Development Trust (CCDT)	Mumbai/Maharashtra
Roma Perera	RNP Communications	Mumbai
Pooja Choudhari	RNP Communications	Mumbai
Ms Chimidtsere	OYUNTSESEG Darkhan Women's Federation	Mongolia
Ms Batsukh Altansetseg	National AIDS Foundation	Mongolia
A. Meenakshi	Imayam Social Welfare Association	Tamil Nadu
A. Satish Babu	HEALDS	Tamil Nadu
A. Planiappa Pillai	Centre for Social Reconstruction (CSR)	Tamil Nadu
A. Saravanam	Society for Serving Humanity	Tamil Nadu
Anbarshi	Rural Education for Development	Tamil Nadu
Anil Kumar	CSR	Tamil Nadu
C. Raman	Pache Trust	Tamil Nadu
Daisy David	Indian Network of People Living with HIV/AIDS	Tamil Nadu
E. Sivaji Rao	Chevaliar Roche Trust	Tamil Nadu

Appendix 1: List of participants

Name	Organisation	Location
Edwin Sam	PWDS	Tamil Nadu
G. Suresh Alfred	Catherine Booth Hospital	Tamil Nadu
J. Reeta	Blossom	Tamil Nadu
K. Muthuselven	CAST	Tamil Nadu
K. Sivakumar	GRAMIUM	Tamil Nadu
Kalaivanan	Master Trust	Tamil Nadu
L. Saravana Priya	Women's Organisation in Rural Development	Tamil Nadu
Lavanya	PWN+	Tamil Nadu
M. Felix	AIRD	Tamil Nadu
Paul Raj	Centre for Action and Rural Education	Tamil Nadu
Poorna Chandran	Society for Rural Development and Protection of Environment (SRDPE)	Tamil Nadu
Samuel Kumar	PWDS	Tamil Nadu
Senthil Kumar	Seva Nilayam	Tamil Nadu
Silyester	SEDCO	Tamil Nadu
Sugaraja	Native Modicare Charitable Trust	Tamil Nadu
T. Mercy Annapurni	Blossom	Tamil Nadu
Thomas Peter	AIRD	Tamil Nadu
E. Thimothi	SAATHI	Tamil Nadu
R. Charukanya	AIDSNet Foundation	Thailand
P. Namphung	AIDSNet Foundation	Thailand
Chutima Saisaengjan	AIDSNet Foundation	Thailand
Becky Whale	International HIV/AIDS Alliance	UK
Divya Bajpai	International HIV/AIDS Alliance	UK
Sujit Ghosh	International HIV/AIDS Alliance	UK
Jud Cornell	International HIV/AIDS Alliance	UK
Kate Harrison	International HIV/AIDS Alliance	UK
Olga Slyuytsia	International HIV/AIDS Alliance	Ukraine
Valentina Pavenko	Regional Association of Assistance to HIV-infected People of Donetsk	Ukraine
Paurvi Bhatt	Step Forward/Abbott	Washington
Linda Susmann	USAID	Washington
Tarak	Cini Asha	West Bengal
Ranjana Dasgupta	GOAL	West Bengal
Biswajit Panda	Bhoruka Charitable Trust	West Bengal

Appendix 2: Resources and websites

Useful resources on children affected by HIV/AIDS

UNAIDS, USAID, UNICEF. *Children on the Brink 2002 – a joint report on orphan estimates and program strategies.* Available at www.usaid.gov or www.unaids.org or www.unicef.org or by writing to: UNICEF, 3 United Nations Plaza, New York, NY 10017, USA. email: pubdoc@unicef.org

International HIV/AIDS Alliance, DFID, USAID. (2002) *100 Ways to Energise Groups: games to use in workshops, meetings and the community.* Available from: www.aidsalliance.org

International HIV/AIDS Alliance, USAID. (2003) *Building Blocks – Africa-wide briefing notes.* Available from: www.aidsalliance.org/building_blocks

VMM/International HIV/AIDS Alliance. (2004) *Moving Forward: a report on pioneering responses to children affected by HIV/AIDS in Andhra Pradesh, India.* Available from: www.aidsalliance.org

Erikson, E. H. (1987) *Childhood and Society.*

Useful websites about children affected by HIV

www.aidsalliance.org
The website of International HIV/AIDS Alliance, with guidance and resources on all aspects of HIV/AIDS prevention and care.

www.act.org.uk/pages/start.asp
ACT's website contains references and links on the palliative care of children and paediatric AIDS.

www.bernardvanleer.org
This website details Bernard van Leer programmes (in 40 countries), and also contains publications and links on early childhood development (ECD).

www.childhopeuk.org
ChildHope is an international NGO addressing issues faced by street children. The website details their projects, publications and resources and has links to other similar organisations.

www.unicef.org/crc/crc.htm

UNICEF's website details the UN convention on the Rights of the Child and which countries have signed and ratified the convention.

www.crin.org

Child rights information network website contains recent publications and useful websites on child rights, arranged in themes and regions.

www.childtraumaacademy.com

This website offers free online courses on creative and practical approaches to understanding and working with maltreated children.

www.resiliency.com

Resiliency in Action is a US-based website which contains bibliographies, virtual library, literature reviews and internet resources on resiliency.

www.eldis.org/children/index.htm

Eldis's children and young people resource guide contains useful articles and links categorised by theme.

www.plan-international.org

Plan is an international organisation working on children's issues. The website details current programmes.

www.savethechildren.org.uk

Save the Children's website contains policy papers on prevention, care and treatment in relation to children.

www.unicef.org/lifeskills/index.html

UNICEF's life-skills-based education programme.

www.child-to-child.org

Child to Child's website details their work on HIV/AIDS and children, their online publications and resources.

www.stretchchildren.org.uk

This website details current programmes with street children and contains links to resources and publications.

www.pedaids.org

Elizabeth Glaser Pediatric AIDS Foundation details current programmes and projects.

www.who.int/child-adolescent-health/HIV/HIV_improving.html

Part of the WHO website discussing improving care for children with symptomatic HIV infection.

Appendix 3: Acronyms

Acronym	Organisation
AIDS	acquired immune deficiency syndrome
AIRD	Association for Integrated Rural Development
CBO	community-based organisation
HIV	human immunodeficiency virus
LIC	life insurance corporation
NACO	National AIDS Control Organisation
NGO	non-governmental organisation
PWDS	Palmyrah Workers Development Society
SEDCO	Scientific Educational Development for Community Organisation
WORD	Women's Organisation in Rural Development

Appendix 4: Draft policy paper

This paper builds on discussions that took place at the National Thematic Meeting and Workshop on Children Affected by AIDS, 17th–19th December 2002, Delhi, and proposes a policy agenda for further development and action.

Policy recommendations

At the National Thematic Meeting, Meenakshi Datta Ghosh, Project Director of the National AIDS Control Organisation (NACO), acknowledged the government's commitment to upholding the declaration on the rights of the child. We must ensure that this commitment is translated into practice.

A clear opportunity exists for civil society and the NGO sector actively to inform phase three of the National AIDS Control Programme to ensure that children are central to the response to HIV/AIDS in India. We must rise to this challenge and ensure that the learning and experiences of working with children and placing them at the centre are conveyed to, and heard by, NACO and other policy makers in India.

We need to recognise that children's needs are diverse and that multi-sectoral responses are needed to address these, at both the community and the government level. We must collaborate and foster partnerships so that we can provide the relevant range and depth of interventions.

The way in which the phrase 'children affected by AIDS' is interpreted and used can limit the scope, nature and appropriateness of interventions. Much work with children affected by HIV/AIDS remains responsive and reactive. It is often the case that interventions tend to be limited to those children who are already suffering AIDS-related loss and trauma. We must intervene early to prevent children from finding themselves in situations that leave them exposed to the impact of AIDS.

We must talk to and listen to children for solutions, to ask how we can best meet the challenges they are facing. Amongst many things identified as being critical to children is the importance of care and support within their families and communities. In India, placing children in orphanages is often proposed as the first course of action. We must ensure that this becomes the last resort and that we expand community-based responses for children affected by HIV/AIDS that have been demonstrated to work effectively.

It is important to work in partnership with each other and with policy and decision makers, including government, to ensure that we achieve meaningful change for our children.



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