Supporting Community Action on AIDS in India

Building Blocks

India Briefing Notes

Young children and HIV

Strengthening family and community support
What is the International HIV/AIDS Alliance?

Established in 1993 with a Secretariat in Brighton, UK, the International HIV/AIDS Alliance is a global partnership of people, organisations and communities working towards a shared vision that supports effective and integrated community responses to HIV and AIDS. This approach is based on the belief that those at the frontline of the struggle against HIV and AIDS must have the resources to take on the challenges that the epidemic presents.

The Alliance operates through a global network of in-country intermediary non-governmental organisations, known by the Alliance as Linking Organisations (LOs), who in turn work with partnerships and networks of NGOs and other community-based organisations (CBOs) to mobilise, facilitate and scale-up sustainable community-based response to HIV and AIDS. This is achieved through building their capacity, and in the process, developing synergy of resources and the ability to collectively mobilise resources and influence policy at different levels. Through the joint actions of its partners, the Alliance has established itself as a leading player in the global response to the HIV and AIDS epidemic.

The India HIV/AIDS Alliance

The India HIV/AIDS Alliance was established in 1999 to expand and intensify the International HIV/AIDS Alliance’s global strategy of supporting community action to reduce the spread of HIV and mitigate the impact of AIDS. Since its inception, the Alliance has been committed to fostering and supporting the development of community-driven approaches to HIV/AIDS prevention, care and support and impact mitigation in India, with an emphasis on local leadership and responsibility.

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The India HIV/AIDS Alliance currently provides programmatic, technical, strategic, organisational development and financial support to a country-wide network of over 75 NGOs through a national Secretariat based in Delhi and six linking organisations (or, Lead Partners) and state partner organisations in Delhi, Tamil Nadu, Andhra Pradesh, Punjab and Manipur States.

Our Vision

The vision of the International HIV/AIDS Alliance is of a world in which people do not die of AIDS.

For us this means a world in which all human rights are respected: a world where every person can live with dignity, regardless of their gender, religion, class, race, ethnicity or sexual orientation; and where communities have brought HIV and AIDS under control through promoting and facilitating access to affordable and appropriate prevention, care, support and treatment information and services.

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Introduction

This briefing note is part of a set of eight, comprising an overview and the following seven topics:

- Overview
- Education
- Health and nutrition
- Care and psychosocial support
- Social inclusion
- Livelihood and economic strengthening
- Protection

This briefing note provides practical guidance on meeting the developmental needs of young children affected by HIV and the care and treatment needs of young children living with HIV. Focusing on children under eight years of age, it aims to assist local organisations and service providers to strengthen family and community support for these children.

It is organised as follows:

- The first section is about both children living with HIV and children affected by HIV. It describes the impact of HIV on the intellectual, emotional, psychological and social development of young children and what organisations can do to help families and communities to meet children’s developmental needs.

- The second section is about children living with HIV. It describes the impact of HIV infection on the physical health of young children and what organisations can do to support families and communities to provide good care and treatment for young children living with HIV.

This briefing note is a version of the Building Blocks: Africa-wide briefing note on “Young Children and HIV”. It has been adapted to make it relevant to the Indian setting, using case studies from India and Africa. The adaptation was guided by the people listed in the acknowledgements section. It is based on background reading (see “References and Useful Resources”) with further additions made during the review meetings in India and Africa, which are referred to as the “Building Blocks development group”. Most of the background reading is available on www.ovcsupport.net, which is also available as a CD-ROM.
Section 1

Meetings the developmental needs of young children living with HIV and young children affected by HIV

## Issues

### Age and developmental stage

**0 to 1 year: Consistency and continuity**

At this stage, children learn about the world through their senses. They respond to faces, voices and bright colours, discover their hands and feet, smile, start to understand and say a few words, sit up, crawl, stand and start to explore and to play with objects.

They need:

- consistent caregivers who respond to them
- physical affection, including being held close and cuddled to help them feel secure
- talk and stories
- things to look at, touch, hear and play with
- Physical protection and a safe environment to explore.

**WHY DO YOUNG CHILDREN NEED SPECIAL ATTENTION?**

Children develop most rapidly in the first few years of life. This is the most important time for children's intellectual, emotional and social development. Good and bad experiences in early childhood have a lasting effect.

- **Intellectual development** Stimulation and attention in early childhood are essential to help children learn about their world, understand and use words and develop the ability to make decisions and solve problems.

- **Emotional development** Love, affection and consistent care from one or two caregivers in early childhood are essential to help children feel secure and happy and develop good relationships with other people as they grow older.

- **Social development** Good care and opportunities to play and take part in social activities in early childhood are essential to help children learn social skills and to their ability to live and work with others in the community.

**1 to 3 years: Encouragement, enthusiasm and independence**

At this stage, children learn to walk and run, understand and speak words, communicate ideas and feed themselves. They become more independent and develop friendships but prefer familiar people. They like to help, can solve simple problems, enjoy learning new skills and show pride in accomplishments, but get frustrated if they cannot do things. They develop friendships and play pretend games and start enacting out familiar scenes. They also can feel shame and develop self-doubt if they are criticised by caregivers.

**WHY ADDRESS CHILDREN'S DEVELOPMENTAL NEEDS?**

Children's physical, intellectual, emotional and social needs are as important as their physical needs. Children reach different developmental milestones and have different developmental needs at different ages.

**HOW DOES HIV AFFECT YOUNG CHILDREN’S DEVELOPMENT?**

The impact of HIV is on the whole family. This in turn will have a strong impact on young children's physical, intellectual, emotional and social development.

All these developmental needs of the child are linked with each other. If one of these needs is not met then it affects all the other.
SECTION 1

Issues

THE IMPACT OF HIV ON YOUNG CHILDREN’S DEVELOPMENT

Lack of love, attention and stimulation Parents who are sick, elderly grandparents and older siblings require support themselves and may not have the time or energy to give young children the love, attention and stimulation they need. Even if they get enough to eat, unhappy children do not grow as well as other children. Girls may get less attention and stimulation than boys.

Lack of consistent caregivers and home environment Children who move away to live with relatives lose their home and sometimes lose contact with their brothers and sisters, and this can be very upsetting. Sudden or frequent changes in caregivers and in the home environment affect children’s emotional and social development.

Lack of time and energy for normal childhood activities Young children who care for sick parents or younger siblings or who have HIV themselves may not have the time or energy for activities like playing with friends. Girls are often expected to take care of their siblings, which further taxes their time and energy for normal childhood activities.

Lack of social acceptance Feeling lonely and isolated affects children’s confidence, self-esteem and social skills. Stigma and discrimination limit opportunities for social activities and for making and maintaining friendships.

The next part describes principles and related strategies that organisations can use to support communities and families (in this briefing note the term “families” includes parents and other caregivers) to meet the developmental needs of young children living with HIV and young children affected by HIV.

Principles

1. Promote community and family action.
2. Help children to learn.
3. Meet children’s emotional and social needs.
4. Communicate with children and help them to cope.
5. Build resilience.
6. Promote children’s participation.
PROMOTE COMMUNITY AND FAMILY ACTION

Raise awareness
Families and communities need to know about children’s development and the special needs of younger children.

- Promote community dialogue and educate families on the developmental needs of young children and the impact of HIV on children’s development, especially on the rights of girls.

- Work with communities to identify children who need help and ways to help them, including building on traditional approaches to passing on knowledge and skills from one generation to another (See box on left hand side).

Encourage existing community groups and leaders and faith based organisations to consider the developmental needs of young children living with HIV and young children affected by HIV (See box on left hand side).

What signs suggest that a child needs help?
- Not playing with other children, not interested in what is going on
- Sadness, fear, withdrawal, not talking or eating
- Too talkative, aggressive, restless, constant repetition of the same activity
- Cries easily, gets irritable and angry quickly
- Sleeping problems, bedwetting
- Not taking care of themselves such as bathing, dressing up.

Media in Education Trust, 2002
The Speak for the Child project in Kenya explored local beliefs about the effects of parental HIV on children, reasons for behavioural problems in children and the effects of bereavement and grief on children. The findings were used to develop appropriate community interventions to support affected children (AED and USAID, 2003).

**Principles and strategies**

**Provide support to caregivers**
Families, including grandparents and older brothers and sisters, are the main carers of children living with HIV and affected children. Supporting them to provide good care for young children is essential.

- In the absence of the main care givers, the extended family members or neighbours are encouraged to take care of children.
- Identify community volunteers or mentors to help families caring for young children, especially families struggling to cope with poverty and illness.
- Encourage community members to visit affected families to provide emotional support and reduce social isolation.
- Establish support groups for carers of young children.
- Promote shared child care, such as anganwadi centres or crèches.
- Provide counselling and training on child development and child care skills.

*Encourage community members to visit affected families.*
The Lea Toto programme helps children living with HIV and their caregivers in communities in Kenya. Social workers and counsellors visit families to give social support and encouragement.

In Uganda, Mildmay's Jajja Home Children's Programme runs rural day care programmes and club activities for children. They provide psychosocial support for children living with HIV and their caregivers, and work with the local community to enable them to support child-headed households. (www.mildmay.org)

Speak for the Child arranges for trained volunteer mentors to visit families at home, establishes caregiver support groups, and links families to community groups. Support group meetings have helped caregivers to solve problems and improve their child care skills (AED and USAID, 2003).

Action for Children in Uganda has set up Grandmothers Action Support to build the capacity of grandmothers who look after young children living with or affected by HIV.

**HELP CHILDREN TO LEARN**

**Keep children well**
Young children who get plenty of food and rest and are healthy learn better than children who are hungry, tired or ill. Practical tips for families include:

- Make sure young children get enough sleep and good food (see 5 Provide good nutrition on page 26), as this helps their brain to grow and develop. Girls should get equal access to food in the family.

- Provide good home care for young children when they are sick and take very sick children to the clinic (see 6 Take care of common conditions on page 30).

**Provide stimulation and attention**
Young children need a stimulating environment and attention to help them to learn. Practical tips for families include:

- Spend time talking, telling stories, singing and dancing with children.

- Encourage children to play, as this helps them to learn and develop problem-solving skills.
**Principles and strategies**

- Show children how to do simple tasks.
- Support local craftspeople to make simple toys for children to play with or set up a toy "library" at a local pre-school or day care centre.

**Promote pre-school care**
Anganwadi centre and day care can improve young children's intellectual as well as social development. Girls should get equal access to these services.

- Support families to enrol and send young children to anganwadi centre if one is available.
- Help the community to set up day care centres and to recruit community volunteers.

### MEET CHILDREN'S EMOTIONAL AND SOCIAL NEEDS

**Give children love and affection**
Love and affection is more important to children living with HIV and children affected by HIV than material comfort. Explain to families that love and affection help children to grow and get better if they are sick, as well as to develop intellectually, emotionally and socially. Children need love and affection of both their parents. Encourage father's involvement in caring for his children.

**Involve children in social activities**
Young children living with HIV and young HIV-affected children need to feel that they are part of a family and a community. It is important for them to do the same things as other children of their age and to have friends. Taking part in social activities is essential for children's emotional and social development, helping them to learn about themselves and to establish relationships with others. Playing with other children of the same age helps children to learn about cooperation, trust and sharing, as well as to develop social skills.

- Organise recreational and sports activities for all children in the community.
- Advise families to involve sick children in daily activities rather than leaving them alone so that they feel included in family life.
- Encourage other children to involve very sick children in watching them play or to devise games that they can play with children who are ill.
SECT ION 1

The practical manual *HIV positive: A book for caregivers* includes the following story that can be used to help young children think about issues such as attitudes towards people with HIV, other people’s feelings and making choices about being kind or cruel.

Rama and her friends were playing together in the playground. Rani was sitting alone. Rama said to her friends, “Let’s ask Rani to play with us,” but her friends did not want to play with Rani. They said, “No, she is HIV positive. She will give us AIDS. I am scared to play with her.” Poor Rani was left on her own. On the way home from school, Rama fell over and hurt her arm. Rani walked past and asked, “What is wrong? Can I help you?” She helped Rama home and Rama’s mother was very pleased. She took Rama to the doctor to check her arm, and while they were there Rama asked the doctor about HIV. The next day Rama and Rani walked to school together. Rama’s friends were shocked. They said, “What are you doing with that girl? How can you be friends with her? She will make you sick.” Rama replied, “Rani is a good friend. She helped me when I hurt my arm. You cannot get AIDS from being friends. The doctor told me. He said you can’t get AIDS from sharing food or hugging or playing together.”

After telling the story, the facilitator can ask children how Rani felt when no one talked to her and how they would feel, and about what the doctor said about being friends with someone who has HIV. (Adapted from: *Media in Education Trust, 2002*).

**Principles and strategies**

- **Provide opportunities for young children living with HIV and affected children to express their feelings and experiences with others in a similar situation. Involve young children in children’s clubs.**

Children enjoy playing together.

Formation of children clubs are one of the initiatives taken by Palmyrah Workers Development Society in Tamil Nadu to reduce HIV-related stigma and discrimination faced by children. Each children club consists of 15 to 25 children and membership of the clubs varies from locations to locations.

Children Clubs are creating an enabling, supportive environment in the community to help children live together with oneness and “we” feeling. Children Clubs created a space and opportunity for the children to bring out their hidden talents as well as to express their inner feelings. The community also plays a vital role to understand the needs and rights of children by making their participation in Children Club activities. In some villages the local community came forward to allow the children to use the community Hall, Church premises, School Campus for organising Children Club meetings.

**Address stigma and discrimination**

- **Children living with HIV and children from affected families often experience stigma and discrimination. This prevents them from developing friendships and makes them feel lonely and sad.**

- **Discuss with community members why and how children are stigmatised and what effect this has on children.**

- **Train community workers to look out for signs that a child is being stigmatised in the household and to discuss this with the family or to refer for counselling and support.**

- **Encourage community and faith-based leaders, teachers and other adults to set a good example and to include children living with and children affected by HIV in community events such as ceremonies and festivals and recreational activities such as games and sports. Care should be taken to include all children in activities, to avoid singling out children affected by HIV and causing further stigma.**
Issues to consider in counselling and communicating with young children

- Make sure that a parent or caregiver is present, as they will be the main person responsible for meeting the child's needs.
- Make the child feel safe and comfortable. Get to know the child, not just their problems. Ask about daily activities and things they like to do.
- Remember that young children express feelings through their behaviour as well as through words. Counsellors can learn a lot by observing a child's body language, facial expressions and play – children often act out feelings or situations when they play.
- Take account of a child's age, understanding and emotional state, and try to see things through their eyes.
- Be aware that you may need to adapt your approach when counselling and communicating with children with disabilities, including those with learning, seeing and hearing difficulties.
- Accept the child's feelings and let the child say things in their own way. Do not try to hurry the child or interrupt. Children can be shy and need time to develop trust.
- Listen to what the child says, take them seriously and give them your full attention.
- Use methods that are appropriate for young children. Playing with dolls, drawing, games, stories and puppets are useful ways to help children express their feelings.
  - Asking a child to tell you a story (for example, about a child who was ill or very sad) can help them to talk about how they feel.
  - Respect children's ability to solve their own problems.

COMMUNICATE WITH CHILDREN AND HELP THEM TO COPE

Provide counselling for children
Counselling can be very helpful for children living with HIV and for children affected by HIV. Good counselling helps children to tell their story, make choices, recognise their strengths, develop a positive attitude to life and cope with problems. It can also help them to deal with fear and anxiety about their own illness or family illness and death.

- Advocate for counselling services for children, including counselling for children before and after a parent dies. Counsellors should be trained in working with young children.
- Build local capacity for counselling children by training teachers, anganwadi workers, local faith based organisations leader and community volunteers.
- Promote approaches such as clubs that meet the needs of all children in communities affected by HIV.

- Work with parents and teachers to tackle stigma and discrimination by children, as negative attitudes in children are usually learned from adults.
- Involves children in identifying children who are excluded and the reasons for this. Use creative methods such as puppets or drama to help children understand the reasons for stigma and discrimination. Ask them to suggest ways that sick or affected children can be included in their activities.

Island Hospice in Zimbabwe provides bereavement counselling and explores options with the family for the children after parental death as part of its home care services. Children are counselled to help them prepare for death and after a parent dies, including through regular group sessions for bereaved children. ([UNAIDS, 2001](#))

In Kenya, a World Vision project trains community volunteers to facilitate interpersonal therapy group discussions or “community conversations” with affected children. The approach takes account of local cultural practices and beliefs about HIV and promotes local solutions. These "community conversations" have helped children to provide mutual support and have improved communication between caregivers and children with problems. ([Building Blocks Development Group.](#))
Issues to consider when talking to young children

• Choose a place to talk where a child feels comfortable and safe.
• Use simple words. Very young children need to be told that something is wrong but do not need lots of detail or to know about HIV. Let a child absorb information bit by bit. You could start by saying that their father or mother is not well and letting a child ask questions, and then talk to them about how ill the parent is at a different time.
• If a child does not want to talk, suggest that you talk another time or that they can choose to talk to someone else. Be clear that they do not have to talk if they do not want to.
• Listen and talk to a child when the opportunity arises. Sometimes children ask questions when you are doing something together like fetching water.
• Listen to what a child says and let them say things in their own way.
• Answer questions honestly. Think in advance about how you will deal with difficult questions.
• Do not be angry or upset if a child reacts in a way you do not expect; for example, if they appear unconcerned by the news or get angry with the person who is ill.

Talk to children about illness and death in the family

It is important to talk to young children about illness in the family. Children may worry that a sick parent is going to die because other adults in their community have died from the same illness. If an adult is taking antiretroviral medicines they should get better, and it is important to help young children deal with their fears and to reassure them that their parent will be well again. Anecdotal evidence shows that children can play an important role in reminding parents to take their medicines.

If an adult is very sick and likely to die, it is important to prepare young children for the death. Adults may think that they are protecting a child by not telling them what is happening, but even very young children know when something is wrong. Not being told why can make children anxious and upset.

• Encourage parents who are very sick and may die to explain what is happening to their children. Explain why it is important to prepare children in advance and to answer their questions.
• Prepare children before they visit a sick or dying parent in hospital, as this can be upsetting. Do not force a child to stay if they are distressed.

Why prepare young children for the death of a parent?

• Talking to children in advance gives them time to get used to the idea and helps them cope better with death and grieving.
• Children like to have the opportunity to ask parents how to do things and to be given last words of advice.
• Having a chance to say goodbye is very important. Exchanging wishes and blessing can stop children from blaming themselves for the death of a parent.
• The prolonged illness of HIV gives us a chance to prepare the child for the death of the parent.
How do children react to parental death?

Common reactions include:
- fear, confusion and insecurity (for example, clinging, fear of going to sleep, nightmares, bed-wetting)
- sadness, depression and withdrawal
- anger, aggression and tantrums
- guilt (for example, thinking that the death is their fault)
- bargaining and denial (for example, “If I am good, my mother will come back”)
- regression (for example, talking like a baby or wanting to be fed instead of feeding themselves)
- physical symptoms (for example, feeling sick).

Reactions depend on a child’s age:
- Children aged less than six months cling, cry and may reject comfort from others.
- Children aged six months to three years show grief physically, through eating and sleeping problems, regression (for example, not walking or talking as well as they did), comfort habits such as thumb-sucking, crying and clinging behaviour. They may also be very sad and quiet.
- Children aged over three years show grief through feelings (for example, guilt, fear) and behaviour (for example, aggression, being naughty) as well as physically.

Plan for the future
Preparing for death should include planning for children, as children often worry about what will happen to them after a parent dies.

- Support parents to make a memory book or box with their children.
- Encourage parents to think about who will care for children after they die and to involve children in choosing their future guardian or foster family.
- Help parents to write a will so that children do not lose their inheritance.
- Advise parents to make sure that they have important documents that children will need, such as birth registration, as well as a will and legal papers about guardianship.

Memory boxes or books help parents to discuss death with children and to collect information about the family and childhood memories. Parents can write their favourite memories of a child, the family tree and relatives, family traditions and special events, a letter describing their hopes and special feelings for the child, and include items such as a child’s drawing and family photographs. Compiling a memory book or box with a child enables the child to ask about their past and plans for their future. These tools are especially valuable for children whose parents die when they are very young, providing insights into parents they do not remember and giving them a sense of identity.

Child In Need Institute (CINI), through its Indian Initiative of Child-Centered HIV and AIDS Approach (IICCHAA) has adapted the process of ‘memory work’ to their local context in West Bengal. The process has encouraged and motivated children and parents to share, record and store their memories, experiences and their personal feelings with each other.

(www.cini-india.org)

Help children who are grieving
Families need to know how grief affects young children and what they can do to support them. They need to be aware of the fact that young children, like adults, are affected by illness and death and that they too experience anxiety, stress and grief. Parental illness and death can cause long-term emotional and behavioural problems if children do not receive help.
Children’s ability to understand death also depends on their age and understanding:

- Children aged less than two years cannot understand the idea of death or what has happened.
- Children aged three to five years may have brief, frequent and intense episodes of grief but seem unaffected in-between. They may not understand that death is final and often expect the deceased parent to come back. They may ask the same questions over and over again.
- Children aged over five years may be able to accept that a parent has died and find a place for them in their memory (for example, think of a parent in heaven or watching over them).

Practical tips for families include:

- Acknowledge the death and explain that adults in the family are also sad.
- Explain that the death was because of illness and reassure the child that they were not responsible.
- Maintain as normal a routine as possible, as this helps children feel more secure. Try not to send the child away to a new environment.
- Make sure that the child feels safe and loved, and give them consistent care, physical affection and attention. Make sure the child has one consistent care giver at that point of time.
- Include children in family rituals, as this helps them to feel they are not alone in their grief, but do not force children to attend funerals if they do not want to or might find the experience frightening.
- If you have to leave the child for a while, explain them where you are going and why. Leave them with someone they know well.
- Accept children’s reactions and behaviour. Try to be patient and do not be angry if a child is naughty, has tantrums, wets the bed or starts behaving like a baby.
- Comfort children when they go to sleep and if they wake up in the night.
- Let the child express his/her feelings. Talk to them about their loss and the person who has died. Help the child to remember the parent and to talk about happy memories. Answer any questions the child has about the deceased parent.
Making a hero book, where a child writes and illustrates a book in which they are the main character, is a process that aims to reinforce children’s resilience. The child tells their story with words and pictures, and, as the “hero”, is helped to feel that they have control over problems and challenges in their lives. However, solving problems is not just the responsibility of the child, and hero books also emphasise mobilising the community to support children. (Morgan, 2004)

The CCATH (Child-Centred Approaches to HIV and AIDS) Project in Kenya and Uganda builds children’s resilience by developing their coping skills, facilitating communication between parents and children, promoting memory books, establishing children’s clubs and supporting older children to give young children emotional support.

The practical manual HIV positive: A book for caregivers includes games and activities to build children’s self-confidence. In the Circle Game, for example, the facilitator asks children to sit in a circle and asks each child to say something good about themselves. Then the children are asked to say something good about the person sitting next to them. This can lead into a discussion about how each person has strengths that may be different but are equally good. (Media in Education Trust 2002)

BUILD RESILIENCE

Resilience is the ability to face, cope with and be strengthened by the hardships of life. A resilient child believes that they can cope with a difficult event because they have some control over their lives. A caring family provides the best environment for children to develop resilience. Emotional and social support from families and neighbours plays a vital role in helping children to cope with adversity, so local organisations also need to work with the whole community to build children’s resilience.

What makes a child resilient?

- **What the child has (“I have”)** A child is more likely to be resilient if they have people who love them, who set limits that stop them from getting into danger or trouble, who set an example of how to behave, who encourage them to do things on their own and praise them for showing initiative, and who help when they need access to services.

- **Who the child is (“I am”)** A child is more likely to be resilient if they have a sense of who they are, feel likeable and loveable, can do kind things for others, are proud of themselves, take responsibility for what they do and think things will be alright.

- **What the child can do (“I can”)** A child is more likely to be resilient if they can talk to others about what worries them, solve problems, control feelings, understand how others feel, establish relationships and find someone to help when they need it.
Why is children’s participation important?

- Participation involves children in making decisions about the things that affect them.
- Participation means working with rather than for children.
- Participation recognises children’s knowledge and abilities, and builds on these.
- Participation develops children’s skills and confidence.
- Participation helps children to learn about cooperation and social responsibility.
- Participation enables children to get support from their peers.

Working with children

- Learn to listen to children, take time to get to know them and gain their trust.
- Use fun activities, play and games to involve children.
- Find out what is important to children rather than imposing an adult agenda.
- Make sure children understand what their involvement will mean.
- Be realistic about how much time children have to participate.
- Protect the confidentiality of children living with HIV.
- Ensure children are part of a supportive peer group such as a club.

Research by the STEPS programme in Malawi with young children living with HIV and affected children found that they had clear ideas about who they would like to care for them after a parent dies. They wanted to meet other children but did not get the opportunity, and felt that adults did not understand the importance of children’s friendships.

Participatory tools used by CCATH to find out about children’s situation include:

- **Communication mapping** Children draw a picture of themselves and people in their lives, adding up to three lines between themselves and the other people depending on how important the person is to them, and explaining what subjects they discuss with them. This provides insights into who children relate to, who gives them support and who they support.

- **Happy and sad** Children draw a picture of what makes them happy and what makes them sad. This provides insights into children’s social environment, including exclusion of positive or affected children and adult attitudes towards children.
Most children living with HIV are infected through parent-to-child transmission. Preventing HIV infection in women and making sure that HIV-positive women have access to interventions that prevent parent-to-child transmission are the most effective ways to prevent HIV infection in children.

Making sure that the parents of children living with HIV receive adequate care and treatment is also important, as children are more likely to stay well if their parents are able to care for them properly.

**HOW ARE CHILDREN INFECTED WITH HIV?**

Infants and young children can be infected with HIV in three main ways:

- transmission from an infected mother during pregnancy, birth or breastfeeding
- transfusion of infected blood or through use of non-sterile needles and syringes
- sexual abuse.

**HOW IS HIV DIAGNOSED IN YOUNG CHILDREN?**

Until recently, HIV has often been difficult to recognise or diagnose in very young children. Diagnosis based on antibody testing, the most common method used in India, is not reliable for children under 18 months. Tests that can detect the virus itself, or components of HIV, and that therefore give a definite diagnosis of HIV infection in this age group, are not yet widely available in India. However, this is changing and India is expanding the availability of effective HIV tests for very young children. This is called PCR testing.

**HOW DOES HIV INFECTION AFFECT CHILDREN’S HEALTH?**

Children living with HIV may get the same common illnesses as uninfected children, but these illnesses are often more severe and frequent, and may not respond so well to standard treatment. Pneumonia, malaria and “failure to thrive” (this means no weight gain, or weight loss) are particularly serious problems in children living with HIV.

Children living with HIV are also at risk of opportunistic infections, because HIV weakens the body’s ability to fight off infections. They are also at risk of tuberculosis (TB) if they live in a household with an HIV-positive adult who has TB disease. Without treatment, death rates are very high in young children living with HIV.

**WHAT CAN BE DONE TO HELP CHILDREN LIVING WITH HIV?**

Children living with HIV can stay well and live for many years if their HIV infection is diagnosed early and they receive good care, treatment and support. Treatment with antiretroviral drugs prevents illness and death in children living with HIV and enables them to lead healthy and happy lives.
This section describes principles and related strategies that organisations can use to support communities and families to help children living with HIV to stay healthy.

**Principles**

1. Advise pregnant women and their spouses about prevention of parent-to-child transmission (PPTCT).
2. Recognise HIV infection as early as possible.
3. Promote access to treatment and help children to take antiretroviral medicines.
4. Help children to stay well.
5. Provide good nutrition.
6. Take care of common conditions.
7. Provide supportive care for children who are very sick and dying.

**ADVISE PREGNANT WOMEN AND THEIR SPOUSES ABOUT PREVENTION OF PARENT-TO-CHILD TRANSMISSION**

Without interventions, one in three babies of HIV-positive mothers will be infected. However, there are ways to reduce significantly the risk of parent-to-child transmission. Ideally these include giving antiretroviral prophylaxis (taking a drug to prevent an infection occurring) to the mother during pregnancy and to the newborn at birth, replacement feeding for infants and Caesarean section. Encourage women to have institutional delivery.

Infants can only benefit from antiretroviral prophylaxis if pregnant women know their HIV status and have access to services that provide it. Caesarean section and replacement feeding are not feasible in most low-income settings because of the cost and the risks to the mother and the infant (see Page 26 for more information about infant feeding).

PPTCT services alone are not enough. It is also important to provide ongoing antiretroviral therapy for HIV-positive mothers so that they stay healthy and can care for their infants and young children. Services providing antiretroviral prophylaxis should also provide antiretroviral therapy for HIV-positive mothers or refer them to facilities offering treatment.
Principles and strategies

- Educate communities about how to prevent HIV infection in women during pregnancy.
- Encourage men and other family members to accompany the pregnant woman for ante- and post-natal care.
- Provide families with simple information about the importance of HIV testing for pregnant women and their partners, and where couples can receive integrated counselling and testing centres.

RECOGNISE HIV INFECTION AS EARLY AS POSSIBLE

Improve identification of children living with HIV
It is important to identify young children living with HIV so that they can be given appropriate care and benefit from life-saving antiretroviral treatment.

- Provide families and communities with simple information about the importance of diagnosing HIV in children and of care and treatment for children living with HIV.
- Train community workers and volunteers in Home and Community Based care and TB programmes to identify children who may be at risk of HIV infection (for example, children in households where an adult has HIV or TB) and children who have signs and symptoms of HIV infection.
- Ensure community workers can advise families about seeking diagnosis and where to take a child for HIV testing.

Support families to decide about testing a child for HIV
Finding out that a child has HIV can help families to obtain advice about how to keep the child well, access care and treatment services and receive support from others in the same situation.

- Advocate for family counselling and child-friendly testing services, including pre-test and post-test counselling to help the family make an informed decision and understand the implications of testing a child for HIV. Factors that the family need to consider include:
  - If the result is positive, will the child be able to access cotrimoxazole prophylaxis and antiretroviral therapy?
Preparing young children for a blood test requires special skills and patience. The child is constantly falling sick and her mother is HIV positive. After interventions by the counsellor mother has decided to test her child for HIV.

Counsellor: I am relieved to hear that you have decided to take your child for HIV testing. And why do you appear so tense?

Mother: I am scared as I don't know how to tell her about the test.

Counsellor: It is natural for you to be scared. But don’t worry. If you want we both can sit together and talk to Sonu.

Mother: Thank you. It is such a relief to know I have someone to assist me. Can you come now?

Counsellor: Sure

Sonu: Namaste Didi

Counselor: Namaste beta, how are you feeling now?

Sonu: I am ok. But why do I keep falling sick?

Counsellor: Your mother too is worried and wants to take you for a blood test.

Sonu : Blood test? What is it?

Counsellor: In a blood test, a doctor or a nurse draws a little bit of blood from your hand with a needle. Then they will check it under one machine to see if you have any germs which cause illnesses. And if so, we will start treatment accordingly.

Sonu: Needle! It will pain me a lot.

Counsellor: Not at all! It is only a little prick or just like an ant bite. Your mother will be sitting by your side.

Mother: Yes Beta, I will be there with you. There is nothing to fear. I too had a blood test.

Counsellor: Are you ready for the test?

Sonu: Yes didi.

Counsellor: Very good! Sonu is a brave girl. Sonu smiles, holding her mother’s hand.

(Case study from CCDT's project in Mumbai)

### Principles and strategies

- Are the parents aware of their HIV status? If they are, do they want to disclose it? If they are not, are they prepared to find out?
- Is there is a risk that a positive diagnosis will result in the child being neglected or discriminated against, or that the family will experience stigma and discrimination?

- Give families practical advice about what to tell a child about testing. Children old enough to understand need to know in advance that some of their blood will be taken and that this might hurt.

- Explain that a parent or guardian will need to give consent before a child is tested. It is also important that the child agrees to be tested if they are old enough to understand what is happening.

- In the case of street children or child-headed household, NGOs can sign as local guardians to enable testing.

- Refer families to support groups where they can discuss anxieties about testing and disclosure, share experiences and can encourage others.

### Help families to decide when and how to tell a child

If a young child has a positive test result, families will need to decide when and how to tell them. This information should never be forced on a child who is not ready for it. There is no ideal age for children to learn their HIV status. The right time for this will depend on the child’s age, maturity and understanding.

Disclosure is a process. Very young children can be told using simple words that they have a chronic illness without mentioning HIV. As they grow older and can understand and cope with the consequences of knowing their HIV status, children can be given more information.

- Explain to the family that it is best if a parent or someone the child trusts tells the child. And provide them with advice about how to do this carefully and sensitively.

- Refer the family to a counsellor or support group where they can seek advice about what and how to tell a child.

- Encourage whoever tells the child to provide as much information as is necessary. Answer questions as honestly as possible.

- Give children opportunities to share their feelings and problems with other children in the same situation. Refer them for counselling if this is available.
PROMOTE ACCESS TO TREATMENT AND HELP CHILDREN TO TAKE ANTIRETROVIRAL MEDICINES

Raise awareness about treatment
Families need to know that antiretroviral therapy can prevent HIV-related death and illness in young children. Children living with HIV should have access to antiretroviral medicines as part of a package of health and nutrition services.

- Provide families and communities with information about treatment services. It is important to start all children living with HIV (boys and girls) with antiretroviral therapy as soon as possible.

- Ensure there is no gender based discrimination in accessing treatment services. Girls and boys have equal rights to access treatment services.

- Support families, communities and health services to advocate for increased access to antiretroviral therapy for children living with HIV.

- Promote links between the community and treatment services. Home and community based care programmes can play an important role in referring children living with HIV to treatment facilities.

- Explain to families when and why treatment is started and what drugs are used. Advise families that other medicines from a pharmacy, shop or traditional healer may stop antiretroviral drugs from working well, so they should seek advice before giving other medicines to a child.

- Advise adults on antiretroviral therapy that they should not share their medicine with anyone else.
Factors contributing to poor treatment adherence in children in South Africa included: health workers providing incorrect or inadequate information to caregivers; multiple or changing caregivers; refrigerator breakdown; difficulties with reading labels, opening capsules and mixing medicines with food or water; dropping bottles and spilling the contents; and sharing medicines with others in the family. (Population Council and University of Cape Town, 2005).

In Malawi, caregivers experienced similar problems. For example, grandmothers found it difficult to break and crush adult tablets in order to give the right dose to children. (MSF, 2005)

Help children to take their treatment
Taking medicines as prescribed – in the correct way, the correct dose and at the correct time – is called “adherence to treatment”. Families need to know that the effectiveness of antiretroviral therapy depends on a child taking the right amount of medicine at the right time. Giving less than the right amount means the medicine will not work and giving more can harm the child. It is important to emphasise that children must take their medicines on time – the dose should be taken no later than 30 minutes after the scheduled time – and must not miss a dose. Families need information and support to cope with factors that affect adherence in children, including the number of pills to be taken, bad taste of the medicine and side effects.

Families need clear and accurate information about how to give antiretrovirals to children. They can support treatment adherence by making sure that they supervise and encourage a child to take their medicines. Practical tips include:

- Give the child a clear explanation, appropriate for their age, of why they need to take medicines every day and at set times.
- Make a schedule for taking the medicines that fits with your daily activities and those of the child. Children find it easier if they have a routine where they take medicines at the same time and in the same way each day.
- Think of ways to remind you to give the medicines. For example, put a calendar or checklist where you can see it and add a tick when a dose has been given or use a timer or a watch with an alarm.
- Use a marked cup or measuring spoon to measure the right amount of syrup.
- Tell the child in advance that the medicine may taste bad but explain that this will only be for a short time and that the medicine will help to keep them well. Mix the medicine with a small amount of milk or juice if the child refuses to take it because of the taste and give something to take away the taste afterwards. Make up a song or story that you can tell or sing with the child at medicine time to distract them. Give some water, milk or juice to help children swallow tablets or capsules. Make sure younger children swallow the dose and involve older children in taking their medicines to give them some control over managing their illness.
- Give lemon juice or ginger drink if the medicine makes the child feel nauseous and a dose of paracetamol if it causes headache (see side effects on page 22).

Use a marked cup to give the right amount of medicine
Side effects of antiretrovirals
Side effects are unwanted effects of drugs. Most children only experience minor or temporary side effects when they are taking antiretrovirals. The most common side effects include: nausea, diarrhoea, headache, sleeping problems.

More rarely, children experience serious side effects. These include: severe stomach pain, anaemia, yellow eyes, skin rash, fever, fatigue together with shortness of breath. Children who have any of these serious side effects should be taken to the clinic immediately.

Monitor progress and look out for side effects
Health workers check how well a child is responding to treatment with antiretrovirals by assessing changes in their weight and height and in the frequency of infections. Families can help to check a child’s progress by:

- keeping a record of how well the child is eating and how often the child is ill
- asking the health worker about side effects and how to deal with them.

Praise the child for taking the medicine each time they take a dose.

Talk to other families about how they help children to take their medicines and find out if there are other children who are taking the same medicines. Sometimes it can help if a child sees other children taking their medicines.

Tools developed by MSF in Thailand to help support adherence in children include: fairy tales and dolls used to explain how the virus multiplies in the body and how taking medicines helps to stop this; a medicines weekly wall planner with morning and evening doses in small bags attached to it; a medicines box that looks like a small apartment block with medicines for each day on a different floor; and a medicines card with different stickers representing each medicine and showing when they need to be taken. MSF invites children and their caregivers to meet every three months so they can talk to each other about their problems. (Ponnet, 2002).
**HELP CHILDREN TO STAY WELL**

**Promote cotrimoxazole prophylaxis**

Cotrimoxazole is a cheap, widely available antibiotic. Prophylaxis means giving a medicine to prevent disease. Cotrimoxazole prophylaxis helps children living with HIV to stay well. A daily dose of cotrimoxazole prevents pneumocystis pneumonia (PCP), a severe form of pneumonia that causes many deaths in children living with HIV. It also prevents infections such as malaria and diarrhoea in children living with HIV.

- Cotrimoxazole should only be prescribed by a doctor.
- Raise community awareness of the benefits of cotrimoxazole prophylaxis for children living with HIV.
- Encourage HBC programmes to identify children who could benefit from cotrimoxazole prophylaxis and refer them to the doctor.
- Lobby health services to provide cotrimoxazole for children free of charge.
- Provide simple advice to help families give children the right daily dose.

**Make sure children living with HIV are immunised**

Immunisation protects children from preventable childhood diseases. It is especially important for children living with HIV because they are more vulnerable to these diseases than children without HIV.

- Explain to families about the importance of immunisation for children living with HIV.
- Visit local health centres to find out about the immunisation schedule. Encourage families to take children living with HIV and children who may be at risk of HIV for immunisation.
- Advise families to keep children’s immunisation cards in a safe place. Encourage dying parents to give their immunisation cards to the future guardian.
- Ensure that health workers are aware of the benefits of vaccination for children living with HIV.

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**Cotrimoxazole prophylaxis for children with HIV**

A Zambian study found that giving cotrimoxazole prophylaxis to children living with HIV reduced deaths by 43% and hospital admissions by 23%. Other African studies show that cotrimoxazole prophylaxis can reduce deaths by 25–46% and reduce episodes of diarrhoea and malaria in children living with HIV. (Chintu et al., 2004; Mermin et al., 2004; 2005a).

Cotrimoxazole prophylaxis should be given to:

- All infants born to HIV-infected mothers from six weeks until infection is ruled out (after 15–18 months) and there is no further risk of infection (breastfeeding has stopped).
- All infants and children known to be HIV infected whether or not they have symptoms.

**Immunisation and children living with HIV**

The Government of India and Indian Academy of Paediatricians recommend:

- Children with suspected or confirmed HIV infection but who do not have symptoms of HIV-related disease should be vaccinated like all other children.
- Children with suspected or confirmed HIV infection who have symptoms of HIV-related disease should receive all childhood vaccinations except yellow fever and should be given the injectable form of polio vaccine rather than oral polio vaccine.
- BCG should be given to all children including those living with HIV and born to HIV positive mothers.
Principles and strategies

Give vitamin A supplementation
Vitamin A supplementation reduces the risk of illness and death in all children, including children living with HIV. It protects them against diarrhoea and respiratory infections, prevents serious eye disease and blindness, and helps them to grow.

- Provide families with simple information about the importance of vitamin A supplementation for young children living with HIV and help them to access services providing supplementation.
- Lobby local health services to provide vitamin A supplementation to young children.

Protect children from malaria and TB
Children living with HIV are more at risk of malaria than children living without HIV. Preventing malaria by protecting children living with HIV from mosquito bites is critical. Sleeping under an insecticide-treated net can reduce malaria in children by half. Children living with HIV are at higher risk of TB if they live in a household with an adult who has TB disease.

- Advise families to make sure all young children sleep under an insecticide-treated net and find out where families can obtain free or subsidised treated nets.
- Establish links with community TB and DOTS programmes and ensure that TB screening, prevention and treatment is offered for children as well as adults.

Sleeping under an insecticide-treated net helps to prevent malaria.
**Good hygiene practices**

To prevent diarrhoea:
- Make sure children wash their hands with soap after using the toilet and before eating.
- Make sure that adults wash their hands with soap before preparing food and after using the toilet, changing soiled bedding, clothes or nappies.
- Keep children’s fingernails and toenails short and clean.
- Keep areas where children play free from animal faeces.
- Store food in a clean, covered container, reheat cooked food thoroughly to kill any germs and avoid keeping cooked food for more than 24 hours.

To prevent skin, eye and mouth infections:
- Bathe children every day.
- Keep children’s clothes and bedding clean.
- Help young children and show older children how to keep their teeth and mouth clean.

**Promote safe water and good hygiene**

Children living with HIV are more likely to get diarrhoea than children without HIV. Safe water and good hygiene helps to protect them from the germs that cause diarrhoea.

- Advise families to use clean water for drinking and preparing food, to store water in a clean, covered container, to boil water for drinking and food preparation. If there is no source of clean water or if it is not possible to boil water, use simple water purification methods.
- Provide families with practical information about good hygiene practices that can help to prevent diarrhoea and other infections (see opposite).
- Support community efforts to improve access to safe water, including lobbying local government and making links with water programmes.

- Boiling of water: the water should boil for at least 10 minutes
- Use of Chlorine tablets in water: use one Chlorine tablet for one litre of water. The water is ready for use after 30 minutes.
- Use of Tap filters (These are filters which can be directly fitted to the tap to get purified water. These are inexpensive and easily available in the local markets.)
Women with HIV and infant feeding

Replacement feeding (with formula or animal milk) and avoiding breastfeeding is recommended where replacement feeding is acceptable, feasible, affordable, sustainable and safe.

- If mothers cannot afford to buy formula or animal milk, or lack the means to prepare and give replacement feeds hygienically, exclusive breastfeeding (breastfeeding only and giving no other fluids, not even water or juice) for the first six months of life and transition to exclusive replacement feeding as soon as alternative feeding options are feasible, is recommended. The infant receives the benefits of breastfeeding, and exclusive breastfeeding has a lower risk of HIV transmission than mixed feeding.

- Mixed feeding (a combination of breastfeeding and other feeding) should be avoided as the risk of HIV transmission and of malnutrition and diarrhoea is higher than with exclusive breastfeeding.

- An HIV positive mother can feed her child with breast milk after “flash heating” it. This means placing a glass jar of expressed breast milk in a pan of water and heating them together over a flame or single burner. Once the water reaches a rolling boil, the jar of breast milk is immediately removed and allowed to cool.

(Summary of NACO recommendations on National Paediatric Guidelines on ART).

Principles and strategies

Take children for regular check-ups

Regular check-ups for children living with HIV should include assessing their weight and immunisation and nutritional status, and whether or not they have received vitamin A supplementation. Health workers should also check children’s developmental milestones and their eyesight and hearing.

- Encourage families to take children living with HIV for regular checks.

- Ensure that health workers are aware of the preventive measures that can help children living with HIV to stay well.

- Encourage local health centres to establish child-friendly services.

- Identify community volunteers to take young children living with HIV for check-ups if their parents are too sick to travel to the clinic, and provide these volunteers with training to ensure that they can provide this support effectively.

Provide good nutrition

Promote safe infant feeding

Families and women with HIV need to know how to feed infants in a way that reduces the risk of HIV transmission and ensures infants get the best possible nutrition (See box on left hand side for a summary of NACO recommendations).

- Provide families with practical information about HIV and infant feeding.

- Refer positive women for counselling about infant feeding. If counselling is not available, provide clear advice about the safest method of infant feeding in their circumstances.

- Encourage positive mothers who are breastfeeding to take good care of their nipples and to seek help if they develop cracked nipples as this increases the risk of HIV transmission.

After several consultation sessions with children and their families, CCDT’s CHILD project formed a Child Friendly Ward in a Municipal Hospital in Mumbai. The Child Friendly Ward is linked with a residential shelter for children living or affected by HIV and AIDS. Coping with complex issues, the Child Friendly Ward aims to build bridges of understanding in a hospital setting, and create an enabling environment to reduce stigmatising and discriminatory practices. It is an entry point to learn problems and needs of children living with HIV and AIDS and respond to them through counselling. For more information log on to http://www.ccdtrust.org
**Advice on how to stop breastfeeding early**

An HIV positive mother may want to consider stopping breastfeeding early so that her baby is no longer exposed to HIV. The best time to stop is different for every woman and depends on her baby’s health, her own health and her family situation. Consult a doctor to discuss the time for stopping breastfeeding. Once one decides to stop, following steps can help to make it easier:

- Show the baby how to drink expressed breast milk from a cup.
- Once the baby can drink from a cup, replace one breastfeed with a cup feed. After a few days, replace another breastfeed with a cup feed. Repeat this until all feeds are given by cup.
- Replace the breast milk with formula or home-modified animal milk within two weeks.
- Stop putting the baby to the breast as soon as the baby is accustomed to frequent cup feeding and taking alternative milk.
- Express milk to prevent breast engorgement and discard the milk.
- Do not begin breastfeeding again once it’s been stopped.

*(Adapted from WHO infant feeding counselling flyers 2005.)*

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**SECTION 2**

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**Principles and strategies**

- Provide positive mothers with support for safe infant feeding, whatever feeding option they choose.
- Provide positive mothers with support for early weaning *(see box on left hand side)*.

**Raise awareness about malnutrition and how to prevent it**

Young children living with HIV are at increased risk of malnutrition. Although malnutrition in children living with HIV can be treated with good hospital and home-based care and feeding, they may take longer to recover than uninfected children.

- Provide advice about good nutrition for children living with HIV *(see page 26)*.
- Encourage families to feed actively very young children and to supervise young children during meals to make sure they eat.
- Provide practical advice about feeding sick children *Good nutrition see page 26*.
- Advise families about how to care for a child who has a sore mouth, and to seek help if a child is not eating well or has signs of malnutrition *(see page 28)*.
- Encourage families to give frequent energy-rich and nutrient-rich meals to children recovering from malnutrition and to take them for follow-up checks.
- Link children with anganwadi and other nutrition scheme like mid-day meal.

*Make sure young children eat well.*
Why are young children living with HIV at risk of malnutrition?

- Young children living with HIV need more food than uninfected children of the same age because their body is fighting off infections and needs more energy.
- Young children living with HIV may not get enough to eat because their parents are too poor or sick to buy or grow food, or lack time or energy to prepare meals or feed children.
- Very young children who are unsupervised during meals or have to compete with older siblings for food may not get enough to eat.
- HIV-related illnesses like diarrhoea and mouth ulcers cause loss of appetite and make eating difficult.
- Young children need vegetables and fruits that provide micronutrients like zinc and vitamin A but may only be given staple foods to eat.

Provide advice about good nutrition

Good nutrition helps children living with HIV to grow and stay healthy. Children living with HIV who are well nourished have fewer infections and are less likely to get HIV-related illness. They need a diet that includes energy-giving, body-building and protective foods, and they need more of these foods than children living without HIV.

- **Energy-giving foods** – wheat, ragi, rice, maize, millet porridge, bananas, potatoes, ghee, butter, vegetable oils and bread. Animal fats and vegetable oils are concentrated sources of energy.
- **Body-building foods** – pulses, eggs, milk and milk products, fish, beans, peas and nuts, meat, chicken, liver.
- **Protective foods** – dark green leafy vegetables and orange and yellow fruits like tomatoes, carrots, papaya and mangoes.

Give families information about a good diet for children living with HIV that is based on locally available foods. From six months to two years, start giving complementary foods in addition to animal milk, such as mashed staple foods like bananas, potatoes, rice and dalia. From two years, give family foods.

- Feed children first in the family meal so that they get good portion of food.
- Suggest ways to make complementary and family staple foods more nutritious. Adding vegetable oil or ghee provides energy; adding milk, mashed beans, eggs or groundnuts provides protein; and adding mashed green leafy vegetables or fruits provides vitamins and minerals.
- Explain that young children living with HIV need to eat a variety of foods and to eat more often than older children and adults. Make sure advice is practical. Suggest giving snacks between meals that do not need cooking, such as bananas.
- Encourage use of locally available, inexpensive and easy-to-prepare foods, and support communities and households to grow a range of nutritious foods in kitchen gardens.
- Link households experiencing food shortages to food assistance programmes.
Pay special attention to feeding young children who are sick
Making sure children eat when they are sick or have lost their appetite helps to prevent malnutrition and gets them better more quickly. Advise families to:

- continue to feed a sick child and encourage them to eat
- be patient, as feeding a sick child takes time
- give small meals more often and give foods that the child likes and that are easy to eat
- give lemon juice or ginger in warm water if the child feels nauseous
- give curd or other soft foods if the child has a sore mouth
- support a child who is too weak to sit up and use a cup or spoon to feed children who are too young or weak to feed themselves
- avoid giving spicy or fatty foods, which can make nausea worse
- give more food – if possible an extra meal a day – after illness to help the child recover and regain weight.
Principles and strategies

**How to make gentian violet solution**
1. Add one level 5ml spoonful (approximately 5g) of gentian violet crystals to one litre of clean water.
2. Stir well and leave to settle. Filter the solution through gauze or material or carefully pour the solution into another bottle to remove any undissolved crystals.
3. Mix equal parts of the gentian violet solution and water (for example, 50ml gentian violet solution and 50ml water) to make a 0.25% solution.
4. Do not keep gentian violet solution for more than seven days.

**Take care of common conditions**

**Provide good home care**
Families need to know what they can do at home to care for children living with HIV who are sick. Practical tips on home care for common conditions include:

**Fever** Give plenty of fluids (for example, water, juice or tea) to prevent dehydration and paracetamol to reduce the fever. In cases of high fever, use cold sponging.

**Diarrhoea** Give plenty of fluids to drink to prevent dehydration. The preferred fluids to give are boiled water, oral rehydration salts (ORS) solution, rice water and butter milk. Give fluids slowly with a cup or spoon. Give potassium-rich foods, such as bananas and coconut water. Medicines are not needed to treat most diarrhoea in children.

**Cough** Give warm fluids (ginger tea and tulsi) to soothe the throat. Give turmeric or powdered pepper with milk. Clear a blocked nose by softening the mucus with a cloth soaked in clean salty water.

**Skin problems** Look out for rashes, itchy skin, painful sores and abscesses, which are more common in children living with HIV. Try to stop a young child scratching as this can cause infections. Keep the skin clean by bathing once a day with soap and warm water. Keep the skin dry at other times. If the skin is dry, wash the child less often and apply vaseline or coconut oil. Avoid perfumed oils or soaps as these irritate the skin. Manage shingles (painful rash with blisters) by applying calamine lotion twice a day to relieve itching, bathing the skin with salty water or applying gentian violet to prevent infection, and giving paracetamol for pain.

**Sore mouth** Clean the mouth gently with warm salty water (dissolve half a teaspoon of salt in a cup or glass of boiled and cooled water) and a clean piece of cloth or cotton wool after meals. This should be done at least four times a day. Show older children how to gargle with salt water. Give fluids such as milk, butter milk, fruit juices and mashed or soft foods that are easy to chew and swallow. Avoid spicy or salty foods and acidic fruits like oranges or lemons, because these can make the soreness worse. Comfort the child, as a sore mouth is painful and distressing. Brush the tongue and inside of the mouth with a soft toothbrush several times a day and rinse with salty water if the child has thrush (white patches and ulcers). Treat oral thrush and herpes (painful blisters on the lips) with a 0.25% gentian violet solution three times a day (see opposite).
Principles and strategies

Know when to take a child living with HIV to the clinic
Families need to know when a child needs medical help. Advise them to take a child living with HIV to the clinic immediately if the child has:

- fever that lasts for more than three days
- stiff neck or convulsions (fits)
- drowsiness (difficulty staying awake) or irritability
- difficulty in breathing or breathing faster than usual
- problems with swallowing or drinking
- coughing up blood or sputum that smells bad
- persistent or very severe diarrhoea or blood in the stools
- measles or severe rashes
- ear infection or pus coming out of the ear.

Learn how to give medicines to young children
Children living with HIV need to take prescribed medicines correctly to help them recover from illnesses. Practical tips on helping young children to take medicines include:

- Give liquid medicines with a dropper or pour slowly into the mouth using a spoon.
- Crush tablets and mix with honey or a little sugar to make them easier to take.
- Tell the child in advance if the medicine does not taste very nice.
- Stay calm if the child spits out the medicine or vomits. If this happens within 20 minutes of giving the dose, wait a while and give the dose again.
- When using dispersible tablets, only use a clean implement (not fingers) to stir, and wait for the tablets to dissolve completely.
- Praise the child after they have taken the medicine.
What are the signs of pain in young children?
- Crying or groaning
- Irritability
- Poor sleeping
- Frowning
- Restless movements or refusing to lie still
- Poor appetite
- Rubbing the body
- Loss of interest in play
- Listlessness
- Screwing up the eyes

How bad is the pain?
The Wong-Baker Faces Scale shows six different faces. Face 0 looks happy and means there is no pain. Face 6 looks very sad and means that the pain is the worst. The range of pain in between no pain and the worst pain is represented by Faces 1 to 5. This tool can be used for children aged three years or older. Point to the faces, explain to the child what each face means and ask which face best describes how they feel.

<table>
<thead>
<tr>
<th>The Wong-Baker Faces Scale</th>
<th>NACO Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>🎉</td>
<td>NO HURT</td>
</tr>
<tr>
<td>🎉</td>
<td>HURTS LITTLE BIT</td>
</tr>
<tr>
<td>🎉</td>
<td>HURTS LITTLE MORE</td>
</tr>
<tr>
<td>🎉</td>
<td>HURTS EVEN MORE</td>
</tr>
<tr>
<td>🎉</td>
<td>HURTS WHOLE LOT</td>
</tr>
<tr>
<td>🎉</td>
<td>HURTS WORST</td>
</tr>
</tbody>
</table>

Provide pain relief
Pain is a common symptom in children living with HIV who are very sick or dying. This can be very distressing for the child and those who care for them. No child should suffer pain and families need support to help them recognise and relieve pain in children.

- Believe a child who says they are in pain and ask them where it hurts.
- Look for signs of pain in a child who is too young to tell you (See Wong-Baker Faces Scale).
- Use hands scale to find out how severe the pain is, because children may not be able to describe how bad it is in words.
- Give medicines to relieve and control pain.

If a child has mild pain Give paracetamol or ibuprofen. It is important to give children the right dose of these painkillers. Do not give aspirin because this can cause a serious side effect in young children. Give painkillers before the pain gets too bad and as prescribed (paracetamol every four hours and ibuprofen every six to eight hours) while the pain lasts. The pain killers should not be given on an empty stomach.

If the pain does not get better or is severe Take the child to the clinic as they may need stronger painkillers. Do not give larger or extra doses of paracetamol or ibuprofen.

Practical tips for helping young children in pain include:
- Stay with the child as being alone or frightened can make the pain worse.
- Hold or rock the child, stroke the skin or give gentle massage.
- Talk to the child or ask them to imagine a favourite place or happy activity.
- Encourage the child to do deep breathing.
How to help children cope with being in hospital

- Prepare the child before they go to hospital and explain what will happen.
- Take a favourite object or soft toy or piece of cloth to comfort them.
- Stay with the child.
- Praise the child if they have had painful tests or treatment.
- Talk to the child afterwards and answer any questions they have.

Help children to cope with being ill and being in hospital

Children who know they have HIV infection may worry about being sick. Those who do not know may still be aware that they are different from other children. Children living with HIV need support to help them deal with being ill. Children who are very sick may have to stay in hospital. This can be very frightening, especially if they are separated from their family.

- Provide children living with HIV with counselling and build their resilience (see page 14).
- Help children to cope with being in hospital (see left).

Prevent and manage bed sores

Children who are in bed most of the time or cannot move very much often get sores on the bony parts of the body. Practical tips to prevent or manage bed sores include:

- **Prevent bed sores** Help the child to get out of bed and move around as much as possible. Shift the child's position every two hours. A health worker may need to show families how to do this without hurting the child. Put cushions or pillows under the pressure area.

- **Manage bed sores** Prevent the sores from getting infected by washing them three times a day with clean, warm, salty water. Clean infected sores with an antiseptic solution like potassium permanganate.
Keep the child comfortable
Families can help to relieve distressing symptoms and to make a sick or dying child as comfortable as possible by:

- looking after the child’s mouth (see Caring for children when they are sick)
- giving fluids to prevent dehydration and keeping the mouth moist
- encouraging them to eat little and often
- seeking help if the child develops breathing problems
- spend a lot of time with the child.

Address caregivers’ fears and concerns
Families caring for a child who is very sick may be worried about HIV infection and need basic information about transmission and practical support.

- Make sure families understand how HIV is and is not transmitted.
- Explain that there is little risk of HIV infection from looking after a sick child living with HIV. They can protect themselves by minimising contact with blood and body fluids, covering cuts and wounds, being careful with sharp instruments and rinsing off blood or faeces from bedding and clothes before washing them with hot water and soap.
- Provide families with basic supplies such as antiseptic soap and encourage HBC programmes to give them practical advice and support for nursing care.

Give emotional support to children and their families
Families need emotional support when a child is dying and help to decide when to stop trying to prolong life (for example, when inserting a feeding tube becomes very painful). Children also need emotional support when they are dying.

- Provide counselling or referrals to counselling services or support groups.
- Continue to provide counselling to the family after the child’s death.
- Link families to religious organisations that can provide spiritual support.
- Help families to obtain support from health workers, HBC programmes and the community.
References


Committed Communities Development Trust (CCDT), Comprehensive prevention and intervention programs to address the needs of children and families affected by HIV/AIDS. www.ccdtrust.org


Healthlink Worldwide. Child-centred approaches to HIV/AIDS (CCATH) project www.healthlink.org.uk

JSI Zimbabwe (2005) Young people we care.


Masiye Camp (No date) Training manual for people working with children affected and infected by HIV and AIDS under 6 years old (draft), REPSSI.


Republic of Uganda Nutritional care and support for people living with HIV and AIDS in Uganda: Guidelines for service providers.

Training and Resources in Early Education, www.tree-ecd.co.za


Useful resources

General background


Frameworks and guidelines


Practical manuals and tools
AED Ready to Learn Centre Speak for the Child case study.


SAT (2003) Guidelines for counselling children who are infected with HIV or who are affected by HIV and AIDS.

SAT (2003) Guidelines on how to counsel children and communicate with them about HIV and AIDS.


Practical handbook, with comprehensive information on clinical care.
