

Supporting community action on AIDS in developing countries



Building Blocks

Africa-wide briefing notes

Young children and HIV

Strengthening family and community support

Acknowledgements

What is the International HIV/AIDS Alliance?

Established in 1993, the International HIV/AIDS Alliance (the Alliance) is a global partnership of nationally-based organisations working to support community action on AIDS. Our shared mission is to reduce the spread of HIV and meet the challenges of AIDS.

To date, the Alliance has channelled \$140 million to more than 40 developing countries in support of over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to treatment.

For more information on the work of the Alliance please visit our website at www.aidsalliance.org.

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Contents

Acknowledgements	
Introduction	02
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SECTION 1: Meeting the developmental needs of young children with HIV or affected by HIV	03
Issues	
1 Why do young children need special attention?	03
2 Why address children's developmental needs?	03
3 How does HIV affect young children's development?	03
Principles and strategies	
1 Promote community and family action	05
2 Help children to learn	07
3 Meet children's emotional and social needs	08
4 Communicate with children and help them to cope	10
5 Build resilience	15
6 Promote children's participation	16
<hr/>	
SECTION 2: Care and treatment of young children with HIV	17
Issues	
1 How are children infected with HIV?	17
2 How is HIV diagnosed in young children?	17
3 How does HIV infection affect children's health?	17
4 What can be done to help children with HIV?	17
Principles and strategies	
1 Advise pregnant women about prevention of mother-to-child transmission (PMTCT)	18
2 Recognise HIV infection as early as possible	19
3 Promote access to treatment and help children to take antiretroviral medicines	21
4 Help children to stay well	24
5 Provide good nutrition	27
6 Take care of common conditions	31
7 Provide supportive care for children who are very sick or dying	33
<hr/>	
References	36
Useful resources	37

Introduction

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

- Education
- Health and nutrition
- Psychosocial support
- Social inclusion
- Economic strengthening
- Older carers
- Young children and HIV.

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 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** 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** 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 with HIV.

The briefing note was guided by an international advisory board. It incorporates comments and case studies from organisations working with young children across Africa and from consultative meetings in Kenya, Senegal and Mozambique. This briefing note is based on background reading (see References and Useful resources) with further additions made during the review meetings, referred to as the *Building Blocks development group*. The references, useful resources, and many other resources are available in the Orphans and other vulnerable children support toolkit on CD-ROM (published by the Alliance) and at www.ovcsupport.net.

SECTION 1

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.

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 need:

- opportunities to play with other children and develop independence
- encouragement and praise
- someone who listens to and talks to them.

1 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.

2 WHY ADDRESS CHILDREN'S DEVELOPMENTAL NEEDS?

Children's 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.

3 HOW DOES HIV AFFECT YOUNG CHILDREN'S DEVELOPMENT?

The impact of HIV on families can have a negative effect on children's intellectual, emotional and social development.

Issues

3 to 5 years: Initiative and inspiration

At this stage, children talk a lot, ask questions, like to play with friends, learn to share, feel angry or guilty if they think they have failed; and become competitive, especially with their siblings and playmates. They also become more adventurous and start to imitate adults.

They need:

- opportunities to participate in activities, explore and make choices
- help to learn to use language well through reading, talking and singing
- praise when they try new things and do things well.

6 to 8 years: Curiosity and learning

At this stage, children show increased interest in the world, people, letters and numbers. They become more physically confident, start to take responsibility, play cooperatively and build trust with friends, and use words to express feelings.

They need:

- support to develop additional language, physical and thinking skills
- encouragement with school work
- opportunities to learn cooperation and self-control, to take responsibility and complete tasks.

THE IMPACT OF HIV ON YOUNG CHILDREN'S DEVELOPMENT

- **Lack of attention and stimulation** Parents who are sick, elderly grandparents and older siblings may not have the time or energy to give young children the attention and stimulation they need.
- **Lack of consistent caregivers and home environment** Sudden or frequent changes in caregivers and in the home environment affect children's emotional and social development. 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.
- **Lack of good quality care** Young children who are neglected or abused suffer psychological and emotional damage and do not develop well physically. Even if they get enough to eat, unhappy children do not grow as well as other children.
- **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. Stigma and discrimination limit opportunities for social activities and for making and maintaining friendships. Feeling lonely and isolated affects children's confidence, self-esteem and social skills.

This section 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 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.

Principles & strategies

1 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.
- Work with communities to identify children who need help and ways to meet their developmental needs, including building on traditional approaches to passing on knowledge and skills from one generation to another.
- Encourage community orphan and vulnerable children (OVC) committees to consider the developmental as well as the material needs of children with HIV and affected children, and to identify children who need help.
- Encourage community and religious organisations to address the developmental needs of younger children in their activities.

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
- Too talkative, aggressive, restless, constant repetition of the same activity
- Cries easily, gets irritable and angry quickly
- Sleeping problems, bedwetting

Media in Education Trust, 2002

Principles & strategies

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 support affected children. *AED and USAID.*

Training and Resources in Early Education (TREE), trains women to assess the needs of young children, provide counselling and identify sources of help in the community. TREE also encourages families to play with children using traditional toys and games.

The Journey of Life, a workshop developed by REPSSI, helps communities consider the needs of young children and ways to support them.

Children with difficult lives helps participants to think about how children behave when they have problems, what happens to children who behave this way and what the community can do to help them.

Building the inner strength of children gets participants to think about what they can do to help children become strong. Using a gift box, participants consider the gifts they can give to children; for example, love, listening, praise, attention and guidance. These activities lead to the development of a community plan of action. *REPSSI, 2005.*

Understanding and challenging HIV stigma, a practical toolkit, includes an activity to help adults consider how their attitudes and behaviour affect children's lives. *Kidd and Clay, 2003.*

Provide support to caregivers

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

- 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 community day centres or crèches.
- Provide counselling and training on child development and child care skills.



Encourage community members to visit affected families.

Principles & strategies

The **Lea Toto Programme** leads into a discussion about how children depend on adults and how beliefs about children affect the way adults treat them and influence children's development.

Kidd and Clay, 2003.

To tackle stigma and discrimination and promote compassionate and caring community attitudes, a Namibian NGO called CAFO is encouraging church ministers to integrate stories about children affected by HIV into their sermons. CAFO helps ministers to select a monthly topic, supported by relevant readings from the Bible and examples of children's real life experiences provided by child care committees. *Building Blocks Development Group.*

The **Lea Toto Programme** helps children 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 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.*

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

2 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 27), as this helps their brain to grow and develop.
- 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 31).

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.
- Allow children to play, as this helps them to learn and develop problem-solving skills.

Principles & strategies

Speak for the Child found that enrolling children in pre-school improved their social skills. Families reported that children had learned how to play and cooperate with other children and how to greet visitors. Children's nutrition also improved because families had more time to farm and prepare meals. *AED and USAID.*

In Malawi, with support from Save the Children UK, villagers established a pre-school for young children, which provides play facilities, makes sure children get at least one good meal a day and integrates orphans and non-orphans. Children who attend do better when they go on to primary school. The village orphan care committee provides an allowance to pre-school teachers, the community contributes maize and groundnuts, and families pay a small fee each month. However, sustaining support has been a challenge.

Speak for the Child found that support from community mentors helped caregivers to change the way they care for young children. Regular visits made caregivers feel less stressed, isolated and depressed. A joint problem-solving approach made caregivers feel more confident and respected, and had a positive impact on child care. Caregivers said that they had stopped beating young children to discipline them and now spent time talking to them and providing explanations. They also spent more time listening to children and talked gently to them instead of shouting. *AED and USAID.*

In Uganda, Health Alert found that children with HIV who receive love and affection from adults who care for them are healthier and respond better to HIV treatment than children who do not. *Building Blocks Development Group.*

- 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

Pre-school and day care can improve young children's intellectual as well as social development.

- Support families to enrol and send young children to pre-school if one is available.
- Help the community to set up pre-schools or day care centres and to recruit nursery teachers or community volunteers.
- Encourage local primary schools to provide pre-school services.

3 MEET CHILDREN'S EMOTIONAL AND SOCIAL NEEDS

Give children love and affection

Love and affection is often more important to children 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.

Involve children in social activities

Young children 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 or in a dark room, so that they feel included in family life.

Principles & strategies

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:

Nandi and her friends were playing together in the playground. Buhle was sitting alone. Nandi said to her friends, "Let's ask Buhle to play with us," but her friends did not want to play with Buhle. They said, "No, she is HIV positive. She will give us AIDS. I am scared to play with her." Poor Buhle was left on her own. On the way home from school, Nandi fell over and hurt her arm. Buhle walked past and asked, "What is wrong? Can I help you?" She helped Nandi home and Nandi's mother was very pleased. She took Nandi to the doctor to check her arm, and while they were there Nandi asked the doctor about HIV. The next day Nandi and Buhle walked to school together. Nandi'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." Nandi replied, "Buhle 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 Buhle 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. *Media in Education Trust, 2002.*

- 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.
- Provide opportunities for young children with HIV and affected children to talk about their feelings and experiences with others in a similar situation.



Children enjoy playing together.

- **Involve children in social activities**
Children 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 religious leaders, teachers and other adults to set a good example and to include children with and children affected by HIV in community events such as ceremonies and festivals and recreational activities such as games and sports.
- Work with parents and teachers to tackle stigma and discrimination by children, as negative attitudes in children are usually learned from adults.
- Involve 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.

Principles & strategies

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.
- 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.

4

COMMUNICATE WITH CHILDREN AND HELP THEM TO COPE

Provide counselling for children

Counselling can be very helpful for children 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.
- Build local capacity for counselling children by training teachers, church leaders and community volunteers.
- Encourage OVC and home-based care (HBC) programmes to train volunteers in counselling children and to include children in family counselling sessions.
- Strengthen traditional community counselling approaches that do not depend on professionals or outsiders.
- Promote approaches such as peer groups and clubs that meet the needs of all children in communities affected by HIV.

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.*

Principles & strategies

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.

Principles & strategies

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 under 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.
- 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.

Help children who are grieving

Families need information about how grief affects young children and what they can do to support them. They need to be aware 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.

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.

Principles & strategies

Children's ability to understand death also depends on their age and understanding:

- Children aged under 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).

- 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.
- 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. Children could be helped to hold their own ceremony for a parent or sibling who has died or to plant a tree or garden in memory of the person.
- Explain where you are going and why if you have to leave the child for a while, and 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 their 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.



Involve children in family rituals, such as planting a tree in memory of a loved one.

Principles & strategies

In Zimbabwe, Masiye Camp, run by the Salvation Army, organises camps for affected children under five years and their caregivers. Play is used to help children express their feelings and develop social skills. Counselling, discussion groups and training (for example, on the effects of child abuse, living with HIV, care for sick children, parenting skills and preparing a memory book) helps caregivers to understand children's needs and provide appropriate care and support for children with HIV. *UNAIDS, 2001.*

Also in Zimbabwe, the Young People We Care initiative encourages young people in the community to provide practical and emotional support to younger children, including helping with school work and playing games. *JSI UK Zimbabwe, 2005.*

HUMULIZA in Tanzania trains NGOs and teachers to identify children's problems and communicate with children. HUMULIZA also organises peer group counselling, where children can share experiences and provide mutual support. Weekly group sessions help children to feel they are not alone with their problems and to address their feelings of isolation. Sessions start by asking each child to tell the group about something important that happened during the week. Drama and puppets help children talk about problems. Games, songs and activities help to build self-esteem. *UNAIDS, 2001.*

The Mothers Support Group in Nigeria runs children's clubs and camps, which provide a safe place for children to think about their problems and work out solutions with the support of caring adults. *www.healthlink.org.uk.*

CARE International supports the Nkundabana Initiative for Psychosocial Support (NIPS) in Rwanda, which will train 600 mentors (Nkundabana) to assume a parental support role for 3,000 child-headed households to help meet their emotional and psychosocial needs. Mentors selected from the community must be agreed by children. *www.repssi.org.*

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.

A 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.*

5 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, peers 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 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.

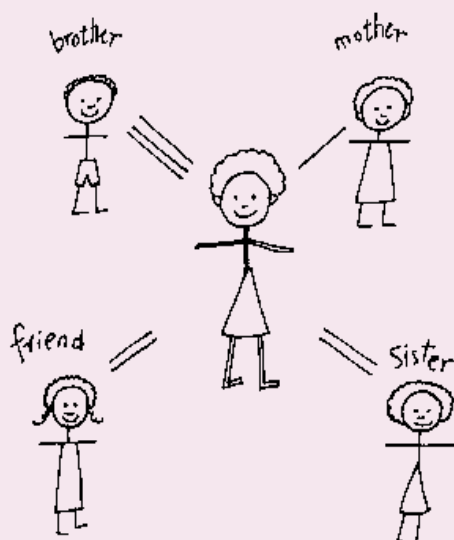
Principles & strategies

Why is children's participation important?

- 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 with HIV.
- Ensure children are part of a supportive peer group such as a club.



An example of communication mapping.

6 PROMOTE CHILDREN'S PARTICIPATION

Even if children are very young, it is important to find out what they think and what matters to them before deciding how to help them. Only children themselves can describe their situation and how they feel. Participation can not only ensure that activities respond to children's needs, but can also help to improve their psychosocial well-being and build their resilience.

- Share findings about young children's needs and priorities with the community.
- Sensitise community leaders and committees about the value of children's participation and encourage them to involve children in a meaningful way.
- Build children's confidence and skills to contribute to adult discussions. Alternatively, facilitate separate meetings for children where they can express their views and identify a representative to share these views with community leaders.

Research by the STEPS programme in Malawi with young children 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.
- **River of life** Children draw a river of their life starting from birth and looking five years into the future, showing the river flowing up when things are going well and down when times are bad. This provides insights into children's problems.
- **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.

SECTION 2

Issues

Most children with HIV are infected through mother-to-child transmission. Preventing HIV infection in women and making sure that HIV-positive women have access to interventions that prevent mother-to-child transmission are the most effective ways to prevent HIV infection in children.

Making sure that the parents of children 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.

1 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.

2 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 Africa, is not reliable in 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, have not been widely available. However, this is changing and many countries are expanding the availability of effective HIV tests for very young children.

3 HOW DOES HIV INFECTION AFFECT CHILDREN'S HEALTH?

Children 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 are particularly serious problems in children with HIV.

Children 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 with HIV.

4 WHAT CAN BE DONE TO HELP CHILDREN WITH HIV?

Children 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 with HIV and enables them to lead healthy and happy lives.

Principles & strategies

This section describes principles and related strategies that organisations can use to support communities and families to help children with HIV to stay healthy.

Principles

1. Advise pregnant women about prevention of mother-to-child transmission (PMTCT).
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.

1 ADVISE PREGNANT WOMEN ABOUT PREVENTION OF MOTHER-TO-CHILD TRANSMISSION

Without interventions, one in three babies of HIV-positive mothers will be infected. However, there are interventions that can reduce significantly the risk of mother-to-child transmission. These interventions 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.

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 countries because of the cost and the risks to the mother and the infant (see *'Provide good nutrition' for more information about infant feeding, page 27*).

PMTCT 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 & strategies

- Educate communities about how to prevent HIV infection in women during pregnancy.
- Provide communities with simple information about the importance of HIV testing for pregnant women and their partners, and where couples can receive voluntary counselling and testing services.
- Promote community awareness of interventions that can prevent mother-to-child transmission of HIV, especially antiretroviral prophylaxis, and of programmes and facilities that offer PMTCT services.

2 RECOGNISE HIV INFECTION AS EARLY AS POSSIBLE

Improve identification of children with HIV

It is important to identify young children 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 with HIV.
- Train community workers and volunteers in OVC, HBC 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?

Principles & strategies

Stories are a good way to deal with children's fears about a blood test. This one is adapted from *HIV positive: A book for caregivers*. Siyabonga needs to have a blood test at the clinic. He is very scared. The nurse explains what she is doing to stop him feeling so scared.

Siyabonga: I am scared.

Nurse: Everyone is scared of new things but there is no need to worry about a blood test. I have done many of these and I know you will be fine.

Siyabonga: What are you doing now?

Nurse: I am cleaning a little spot on your skin so that no germs can get in. I am going to put this needle into your vein. You might feel a little prick. Here comes the blood into the tube. Now I've got all the blood I need. That wasn't bad, was it?

Siyabonga: It was OK. I just felt a little prick. Now I can't feel anything. How are you going to stop the bleeding?

Nurse: I am going to put a little piece of cotton wool on the spot and this tape will keep it in place. When you get home you can take it off and there will be no bleeding.

Siyabonga: Can I show it to my friends?

Nurse: Yes. Leave the cotton wool and tape on until you show your friends. You have been a very good and brave boy. Well done.

As soon as he got home, Siyabonga raced off to show his friends. He told them that the nurse said he was very, very brave. He felt very proud. *Media in Education Trust, 2002.*

- 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 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 (*see opposite*).
- Explain that a parent or guardian will need to give consent before a child is tested and that it is also important that the child agrees to be tested if they are old enough to understand what is happening.
- Refer families to support groups where they can discuss anxieties about testing and disclosure, and share experiences.

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 and answer questions as honestly as possible.
- Refer children for counselling if this is available or set up peer support groups or clubs where they can share their feelings and problems with other children in the same situation.

Principles & strategies

With support from Save the Children, the NGO Health Alert works in Gulu District in Northern Uganda to promote access to treatment and care for children with HIV and support for children receiving antiretroviral therapy and cotrimoxazole prophylaxis. Specific activities include:

- linking communities to health facilities
- raising awareness of the importance of testing children and providing treatment for children who need it
- giving families basic information about antiretrovirals, including how to give medicines to children and how to manage side effects
- training children as treatment adherence peer educators
- supporting children with HIV to communicate their needs to a wider audience through radio programmes
- establishing peer support clubs for children regardless of HIV status.

The project has shown that increasing access to treatment for children and home management of children on antiretroviral therapy is feasible in resource-poor settings. Communities have a better understanding of the importance of testing and treatment for children, and parents and children appreciate the importance of taking their medicines. Peer support clubs have been very effective in helping parents to tell children that they have HIV, promoting adherence and reducing stigma towards children with HIV. *Building Blocks Development Group.*

3 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 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, treatment services and the importance of starting children with HIV who need it on antiretroviral therapy as soon as possible.
- Support families, communities and health services to advocate for increased access to antiretroviral therapy for children with HIV.
- Promote links between the community and antiretroviral therapy services. Community AIDS and children's committees, and HBC and OVC programmes, can play an important role in referring children 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 families that adults on antiretroviral therapy should not share their medicines with children.

Principles & strategies

Factors contributing to poor treatment adherence among 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, the bad taste of the medicine and side effects.

In South Africa, counsellors at children's clinics use stickers to help children understand why they need to take their medicines.

"Vuli (child's name), there is a germ in your blood. When you take the correct amount of medicine every day you will feel well. Let's use these different coloured stickers to show how it works:

- These red stickers are like blood. (Put lots of red stickers on a clean surface.) Your blood has soldiers that protect you from getting ill.
- The germ wants to attack the soldiers to make them weak. These black stickers are like the germ. (Put some black stickers on the surface. More can be added to illustrate that the virus replicates.)
- The medicine helps to make your body's soldiers strong. (Put some green stickers on the surface.)
- When you take your medicine, it helps the soldiers to fight the germ. (Remove the black stickers gradually.)
- When you forget to take your medicine, the black stickers attack your body's soldiers very quickly and you start to feel ill. (Take away the green stickers and add more black stickers.)"

During this explanation, the child can ask questions and the counsellor explains to the child and caregiver how they can remember the times for taking the medicines.

Building Blocks Development Group.

Principles & strategies



Use a measuring spoon 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.

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.
- Put different medicines in different coloured bottles to avoid confusing them. Use a marked cup or measuring spoon to measure the right amount of syrup.
- Put enough medicines for one week into separate packages to make it easier to check that all the doses have been taken.
- 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 from the bad taste. 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 a ginger drink if the medicine makes the child feel nauseous and a dose of paracetamol if it causes headache (see opposite).
- 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.

Principles & strategies

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.*

In Malawi, MSF uses health diaries, calendars and stories to help children with HIV to take their medicines. *MSF, 2005.*

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.

4

HELP CHILDREN TO STAY WELL

Give cotrimoxazole prophylaxis

Cotrimoxazole is a cheap, widely available antibiotic. Prophylaxis means giving a medicine to prevent disease. Cotrimoxazole prophylaxis helps children 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 with HIV. It also prevents infections such as malaria and diarrhoea in children with HIV.

- Raise community awareness of the benefits of cotrimoxazole prophylaxis for children with HIV.
- Encourage HBC programmes to identify children who could benefit from cotrimoxazole prophylaxis.

Principles & strategies

Cotrimoxazole prophylaxis for children with HIV

A Zambian study found that giving cotrimoxazole prophylaxis to children 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 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.

- 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 with HIV are immunised

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

- Explain to families about the importance of immunisation for children with HIV.
- Visit local health facilities to find out about the immunisation schedule and encourage families to take children with HIV and children who may be at risk of HIV for immunisation.
- Advise families to keep children's health cards in a safe place and encourage dying parents to give children's health cards to the future guardian.
- Ensure that health workers are aware of the benefits of vaccination for children with HIV (*see overleaf*).

Give vitamin A supplementation

Vitamin A supplementation reduces the risk of illness and death in all children, including children 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 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 with HIV are more at risk of malaria than children without HIV. Preventing malaria by protecting children with HIV from mosquito bites is critical. Sleeping under an insecticide-treated net can reduce malaria in children by half. Children with HIV are at higher risk of TB if they live in a household with an adult who has TB disease.

Principles & strategies

Immunisation and children with HIV

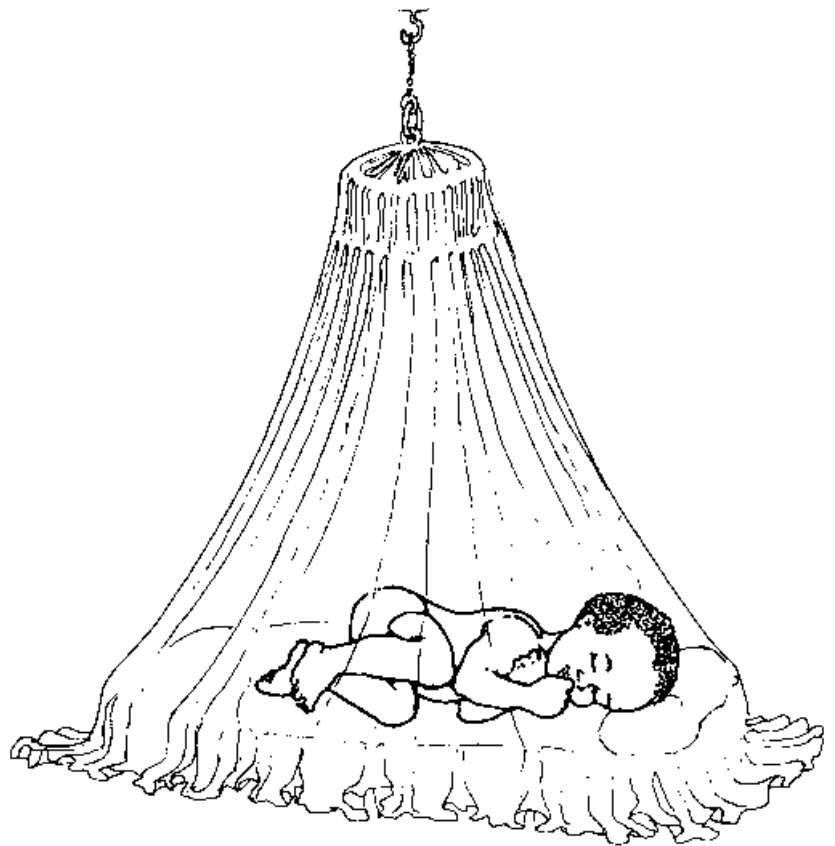
The World Health Organization (WHO) recommends:

- 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.
- All HIV-positive or HIV-exposed infants (children born to positive mothers but whose HIV status is unknown), whether or not they have symptoms of HIV, should have a dose of measles vaccine at six months in addition to the normal dose at nine months.

Recommendations for BCG vaccination depend on the prevalence of TB in a country (and also on national policy):

- In countries with high prevalence of TB (where the benefits of BCG vaccination outweigh the risks), BCG should be given to all children (including those with HIV) except those with symptoms of HIV-related disease.
- In countries with low prevalence of TB, BCG should be given to all children except those with HIV or with symptoms of HIV-related 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. These may be available from the National Malaria Control Programme.
- Establish links with community TB and Directly Observed Treatment Short Course (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.

Promote safe water and good hygiene

Children 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 to use simple water purification methods if it is not possible to boil water.

Principles & strategies

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.

- 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.

Take children for regular check-ups

Regular check-ups for children 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 with HIV for regular checks.
- Ensure that health workers are aware of the preventive measures that can help children with HIV to stay well.
- Encourage local health facilities to establish child-friendly treatment rooms.
- Identify community volunteers to take young children 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.

5 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 that infants get the best possible nutrition. See page 28 for a summary of WHO recommendations.

- Provide families with practical information about HIV and infant feeding.
- Refer positive women for counselling about infant feeding or, 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.

Principles & strategies

Women with HIV and infant feeding

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

How to stop breastfeeding early

You may want to consider stopping breastfeeding early so that your 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. You can discuss the best time for you if you go back to see your health worker before you stop breastfeeding. Once you decide to stop, these steps can help to make it easier:

- Show your baby how to drink expressed breast milk from a cup.
- Once the baby can drink from a cup, replace one breastfeed a day with a cup feed. After a few days, replace another breastfeed with a cup feed.

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

Raise awareness about malnutrition and how to prevent it

Young children with HIV are at increased risk of malnutrition. Although malnutrition in children 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 with HIV (*see page 27*).
- 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 (*see opposite*).
- 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 opposite*).
- Encourage families to give frequent energy-rich and nutrient-rich meals to children recovering from malnutrition and to take them for follow-up checks.
- Support pre-school or day care feeding programmes.



Make sure young children eat well.

Principles & strategies

Repeat this until all feeds are given by cup.

- Gradually replace the breast milk with formula or home-modified animal milk.
- Stop putting your baby to the breast as soon as they are 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 you have stopped.

Adapted from WHO infant feeding counselling flyers.

Why are young children with HIV at risk of malnutrition?

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

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

- Give families information about a good diet for children 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 sweet potatoes, rice, maize or millet porridge. From two years, give family foods.
- Suggest ways to make complementary and family staple foods more nutritious. Adding vegetable oil or margarine provides energy; adding egg, milk, mashed beans or groundnuts provides protein; and adding mashed green leafy vegetables or fruits provides vitamins and minerals.
- Explain that young children 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.
- Link households experiencing food shortages to food assistance programmes.

Principles & strategies

Speak for the Child-trained mentors have helped caregivers to identify practical ways to improve child nutrition. These include giving younger children a separate plate so they do not have to compete with older children for food, feeding children more often and planting vegetables in between maize to provide a more varied diet. *AED and USAID.*

Community volunteers care for pre-school children at *neighbourhood care points* in Swaziland. The aim is to improve young children's health and nutrition, give psychosocial support and enable older siblings to go to school. UNICEF provides cooking pots and the World Food Programme provides corn soya blend. *UNICEF, 2003.*

CCATH uses the Child-to-Child approach to improve nutrition. Children learn about the importance of good nutrition for people with HIV-related illness and local foods that are good for people who are ill and help sick children to eat. www.healthlink.org.uk.

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 and yoghurt or other fermented foods like sour porridge 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 & 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.

6

TAKE CARE OF COMMON CONDITIONS

Provide good home care

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

Fever Give plenty of fluids (for example, water or juice) to prevent dehydration and paracetamol to reduce the fever.

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

Cough Give warm fluids to soothe the throat. 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, scabies and ringworm, which are more common in children 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 or at least four times a day. Show older children how to gargle with salt water. Give fluids such as milk, yoghurt and 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 & strategies

Know when to take a child with HIV to the clinic

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

- fever that lasts for more than three days
- a stiff neck or convulsions (fits)
- drowsiness (difficulty staying awake) or irritability
- difficulty 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
- an ear infection or pus coming out of the ear.

Learn how to give medicines to young children

Children 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 porridge 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.
- Praise the child after they have taken the medicine.

Principles & strategies

The signs of pain in young children are:

- crying
- 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.

The Wong-Baker Faces Scale



0 NO HURT



1 HURTS LITTLE BIT



2 HURTS LITTLE MORE



3 HURTS EVEN MORE



4 HURTS WHOLE LOT



5 HURTS WORST

From Wong, DL, Hockenberry-Eaton M, Wilson D, Winkelstein ML, Schwartz P: *Wong's Essentials of Pediatric Nursing*, ed. 6, St. Louis, 2001, p.1301. Copyrighted by Mosby, Inc. Reprinted by permission.

7 PROVIDE SUPPORTIVE CARE FOR CHILDREN WHO ARE VERY SICK OR DYING

Provide pain relief

Pain is a common symptom in children with HIV who are very sick or dying and is 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.
- Use a Faces Scale (*see below left*) 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 called Reye's Syndrome. 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.

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.
- Put something cold on the place that hurts.
- Talk to the child or ask them to imagine a favourite place or happy activity.
- Encourage the child to do deep breathing.

Principles & strategies

How to help children cope with being in hospital

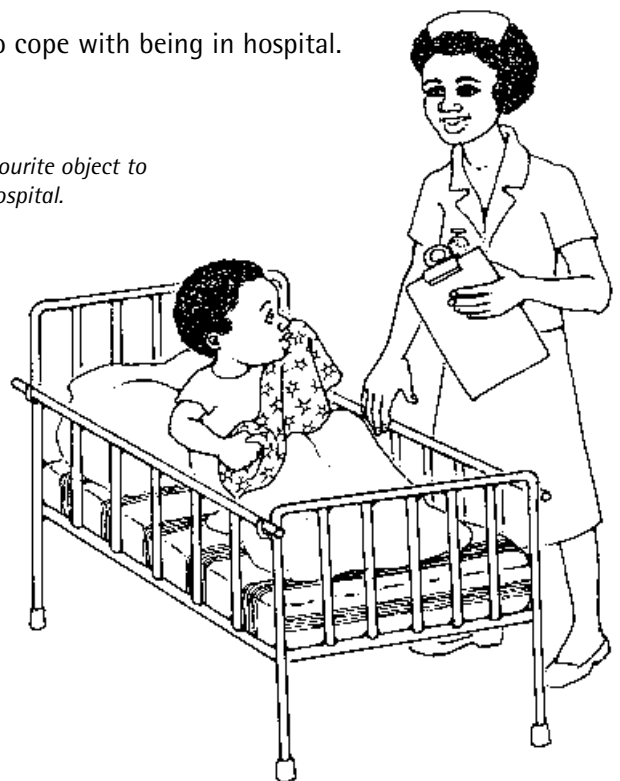
- Prepare the child before they go to hospital and explain what will happen.
- Take a favourite object or soft toy or piece of cloth to comfort them.
- Stay with the child. If this is not possible, make sure that someone they know visits them every day, and tell them when visitors will be coming.
- Praise 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 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 with HIV with counselling and build their resilience (*see opposite*).
- Help children to cope with being in hospital.

Give children a favourite object to comfort them in hospital.



Prevent and manage pressure 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 pressure sores include:

- **Prevent pressure 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 pressure 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.

Principles & strategies

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 *section 6, Take care of common conditions, page 31*).
- giving fluids to prevent dehydration and keeping the mouth moist
- encouraging them to eat little and often
- seeking help if the child develops respiratory distress.

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 with HIV and that 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 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.
- Link families to religious organisations that can provide spiritual support.
- Help families to obtain support from health workers, HBC programmes and the community.

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