Supporting community action on AIDS in developing countries

Building Blocks: Asia
Briefing notes for communities working with orphans and vulnerable children
Care and psychosocial support
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What is the International HIV/AIDS Alliance?

The International HIV/AIDS Alliance (the Alliance) is the European Union’s largest HIV-focused development organisation. We were established in 1993 as an international non-governmental organisation to support community action on HIV/AIDS. Since then, we have worked with over 2,000 community-based organisations in over 40 countries, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support and improved access to treatment.

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The International HIV/AIDS Alliance, with funding from USAID, has produced this series of practical briefing notes to assist policy-makers, programme managers, non-governmental organisations (NGOs), community-based organisations (CBOs), local government and communities to respond to the needs of children affected by HIV and AIDS in Asia. The briefing notes focus on how programmes can strengthen the capacity of children, families and communities. They do not include general information on HIV and AIDS, as this is available in many other publications.

These briefing notes are part of a set of seven, comprising six topics and an overview:

- Health and nutrition
- Livelihoods and economic strengthening
- Education and training
- Care and psychosocial support
- Social inclusion
- Protection

All these areas are important and should be considered together in an integrated response. Each briefing note introduces issues, and provides principles and strategies for guiding the response, while also offering examples of best practice from programme experience. The strategies reflect international good practice and the experience of people working with orphans and vulnerable children in Asia. Some of the guides also include case studies from Africa to illustrate practical actions that can be taken.

The briefing notes were developed through a highly participatory process, guided by an international advisory board. Initial content for the notes was developed during a workshop in Chiang Mai by members of the development group for Building Blocks: Asia, acknowledged above. This was then written up in English by a consultant, Kathy Attawell, and then translated, reviewed and revised in Cambodia, India and Thailand. These revised editions are available in Khmer, Hindi and Thai – see www.aidsalliance.org for more information on these publications. This English edition is based on the original content developed during the Chiang Mai workshop, with revisions and editions based on the country-level reviews and feedback from the international advisory board. Examples and case studies from this process have been noted as coming from a ‘Member of the development group for Building Blocks: Asia’.

1 The term ‘children affected by HIV and AIDS’ includes children living with HIV as well as those who have lost family members to AIDS or who are living in families or communities affected by HIV and AIDS.
Background

The briefing notes in Hindi

The briefing notes are all divided into three sections:

Introduction
This section explains the topic and how it relates to children and families affected by HIV and AIDS.

Issues
An outline of the impact of HIV/AIDS on children.

Principles and strategies
Guidelines and possible ways of taking action to strengthen support for orphans and vulnerable children.
Children’s psychosocial and emotional needs are as important as their physical needs. Caring for a sick parent, living in an HIV or AIDS-affected household, or losing one or both parents, have a powerful effect on children’s psychological and emotional well-being. Programmes for children affected by HIV and AIDS should pay as much attention to children’s needs for love, affection and understanding as they do to their needs for shelter, food and clothing.

Parental illness and death is traumatic, stressful and sad for children. Children are often encouraged to keep their emotions to themselves or may find it difficult to express their feelings. Approaches to counselling that are appropriate for children are needed. Helping children cope and to talk about how they feel at an early stage in the process (‘early intervention’) is essential to prevent long-term psychological damage. Children who have lost their parents often also lose their home, friends and schooling. Their emotional distress is worsened by poverty, stigma and discrimination and increased responsibilities, which may prevent them from feeling that they are part of the community. Programmes need to encourage communities to provide children with practical help and to promote social integration of children affected by HIV and AIDS.

Due to the strong links between poverty and psychosocial problems, organisations and communities need to address underlying causes as well as the problems themselves. Making sure a child has enough to eat, a caring and supportive family and community environment, and can go to school, are some of the most important interventions to prevent or address psychosocial needs. For psychological well-being, children need:

- safety
- adequate access to the physical and material requirements for health
- social support and integration
- emotional support
- age-appropriate opportunities to learn and achieve developmental tasks
- personal and cultural identity opportunities for spiritual expression.

Thus programmes can address any or all of these factors to support children.
Introduction

Caregivers themselves also need psychosocial and emotional support to help them cope with their own grief, fears, stress and worries about the future, and to enable them to give children the best possible care.

This guide is divided into two sections:

Issues

This section considers how HIV and AIDS affects the care of children and their psychosocial and emotional well-being, and explains why programmes need to pay attention to the psychosocial and emotional needs of children affected by HIV and AIDS.

Issues include:

- Family poverty and stress
- Anxiety and worry
- Stigma, discrimination and rejection
- Feelings and behaviour
- Loss of home and identity
- Loss of childhood
- Lack of adult care and support
- Long-term psychological problems
- Coping with HIV

Principles and strategies

This section outlines principles of programming to provide care and psychosocial support, and describes possible ways of taking action to address the needs of children affected by HIV and AIDS. Case study examples are included to illustrate practical application of some of these principles and strategies.

Principle 1
Protect the rights of children

Principle 2
Promote early intervention

Principle 3
Strengthen the capacity of families and communities

Principle 4
Support family and community models of care

Principle 5
Help children to help themselves
HIV and AIDS affects the care and psychosocial and emotional well-being of children with sick parents, children who have lost their parents, and children with HIV. The impact on children includes:

**Family poverty and stress**

Families affected by HIV and AIDS have to cope with many problems. Living in poverty causes psychological stress for adults and children. Parents in affected families may be too busy or worried to give children proper care or to talk to them about what is happening. Sometimes HIV and AIDS cause domestic violence or family breakdown. Parents may separate or divorce, or in extreme cases an HIV-positive woman may be thrown out of the house. Family stress and separation has a serious impact on children’s emotional health.

**Anxiety and worry**

Children worry about whether or not sick parents will die, and what will happen to them, where they will live and who will take care of them afterwards. Sometimes they worry that they have HIV and will die themselves. If adults do not explain to children what is happening or talk to them about who will care for them in future, children may become very anxious.
CARE AND PSYCHOSOCIAL SUPPORT

A 14-year-old girl described how she worried about whether her mother had HIV.
“What I remember from when I was in grade 2 is the gossip about my mother and AIDS. I didn’t know what AIDS was, except that it must surely be a bad thing, but my mother did not say anything about it. When I was older I was sure that my mother had AIDS, because I saw some PLHA group leaflets. But it was not until I was in grade 8 that she talked to me about AIDS. She explained that it could not be easily transmitted and was not a frightening thing. Then she told me she was infected, and that she had not said anything when I was younger because she did not want to make me sad or worried. But I feel that keeping it secret made me feel more sad and worried.

Member of the development group for Building Blocks: Asia

A four-year-old boy was living with his mother and grandmother. The father had died of AIDS before the boy was born. The mother told people that she did not love her son because she was angry with his father for infecting her with HIV. He found it difficult to stay still, and his mother often beat him very hard. Sometimes the boy fought back by biting her. When he was upset he stayed away from his friends. When he saw other fathers he called them “Papa” like his friends.

Orchid Clinic, Chiang Mai (personal communication)

Issues

Stigma, discrimination and rejection

Children with HIV commonly experience stigma and discrimination from neighbours, relatives or other children. Children from families affected by HIV and AIDS may be stigmatised and discriminated against because people assume that they too have HIV. Hostility and rejection increase children’s psychological stress. They may feel isolated and unable to talk about their problems outside the home because of the shame associated with HIV and AIDS. Sometimes parents with HIV physically distance themselves from their children because they do not understand fully how the virus is transmitted, and are afraid of infecting them. This makes children feel unloved and rejected, especially if they do not know that their parents have HIV.

Feelings and behaviour

Children who have lost their parents or siblings may experience feelings of sadness, anger and guilt. Children who are distressed may show aggressive, difficult or disturbed behaviour. If they are punished for their behaviour, this adds to their distress. Older children may feel angry with their parents for dying or with whoever they think has caused their parents to die. They may lose their confidence or self-esteem. Younger children may lose their appetite. Sometimes children mistakenly think that they are to blame when their parents are ill or die, or feel guilty because they were unable to keep their parents alive.

Loss of home and identity

Children may lose their home if their parents divorce or die. Sometimes when the father dies, the mother has to return to her family home, taking the children with her. Children who have lost both parents may move away from their home and community to live with relatives in an unfamiliar environment. They may also be separated from their siblings. Losing contact with their brothers or sisters and friends in addition to losing their parents is very traumatic for children.

Loss of childhood

Children caring for sick parents or who are living without parents have to take on adult responsibilities, such as earning money, preparing meals and looking after younger brothers and sisters. They do not have the time or energy for normal childhood activities that are important for their psychological and emotional development, like going to school or playing with friends.
A 16-year-old girl is working in town and living with her employer, 15 kilometres away from her family home, and she goes home at weekends. Her parents died several years ago and she is responsible for her 80-year-old grandmother and 12-year-old brother, who has HIV infection. Although her brother started antiretroviral treatment, he does not always take his medicines correctly because there is no one to supervise him. Sometimes she has to take her brother to the hospital. She always looks sad and seems more mature than other girls of the same age. 

Member of the development group for Building Blocks: Asia

A 10-year-old girl with HIV said: “A long time ago, I could not remember at what age, I got herpes. My mother took me to the hospital and she told me that I had AIDS just like her. At that moment I did not want to think about AIDS. I had a headache. No friends played with me and they feared me because they were afraid of getting AIDS from me. I also worry that my friends will tease me. AIDS makes my mother sick and will make her die. I used to think about committing suicide.”

AIDSNet newsletter, Vol.4, April–September 2003

Issues

Lack of adult care and support

Children caring for sick parents are often left to cope alone without social and emotional support. After their parents die, they are left to cope with younger brothers and sisters or elderly grandparents. Orphaned children miss out on parental love, protection, advice and encouragement, and may lack adult support to help them develop social skills or a sense of self. Sometimes children sent to live with relatives are neglected or treated badly. Sometimes relatives refuse to care for children whose parents have died of AIDS or children with HIV, and these children may be abandoned or placed in institutions.

Long-term psychological problems

In some cultures, adults do not discuss illness or death with young children or find it difficult to talk to children about these subjects. They may not be aware of children’s psychological and emotional needs or know how to help children grieve. Without appropriate counselling and the chance to mourn their parents or to talk about how they feel, children may experience psychological problems later in life or try to cope in ways that are harmful, such as abusing drugs or alcohol. In many settings, there is a lack of specialised counselling and support services for children.

Coping with HIV

Children with HIV who are often ill may feel afraid or worried. They need special help to cope with and come to terms with their illness, to learn to live positively with HIV, to deal with stigma and discrimination and prepare for the future.

Children need someone to talk to about their feelings
Principles & strategies

Protect the rights of children

Programmes should centre on the best interests of the child. Addressing children’s needs for psychosocial and emotional support is as important as addressing their physical needs for food, shelter and clothes. Children affected by HIV and AIDS have the same rights to identity, love, leisure and individual development as other children. All children, especially those who are vulnerable, need to feel secure and valued.

THE CONVENTION ON THE RIGHTS OF THE CHILD STATES:

- Children have the right to a name, nationality and sense of identity.
- Children have the right to affection, love and understanding.
- Children have the right to opportunities for play and recreation.
- Children have the right to be a useful member of society and to develop individual abilities.

Strategies for action

- Take a holistic approach, promoting collaboration between health, education and social welfare services and organisations providing counselling and support services.
- Raise community awareness about the importance of psychosocial and emotional support for children.
- Promote integration of children affected by HIV and AIDS in the community. Possible actions include:
  - Keep children with HIV together with other children in schools or health facilities.
  - Support efforts to tackle stigma and discrimination.
Principles & strategies

- Establish children's clubs and play groups for all children in the community.
- Involve children in community development projects to give them opportunities to interact with adults and other children.
- Encourage and support parents to register their children's births, so that they have an official name and identity.
- Make sure that children are aware of their rights, and promote the active participation of children in decisions about their lives.

2 Promote early intervention

Early intervention can prevent adverse effects on children's long-term development. It is important to prepare children for parental death, and to identify and help children with psychosocial and emotional needs before they develop serious problems.

Strategies for action

- Help parents to plan for their children’s future while they are still well, and to include children in decisions. Possible actions include:
  - Assist parents to make a legally binding Will that protects children’s inheritance and states who will care for the children.
  - Involve community leaders in encouraging families to discuss the future of children.
  - Document the wishes of parents and children about who will care for children in the future.
  - Ensure that contact information for relatives is recorded before parents die.

In Thailand, an HIV-positive child and his aunt fought against discrimination at his school, with support from the Centre for AIDS Rights and MSF-Belgium. “Now, there is no problem at my school. I have the right to study.”

Member of the development group for Building Blocks: Asia

In India, Project CHILD works with children in affected households where parents are very sick to prepare them to cope with parental death, if the parents have disclosed their HIV status to the children. All children in affected households are given skills training in first aid, household budgeting, home management and dealing with crisis situations.

Member of the development group for Building Blocks: Asia

Making sure that contact information for relatives is available to children
Principles & strategies

One NGO in Cambodia monitors children whose parents are sick and encourages parents to decide who will care for the children after they die. The organisation also provides counselling to help children before and after their parents die, and intervenes when necessary to ensure that children are not abandoned. In one case, relatives only wanted to take the younger of two orphaned children, suggesting that the older child go to a home. The NGO negotiated with the family, explaining the importance of keeping brothers and sisters together.

Member of the development group for Building Blocks: Asia

A woman who was the leader of a group of people living with HIV in Thailand decided to tell her two children aged seven and twelve years about her HIV status. She believed that the mother should be the person to tell her children, help them learn about HIV and AIDS and how to lessen its impact. She planned carefully how to prepare other family members and her children. To prepare her children, she introduced information about HIV and AIDS in daily conversation in a natural and informal manner, telling them about HIV transmission and treatments available for people living with HIV. She also took the children to visit friends with HIV who were living normally with other people in the community. After several months, when she felt confident that her daughters had a good understanding, she told them about her HIV status. She explained that they would stay together, that she was taking good care of her health and feeling well. She also told them that she was not angry or upset. She prepared a notebook of memories with drawings about herself and their father, and their feelings about their children. She continued to write in the notebook, including more stories and information, and letting her daughters read it periodically, observing their reactions. She also talked to them about future plans and what they would do in certain situations. These two children have grown up not feeling that HIV and AIDS are abnormal or frightening. – Member of the development group for Building Blocks: Asia

- Prepare children and parents for death. Possible actions include:
  - Encourage parents to be open and truthful, and to talk about their illness and possible death with children, to help prepare them to cope with grief and loss.
  - Give parents advice about how to talk to their children about difficult issues in a way that they can understand and that is appropriate to the needs of the individual child.
  - Provide counselling services for children in and out of school and for parents.
  - Put together a ‘memory box’ for children that contains information about the family and things that are relevant to the child’s history and background, or encourage parents to write a ‘memory book’ with their children (see Useful resources for more information).
  - Encourage religious leaders and traditional healers to provide spiritual support that is appropriate for children.
  - Give children practical information about what is going to happen to them, where they will live, who will care for them and where they will go to school.
  - Make sure that children visit and know their extended family well while the parents are still alive, so that children feel part of their larger family.
  - Train carers, teachers and health workers to recognise the early signs of developmental, psychological and emotional problems in children.

Parents prepare for the future by making a Will
Principles & strategies

Strengthen the capacity of families and communities

Families and communities are the most important resource for providing children with psychosocial and emotional support. Programmes should focus on strengthening the capacity of families and communities to care for children, rather than targeting children directly. Support for families can help to avoid children being abandoned or placed in institutions. It is also important to provide psychosocial and emotional support for carers such as grandparents, to help them cope with their own grief, stress and social isolation, and with looking after children with psychological and emotional problems.

Also in Thailand, the AIDS Access foundation, AIDSNet Foundation and MSF-Belgium have worked together to develop a curriculum on communicating with children affected by HIV and AIDS, including understanding how to talk to children and the cultural context of the relationship between children and adults, and to conduct training for people who work with children. Methods such as drawing pictures, telling stories and role-play are used to help identify and address issues that are worrying children. Member of the development group for Building Blocks: Asia

A community worker educates a family about caring for children’s emotional needs.

In some rural areas of Cambodia, relatives were reluctant to take responsibility for orphans, wanting to send them to orphanages or Buddhist temples. The main reason was lack of understanding about HIV and AIDS and thus fear that they would become infected with HIV through looking after these children. Volunteer members of the Kien Kes Health Education Network have helped grandparents and other relatives to understand that HIV cannot be transmitted through normal daily contact, and people are now agreeing to take care of orphaned children in the family. Member of the development group for Building Blocks: Asia

Strategies for action

- Educate communities about HIV and AIDS to reduce fear and encourage them to take responsibility for caring for children affected by HIV and AIDS.

- Provide families with practical support so that they can continue to take care of their children. Possible actions include:
  - Give practical advice about caring for children with HIV, including preventing the transmission of HIV or other infections. Provide materials to help with this, such as latex gloves and disinfectant.
  - Establish day care centres or nurseries for pre-school children.
In Thailand, the Orchid Clinic found that most families affected by HIV and AIDS want to continue caring for their children, but sometimes find it hard to cope. The Clinic established a day care centre, supported by the government, and this has prevented parents from abandoning their children or placing them in institutions. Day care is less expensive than institutional care and enables children to stay with their families. The centre takes a comprehensive approach, encompassing nutrition, emotional care and child development, and referrals for medical care. It also follows up children after they go on to school, to encourage teachers to be supportive.

Member of the development group for Building Blocks: Asia

The Indian NGO, Committed Communities Development Trust, runs a crisis intervention centre, which provides short-term residential care and support for HIV-positive women and their children, including promoting mother-child bonding and coping skills, while they look for longer-term alternatives in the community. There is also a drop-in centre where women can obtain psychosocial support.

Member of the development group for Building Blocks: Asia

In India, Project CHILD recognised that it was often grandparents who were taking responsibility for looking after children, and that they had their own care and support needs. Following consultation with older carers, the project established a support group to help them share experiences and problems, cope with their responsibilities and take better care of their grandchildren.

Member of the development group for Building Blocks: Asia

- Organise respite care and support during times of family crisis to prevent children being abandoned or left in institutions.
- Strengthen the capacity of families to meet their own livelihood needs.
- Provide emergency food and material support to extremely vulnerable households that are not able to meet their own needs.
- Mobilise organised monitoring and care by community members to particularly vulnerable children and their households.

- Ensure that carers receive psychological and emotional support. Possible actions include:
  - Encourage neighbours, relatives and other community members to provide moral support and social contact; for example, through informal visits, sharing meals, invitations to community activities.
  - Establish peer support groups; for example, older people’s associations.
  - Ensure the social integration of vulnerable children in social and cultural activities such as sports, youth groups and religious activities.
  - Train home-based care teams to provide psychological and emotional support during home visits.
  - Involve religious leaders and organisations in providing and mobilising support.
  - Build the capacity of groups of people living with HIV to help affected families.
  - Train government and NGO staff in counselling skills.
  - Facilitate access to family and individual counselling services, where possible.
CARE AND PSYCHOSOCIAL SUPPORT

The Vietnam Women’s Union, in partnership with Help Age International, has established clubs for older women who are caring for orphaned grandchildren. These clubs are a forum for mutual support, sharing experience and knowledge about HIV and AIDS, and care of the sick, as well a source of loans for income-generation activities. Club members visit each other and other affected families, and educate the community to reduce discrimination.

Economic and Social Commission for Asia and the Pacific. HIV/AIDS prevention, care and support: stories from the community, UN and AusAID

In Thailand, some groups of people living with HIV have expanded to include relatives and also those caring for affected children. Some groups are organising counselling sessions for people taking care of children, providing advice about childcare, promoting mutual support among caretakers, organising recreational activities for children who are being cared for by their grandparents, promoting better communication between caretakers and children, and encouraging the community to help grandparents whose ability to take care of children is limited.

Member of the development group for Building Blocks: Asia

In Cambodia, a network of volunteers led by a Buddhist monk carries out home visits to give psychosocial and emotional support to affected families and children. The Sangha Metta project in Thailand trains Buddhist monks and nuns to provide emotional support, comfort and counselling to affected children and families to help them cope with grief after death as well as ongoing problems. Support is provided through home visits, temples, which are used as counselling centres, and instruction in meditation to reduce emotional distress.

Temples are also an important source of support for older carers in Thailand, helping to reduce stigma, isolation and emotional stress and promoting peer support and interaction between families.

Member of the development group for Building Blocks: Asia

Principles & strategies

- Help carers to give children psychosocial and emotional support. Possible actions include:
  - Help carers to understand stages of childhood development in locally and culturally meaningful terms.
  - Offer training in parenting and communication skills.
  - Develop strategies to support and encourage the social integration of children who are withdrawn, depressed or aggressive.
  - Help children to deal with stigma, discrimination and rejection.
  - Encourage carers to make children feel special and loved; for example, mark children’s birthdays with cards, gifts or a special meal.

- Sensitise communities to children’s psychosocial and emotional needs.

- Sensitise communities and help them to mobilise their own efforts to reduce stigma and discrimination related to HIV and AIDS or orphans; for example, through drama, songs, Participatory Learning in Action (PLA) exercises or role-plays (see Building Blocks in Practice, in Useful resources list).

- Encourage communities to provide children with materials and opportunities for play and recreation, and to promote social integration. Possible actions include:
  - Offer training to community groups in play therapy.
  - Establish a community ‘toy bank’.
  - Build a play area or children’s corner.
  - Organise sports, games and picnics.
  - Involve children in planning and organising community cultural events and festivals.

- Use existing community structures and traditional methods of providing psychosocial and emotional support to children. Possible actions include:
  - Encourage religious organisations, village elders, traditional healers, community groups and women’s and youth groups to identify vulnerable children and involve them in community activities.
  - Sensitise health workers and teachers to the psychosocial and emotional needs of children.
  - Advocate with local government authorities and NGOs to address children’s psychosocial and emotional needs in their programmes.
In Cambodia, a project supported by CARE has organised a structured playgroup for all children in the community, with activities including dance, drama, quizzes, and competitions. – Member of the development group for Building Blocks: Asia

Also in Cambodia, the Lost Child Project works with street children and children who have been exploited and abused. The project uses play as a starting point, since many children have suffered great trauma and have given up playing. Using creative methods such as drama and stories helps children to express themselves and regain their sense of self. – Member of the development group for Building Blocks: Asia

The Phi Rak Nong Elders Love the Younger Project in Lampang province in Thailand provides psychological support for people affected by HIV and AIDS. Youth volunteers from the Group for Children promote social acceptance and try to reduce the isolation and worries of affected families through home visits. The project also encourages older people affected by HIV and AIDS to share their experience with younger members of the family. – Interview with Group for Children

**Support family and community models of care**

Children develop better socially and emotionally in a caring family environment. They also need to feel part of the community and to have opportunities for social interaction. Approaches to providing care for orphans should be socially and culturally acceptable and appropriate to the needs of children. Institutional care is rarely in the best interests of children and should be a last resort. Children in institutions are unlikely to get opportunities to learn life skills or to prepare for adult life in the community in the way they would in a family environment. The quality of care in some children’s homes is poor, and does not provide the love, attachment and individual attention that children need.
A study in Cambodia found that while adults thought that orphanages were a suitable solution for AIDS orphans, children in these orphanages disagreed, saying they would prefer to live in foster families or communities. – KHANA, 2000. Children affected by HIV/AIDS: appraisal of needs and resources in Cambodia

In Thailand, one strategy used to reduce the number of children living in institutions is to place children with foster families while preparations are made for them to return to their family or for adoption. Foster families are paid a stipend by government, and a social worker visits weekly to monitor the child’s care. – Save the Children UK, 2001. Research on available and potential support systems for children infected/affected by HIV/AIDS

Similarly, the Holt Sahathai Foundation in Bangkok has a programme where families provide temporary accommodation for children whose parents are unable to take care of them and for children during the process leading to permanent adoption. Most of these children have HIV-positive parents. The programme ensures that children receive individual attention and care. The temporary foster families, who are carefully selected, receive funds to cover the cost of food and expenses, information about HIV and child health care, family counselling and regular home visits from Foundation staff. – Member of the development group for Building Blocks: Asia

The Vieng Ping Children’s Home, also in Thailand, only places children in the Home as a last resort. Strategies to prevent institutionalisation include family support, reunifying children with their families, adoption or fostering within the extended family or community, and paying for fostering by non-relatives. – Member of the development group for Building Blocks: Asia

Baan Gerda is a village of six houses for children with HIV that operates under the Children’s Rights Foundation in Thailand. Each house has eight to ten children who are looked after by two carers. The aim is to ensure children have a good quality of life and as much happiness as their situation allows. – The sprout of hope, Lemon Publishing House, September 2003

Children who have been in residential care are often stigmatised and discriminated against at school and in wider society. (International Save the Children Alliance. A last resort: the growing concern about children in residential care)

**Strategies for action**

- Strengthen and support the capacity of AIDS-affected households, surviving parents or extended family members to provide care for their children.
- Support older children to care for younger siblings in their family home.
- Arrange informal or formal foster care or local adoption, ensuring in all cases that this is monitored and supported.
- Establish community-based small group homes for adolescents or sibling groups.
- Enable residential institutions to evolve into outreach programmes that provide day care activities and support and otherwise enable vulnerable households to care for their own children.
- Encourage communities to establish care centres for affected and vulnerable children.
- Ensure that children who live in institutions receive care that addresses their psychosocial and emotional needs and have opportunities to integrate with society. Possible actions include:
  - Select well-qualified, trained staff with an understanding of childhood development and a commitment to children.
  - Encourage the community to involve children from institutions in community events and activities.
Principles & strategies

Help children to help themselves

Programmes should strengthen the capacity of children to develop self-reliance and learn how to care for themselves. This means listening to children and involving them in decisions. Encouraging children to participate in making decisions helps them to learn about cooperation, mutual understanding and social responsibility. Strengthening children’s coping capacity also means teaching them life skills and providing them with practical as well as psychosocial and emotional support.

Strategies for action

- Provide children with information, counselling and skills, including communication and negotiation skills. Possible actions include:
  - Establish child-friendly information centres and develop appropriate educational materials.
  - Provide referrals to counsellors trained to help children, where available.
  - Organise skills training for children in areas they feel are important.
  - Identify adults in the community to act as mentors.

- Promote peer support and counselling. Possible actions include:
  - Involve children in planning peer support activities.
  - Identify older children who can provide support to younger children, and train them in counselling skills, especially bereavement counselling.
  - Provide opportunities for children to develop strategies to deal with stigma and discrimination.
  - Establish support groups for children.

The organisation Friends Mith Samlanh works with street children in Cambodia, and one of its objectives is to reintegrate children into schools, families and society. Friends provides counselling and support to encourage reconciliation between children and their families. – Member of the development group for Building Blocks: Asia

In India, the 2001 Juvenile Justice (Care and Protection of Children) Act makes provision for adoption as a way of rehabilitating children who are orphaned, abandoned, neglected and abused. The new Act removes previous limitations on adoption and makes legal adoption by wider range of persons possible. – Lawyers’ Collective HIV/AIDS Unit, Positive dialogue, Issue 9, May 2001

The Community Child Care Centre Network Project in Thailand runs a day care centre for pre-school children, including those whose parents have died or have gone to work elsewhere and are being cared for by grandparents. Community volunteers take it in turns to care for the children. – Member of the development group for Building Blocks: Asia

In 1997, the Suthasinee Noi-in Foundation for Children and Youth in Yasothorn Province set up a home for children affected by HIV and AIDS whose families cannot care for them, and children with drug abuse problems. There is no differentiation between children with and without HIV. Even though the home has almost 50 children, it is organised so that the children can live as if they were in a normal family. Each child has a personal space, older children help to care for the young ones, and children go to school in the community. – Member of the development group for Building Blocks: Asia
Principles & strategies

A 10-year-old girl with HIV in Thailand said: “I want other people to understand people with AIDS. I attend the meetings at the hospital with my mother. I think that I have more understanding. My friends always ask me. Now, my friends understand more about AIDS because I tell them it is not easy to spread HIV. I want to be the one who speaks to others to help them understand AIDS and I want everybody in this country to understand AIDS.”

AIDSNet newsletter, Vol.4, April–September 2003

The Thai Youth AIDS Programme organises summer camps for affected and infected children. These camps give children the chance to relax and get away from their responsibilities, learn new skills, develop new friendships and build peer support networks, and express themselves in a supportive environment.

Member of the development group for Building Blocks: Asia

In Thailand, the AIDS Access Foundation, AIDSNet Foundation, MSF-Belgium and We Understand Group collaborated to set up a children’s art camp for children with HIV aged seven to fourteen years. The children had a chance to learn about art and how to communicate using painting and storytelling. They had fun being creative and also learned to live together and to provide each other with mutual support. Some paintings were bought by members of the public, which made the children very proud; others were displayed at the International AIDS Conference in Bangkok in 2004. Some of the children were very talented – one is now receiving support to study at an art institution. The stories, with titles such as “I’m not a burden”, “I’m fine”, “80 days in a paediatric ward”, “My favourite doctor”, will be used to help other children.

Member of the development group for Building Blocks: Asia

- Use creative ways to help children express themselves and their feelings. Possible actions include:
  - Encourage children to draw their situation or to write poems, stories or letters to deceased parents or absent siblings.
  - Organise role-play and drama to act out situations.
  - Use puppets or models to help children tell their stories.

- Provide children with opportunities to get away from their family and caring responsibilities. Possible actions include:
  - Establish community nurseries and day care for younger siblings.
  - Organise summer camps.
References


Economic and Social Commission for Asia and the Pacific, UN and AusAID, HIV/AIDS prevention, care and support: stories from the community.

International Save the Children Alliance. A last resort: the growing concern about children in residential care.


Orchid Clinic, Chiang Mai (personal communication).

Save the Children UK, 2001. Research on available and potential support systems for children infected/affected by HIV/AIDS.
Useful resources


Investing in our future: psychosocial support for children affected by HIV/AIDS, UNAIDS.

Psychosocial support for children affected by AIDS: practical responses from Zimbabwe and Tanzania.

Building blocks: Africa-wide briefing notes. Psychosocial support.

Building blocks in practice: participatory tools to improve the development of care and support for orphans and vulnerable children.

Guidelines for counselling children who are infected with HIV or who are affected by HIV and AIDS.

Save the children and NACWOLA, 2004. 
Breaking the silence: memory books and succession planning: the experience of NACWOLA and Save the Children UK in Uganda.


Community-based care for separated children, Save the Children Sweden.
Useful resources

Caring for caregivers: managing stress in those who care for people with HIV and AIDS, UNAIDS Best Practice Collection.

Children in distress: a best practice response to children affected by HIV/AIDS.

A family is for a lifetime. Part I: A discussion of the need for family care for children impacted by HIV/AIDS. Part II: An annotated bibliography.

Useful websites

www.icdp.info
International Child Development Programmes

www.repssi.org
Regional Psychosocial Support Initiative (REPSSI)

www.child-to-child.org
The Child-to-Child website has many useful resources on children’s participation in health promotion.