

Supporting community action on AIDS in developing countries



Building Blocks: Asia

Briefing notes for communities working with orphans and vulnerable children

Social inclusion

Acknowledgements

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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Members of the development group for Building Blocks: Asia briefing notes

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Background

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 AIDS¹ 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:

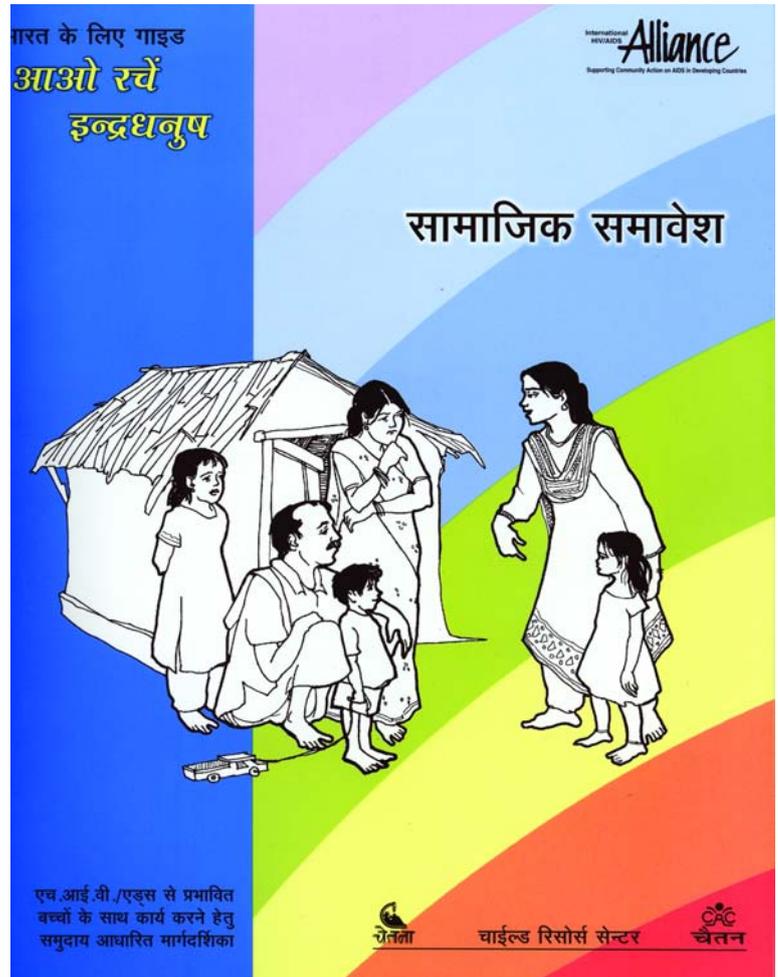
- Health and nutrition
- Livelihoods and economic strengthening
- Education and training
- Care and psychosocial support
- Social inclusion
- Protection

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’.

¹The 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.

Introduction

- Stigma is an attribute that singles out an individual or a group of individuals as different. They are regarded in a negative and judgmental way because they possess this attribute. People with or affected by HIV are stigmatised because HIV/AIDS is associated with taboo issues such as sex, death and blood, and behaviours such as promiscuity, sex work, drug use and homosexuality.
- Discrimination is one of the ways that stigma is shown. It occurs when a person or group of people is treated unfairly or unjustly on the basis of belonging or being perceived to belong to a particular group. Stigmatised people are often discriminated against in laws, policies and social relations.

Stigma and discrimination can affect children both with and without HIV. Children who do not have HIV may still be stigmatised because a parent has HIV or has died from AIDS. Stigma and discrimination are the result of fear and ignorance, and are characterised by rejection, hostility, isolation and violations of rights to health care, education and employment.

Stigma and discrimination increase the impact of HIV/AIDS on children. People who think that orphans also have HIV or that their families have brought shame on the community often discriminate against them, denying them social, economic, emotional and educational support. HIV/AIDS worsens the stigmatisation of children of sex workers or migrants, street children, children in detention and those using drugs. Socially excluded children are more at risk of HIV infection because they lack information and emotional support, and are vulnerable to sexual exploitation and abuse.



A community worker encourages the extended family to care for their niece who has been orphaned

Stigma may prevent people from disclosing their HIV status and seeking help from support and care services. Affected children and their carers are often unaware of their rights and of laws to protect them from discrimination. Sometimes they are aware of their rights but are unable to demand better treatment, have no one to advocate for them and no access to legal advice.

This guide is divided into two sections:

Issues

This section considers how HIV/AIDS-related stigma and discrimination impacts on children and why programmes supporting children affected by HIV/AIDS need to address stigma and discrimination.

Introduction

Issues include:

- Discrimination at home
- Discrimination by the community
- Discrimination at school
- Discrimination by health services.

Principles and strategies

This section outlines the key principles of programming to tackle stigma and discrimination and promote social inclusion of children affected by HIV/AIDS, and describes possible ways of taking action to support children affected by HIV/AIDS. Case study examples are included to illustrate practical application of some of these principles and strategies.

Principle 1

Protect the rights of children and affected families

Principle 2

Treat all children equally

Principle 3

Promote positive attitudes and community action

Principle 4

Strengthen the capacity of children and affected families to cope with stigma and discrimination

Issues

In Thailand, a 15-year-old boy whose parents had died had to leave his three-year-old HIV-positive brother with his grandmother while he went to work. However, she did not want to take care of him because she was concerned about HIV transmission. Some days she left the boy alone in the house. The community childcare centre also refused to accept the young boy because the parents of other children did not agree.

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Despite widespread acceptance of people living with HIV/AIDS in northern Thailand, there are still examples of discrimination. In one case, other parents demanded that the three-year-old child of HIV-positive parents be tested before enrolment in a child development centre, suggesting that the child should not be enrolled if the test result was positive. This would mean the child would miss out on learning until the age of six years, when he would be able to enrol at elementary school.

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In one community in Nepal, an eight-year-old boy whose father had died of AIDS faced high levels of community discrimination, including not being able to go to school or play with other children. A 72-year-old man in Thailand described what happened to his HIV-positive granddaughter, whose parents had both died of AIDS: "At the kindergarten in the village her friends would still play with her, but their parents pulled their children away and told us to stay away. People who used to know and greet us turned their faces away and wouldn't come near us any more".

Help Age International, 2002. Coping mechanisms of poor older men and women affected by HIV/AIDS, International NGO Forum on Ageing, 6 April

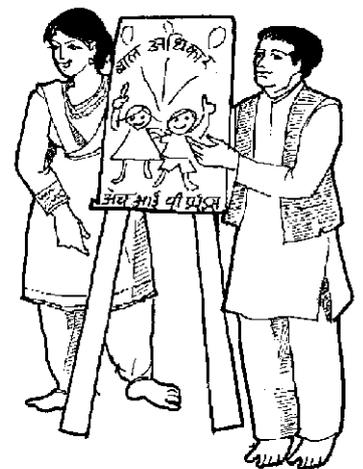
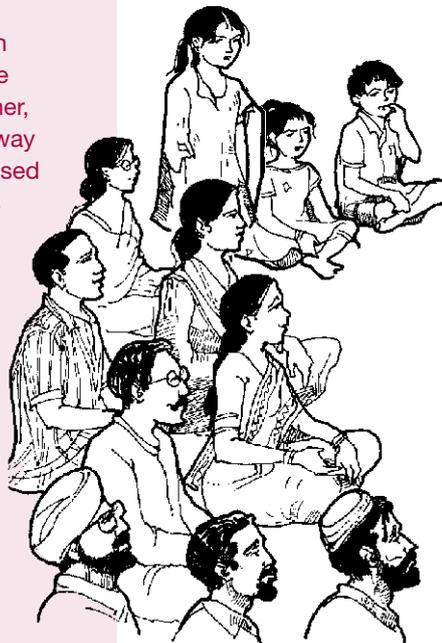
Children with HIV and children affected by HIV/AIDS may be stigmatised and discriminated against in different places and in different ways. Children may experience:

Discrimination at home

HIV-positive women are often highly stigmatised and their children suffer discrimination as a result. In some places, female children with HIV are more likely to be rejected by relatives. Children living with adoptive or foster parents or with relatives may be treated less well than other children in the household. They may receive less food or attention, or may be expected to perform household chores or to work rather than being able to go to school.

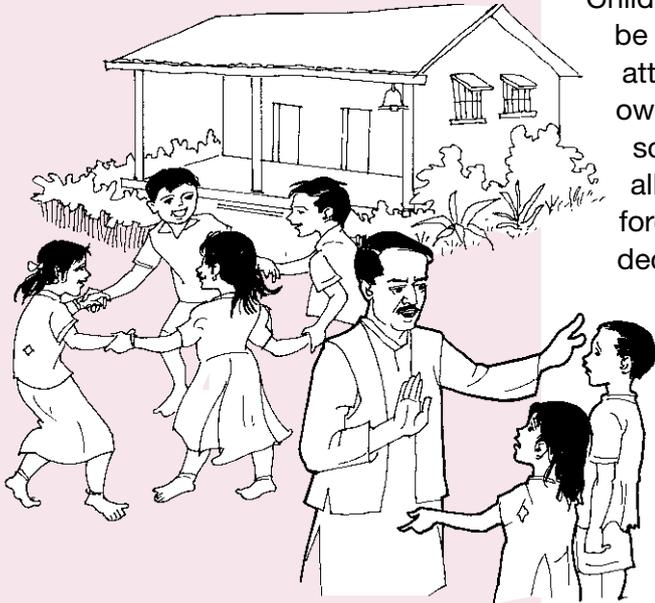
Discrimination by the community

Children in households affected by HIV/AIDS suffer when their families are socially ostracised by neighbours and relatives. Often it is assumed that the children of HIV-positive parents have HIV infection themselves. Children from affected families or with HIV may feel lonely and isolated, either because other children will not play with them or because they choose to stay away from other children. Sometimes other parents refuse to allow their children to eat or play with children from families affected by HIV/AIDS. Communities may also discriminate against children because of the behaviour of their parents. For example, the children of sex workers or drug users are often stigmatised and socially excluded.



Health workers should provide care and support to all

Issues



Children may be denied access to school due to stigma and discrimination

A grandmother in Chiang Rai, Thailand, was caring for her 18-month-old grandson after her son died. She took the boy for a blood test, which confirmed that he was HIV positive. A nurse said that her grandson could not be cured and would probably only live for a short time. The grandmother was upset and decided never to take the child back to that hospital. After participating in counselling sessions and making contact with the AIDS Access foundation, she was able to help her grandson get treatment. He is now 12 years old.

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Discrimination at school

Children with HIV or who are from affected households may be excluded from school because of the discriminatory attitudes of head teachers and teachers. Sometimes their own parents decide it is not worthwhile sending them to school. Sometimes parents of other children refuse to allow infected or affected children to enrol at school or force them to leave school. Children themselves may decide they cannot face going to school because of rejection or teasing by other children, because teachers treat them differently to other children, or because they cannot afford uniforms or books like other children.

Discrimination by health services

Health workers sometimes discriminate against children with HIV, separating them from other children. They may provide these children with poor quality care and treatment because they are afraid of becoming infected. They may consider it a waste of resources, or the carers themselves may be poor or marginalised. Failure to protect the confidentiality of HIV-positive adults and children contributes to stigma and discrimination. Sometimes the parents themselves discriminate against children with HIV, deciding it is not worthwhile taking them for health care.

The impact of stigma and discrimination on children includes:

- Shorter lifespan for children with HIV because of neglect or lack of health care.
- Psychological and emotional distress, withdrawal and depression, and feelings of fear, shame and rejection.
- Social isolation, including separation from the community and exclusion from family gatherings.
- Lack of adult support, understanding and care.
- Loneliness, lack of friends and of opportunities to play.
- Difficult behaviour and limited social skills.
- Poor school attendance and performance, dropping out of school and loss of educational opportunities.
- Physical neglect resulting in poor health and nutrition.
- Low social value, verbal and physical abuse.
- Risk of engaging in behaviours such as use of drugs and alcohol, violence and crime, prostitution.

UN CONVENTION ON THE RIGHTS OF THE CHILD STATES THAT:

- Children should not suffer discrimination in leisure, sport, recreation or cultural activities because of their HIV status or that of family members.
- Children's rights to informed consent, confidentiality and privacy with regard to their HIV status should be respected.

In Uganda, a children's statute provides a comprehensive legal and institutional framework for the protection of children and addresses the rights of children as stipulated in the UN Convention. This was translated into local languages, making it easier to implement locally. The statute makes it clear that children's rights are obligatory, not optional, for all children, and that community officials must fulfil their obligations to all children, including vulnerable children.
– *Member of the development group for Building Blocks: Asia*

In Thailand, the AIDS Access Foundation worked with the Multisectoral Working Group on Rights of Children Affected by HIV/AIDS, with support from UNICEF, to run a media campaign. The campaign, which aimed to promote positive social attitudes towards affected children and increase understanding of their rights, followed media training and provision of facts about children affected by HIV/AIDS to the media.

Member of the development group for Building Blocks: Asia

In Tanzania, a centre for children's rights develops policies and programmes with the full participation of children. It also produces a child rights magazine written by children.

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Police can be supportive to children who are vulnerable

**1 Protect the rights of children and affected families**

Tackling stigma and discrimination requires a supportive legal environment, with laws and policies that support the rights of children and make stigma and discrimination illegal. It also requires that affected families and children are aware of their legal rights and can access legal support.

Strategies for action

- Advocate for legal protection against discrimination, and for laws to protect the rights of children if existing laws do not provide this.
- Improve community awareness about the rights of children – for example, to health care and education – and of the community's responsibility to protect children's rights.
- Promote rights-based approaches that include children's participation in making decisions, planning, implementation and advocacy.
- Make sure that health services and NGOs have systems to protect the confidentiality of children and families affected by HIV/AIDS, including at community level.
- Promote awareness of legal rights and access to legal support. Possible actions include:
 - Promote networking between community workers and organisations and lawyers working on human rights issues.
 - Establish links with centres providing legal aid and advice.
 - Conduct community education campaigns to promote awareness of sources of legal support.
 - Ensure that children and their carers are aware of their rights through radio campaigns, drama, songs and educational sessions in schools.
- Sensitise local government officials – for example, health workers, teachers and police – to children's rights and issues related to stigma and discrimination.

Principles & Strategies

The Cambodian NGO NAPA organises cultural events such as drama in the community and in schools, with young children taking the lead, to reduce stigma and discrimination. For example, a drama on International Women's Day focused on the topic "HIV/AIDS is our problem".

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In Thailand, a group of young people started the Puppet Show Youth Group, touring villages to communicate about HIV/AIDS and promote positive attitudes towards people living with HIV/AIDS.

The group has subsequently expanded its activities to include plays, exhibitions, broadcasting, sports and competitions to maintain people's interest. An important part of the process is talking to communities to find out what they know and think, and using the activities themselves to bring communities together to solve their problems.

UNDP, 2001. Sang Fan Wan Mai Youth Group. Tiny steps by youth to battle the AIDS crisis, UNDP South East Asia HIV and Development Project

Also in Thailand, the Network of People Living with HIV/AIDS has tackled misconceptions by conducting activities using word cards about the risk of HIV transmission of different behaviours. Another activity to change people's attitudes about AIDS includes providing information about HIV infection, opportunistic infections and their treatment, as well as antiretroviral therapy".

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Village rallies along traditional pilgrimage routes have been used in India to promote community awareness and address fears and myths about HIV/AIDS. Children, young people and teachers sing songs, use puppets and hold discussions with communities as they go from village to village on their way to and from the pilgrimage site.

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2 Treat all children equally

All children should be treated equally regardless of their HIV status or that of family members. In places where many families live in poverty, targeting assistance to children affected by HIV/AIDS can cause resentment and increase stigmatisation by singling these children out.

Strategies for action

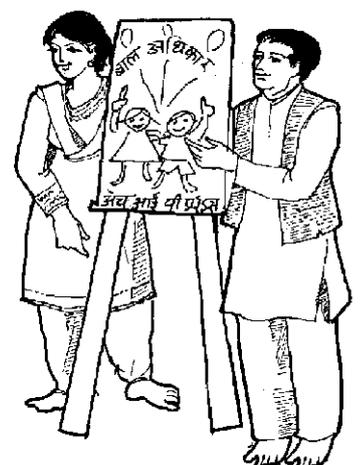
- Target support to all poor and vulnerable children and families.
- Ensure non-discriminatory access to education and to health care.
- Avoid testing children from affected families for HIV.

3 Promote positive attitudes and community action

A supportive community environment is essential to tackle stigma and discrimination. This means educating communities, encouraging influential community members to play an effective role and providing them with the necessary training.

Strategies for action

- Educate communities about HIV/AIDS to reduce fear and ignorance, and tackle myths and misconceptions about HIV transmission.



Educate communities about HIV and AIDS

Principles & Strategies

In Thailand, groups of people living with HIV/AIDS are providing care to children whose parents have died from AIDS, including children being looked after by grandparents. Home visits provide motivation and support, and information about welfare services available. These activities have helped to promote positive community attitudes towards people living with HIV/AIDS, encouraging neighbours also to provide practical and financial assistance for affected children.

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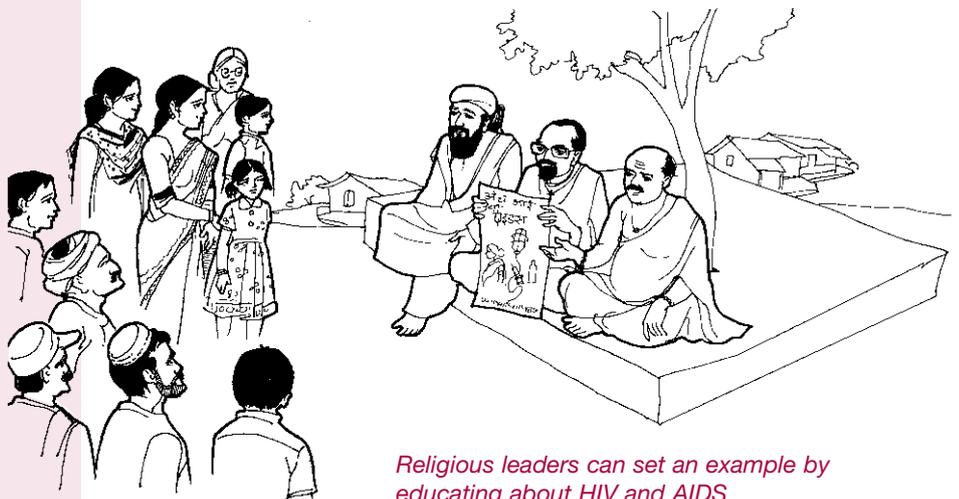
A Save the Children UK project in Nepal found that using community volunteers resulted in increased acceptance of widows and children who have lost husbands and fathers to HIV/AIDS.

Save the Children UK (2001) Mobilising marginalised communities in Nepal. Young people and HIV/AIDS: responding to the new Asian crisis

NGOs in Uganda have encouraged influential members of the community to become involved in helping affected families. This not only encourages others to provide support, it also helps to reduce stigma and discrimination.

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- Promote community-based care and support programmes, which have been shown to reduce stigma and discrimination.
- Encourage community leaders, religious organisations and village elders to tackle stigma and discrimination, and to advocate for community support for children with HIV and children affected by HIV/AIDS. Possible actions include:
 - Mobilise monks, for whom people in Buddhist societies have high respect, to preach compassion and care for people living with and children affected by HIV/AIDS.
 - Mobilise community leaders to challenge stigmatising and discriminatory attitudes and to set an example to others by showing compassion and care for affected families.
 - Identify community volunteers to advocate for children in schools, health centres and other institutions.
- Train and support people living with HIV/AIDS as community educators. This can help to normalise HIV and reduce fear, stigma and discrimination by showing that anyone can get HIV and that people can live positively with HIV.
- Promote integration between children affected by HIV/AIDS and other children. Possible actions include:
 - Involve infected and affected children in community festivals, events and activities, and public meetings.
 - Organise events that bring together affected children with other children – for example, community entertainment using drama and dance – to promote social interaction.
 - Establish community children's clubs.



Religious leaders can set an example by educating about HIV and AIDS

Principles & Strategies

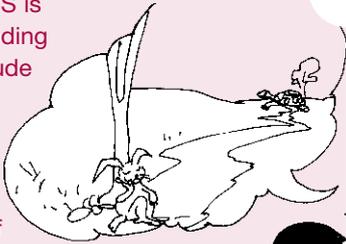
The Thai NGO, ACCESS, implemented a project called My Positive Life to help normalise HIV/AIDS. People living with HIV/AIDS who were willing to be open about their status and to share their experience were involved in organising a photographic exhibition about their lives and telling their stories. The exhibition is shown in schools and communities, and other awareness-raising activities are conducted during the exhibition. ACCESS is considering expanding the project to include the experience of children affected by HIV/AIDS, but this will require careful handling of issues such as confidentiality and informed consent.

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Also in Thailand, groups of people living with HIV/AIDS have been working with other civil society organisations to organise community meetings to improve understanding of HIV/AIDS, changes attitudes towards people living with HIV/AIDS and raise awareness of the problems of affected children. Activities have been conducted to promote the idea that children with and affected by HIV can live normally in the community.

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In Thailand, teachers in one community school provided support for a youth group to carry out “taking care of younger brothers and sisters” activities at weekends. To start with, only orphans were included, but after some time any child from the community who was interested could join in. Young people taking the roles of older brothers and sisters plan and lead activities, which include learning about nature, preparing food, taking care of yourself and making things. Sometimes other members of the community are brought in to teach children particular skills. These activities have helped children to develop meaningful relationships with



Telling a story at a children's club

- Support interventions in schools, including training for teachers and school principals, to promote tolerance and care for people living with HIV/AIDS and to reduce stigma and discrimination towards children from affected families.
- Discuss the impact of stigma and discrimination on children with health workers and provide training in non-discriminatory approaches to care and treatment.
- Encourage and support local companies to establish workplace programmes to reduce stigma and discrimination.

- Work with the media to spread accurate information about HIV/AIDS and the situation of affected children, to develop positive messages about people living with HIV/AIDS, and to stop media reporting that promotes fear and reinforces stigma and discrimination.

4 Strengthen the capacity of children and affected families to cope with stigma and discrimination

Children and families need the skills and resources to challenge stigma and discrimination and to deal with their experience of stigma and discrimination.

other children. One boy, for example, who had lost his parents and was living with his grandmother, developed a brother-sister relationship with a girl living with her sick mother. The activities have also encouraged adults to provide more support for children.

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Also in Thailand, young people in a district of Chiang Rai Province have formed a Youth Long Drum band, members of which include children affected by HIV/AIDS and other children. In another district, the local administration organises activities and provides assistance to all children experiencing difficulties, not just those affected by HIV/AIDS, based on the principle of “no discrimination”.

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In Cambodia, Children in Distress runs playgroups that bring together children affected by HIV/AIDS and other children, and uses art and puppets to educate children about stigma and discrimination.

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Also in Cambodia, CARE's Children in Distress project involves young people providing support to other young people who work as volunteers in villages to form groups of vulnerable children and other children in the communities. Together with their families, they organise community plays using puppets, stories and painting. The plays cover issues such as HIV/AIDS, child rights, discrimination, life skills, nutrition and hygiene, to help communities to improve children's health, reduce discrimination and increase support for children.

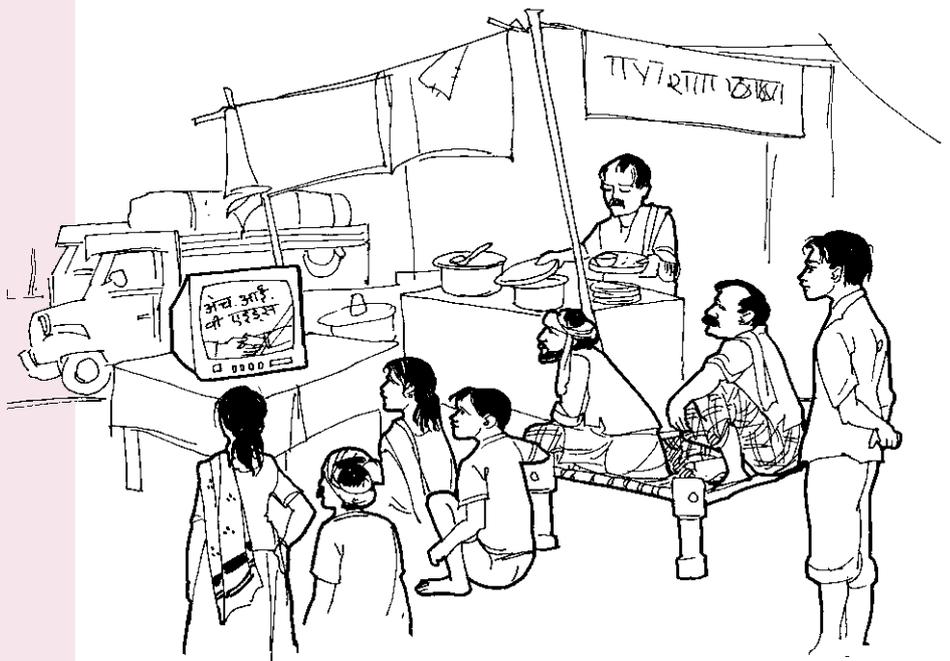
Member of the development group for Building Blocks: Asia

In India, women's groups organise a fun day with activities for children during the festival of Diwali, bringing children with and without HIV together for games, competitions, entertainment, music and dance.

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Strategies for action

- Provide counselling for children affected by HIV/AIDS to help them develop strategies for dealing with stigma and discrimination. Possible actions include:
 - Train traditional healers and elders to provide counselling for children.
 - Train carers such as grandparents to provide support to children who experience stigma and discrimination.
 - Integrate counselling into home-based care programmes.
 - Train older children as peer counsellors.
 - Sensitise teachers and health workers and train them in counselling skills.
- Establish self-help groups for children and families affected by HIV/AIDS, to provide mutual support, share experiences and problems, lobby for rights and non-discrimination, and give children a voice.
- Promote child participation and child-centred approaches, to empower children.



A TV show on HIV/AIDS being shown at a truck stop

Principles & Strategies

MSF-Belgium in Thailand has supported monthly meetings for children receiving antiretroviral therapy and their caretakers. In addition, the We Understand Group, established by a coalition of organisations supporting positive children, takes children and their carers for family camping activities.

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"I want to tell the adults to realise the feelings of people living with AIDS. I want to educate the teachers to have the psychology to understand the children. Although we are sick, we don't give any trouble to others. Adults, please listen to the young. When adults are angry, they should control their mood and be fair to children. I also would like the price of medicines to be cheaper. The Prime Minister should emphasize the AIDS issue and help organisations which work on AIDS."

AIDSNet Newsletter, Vol. 4, April-September 2003

The AIDS Access Foundation, AIDSNet Foundation and MSF-Belgium have developed a curriculum and conduct training on child development, which includes the importance of listening to children and giving them the opportunity to take part in making decisions about their life and future.

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The CHETNA project, Children in Charge, promotes child-centred approaches, which view each child as an individual and help children to develop the skills to make decisions about their lives.

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Children involved in planning a project

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UNDP, 2001.

Sang Fan Wan Mai Youth Group. Tiny steps by youth to battle the AIDS crisis, UNDP South East Asia HIV and Development Project.

Useful resources

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Strode, A. and Barrett-Grant, K., 2001.

The role of stigma and discrimination in increasing the vulnerability of children and youth with and affected by HIV/AIDS, Save the Children UK.

UNAIDS, 1999.

Best practice case Study: reducing girls' vulnerability to HIV/AIDS. The Thai approach.

UNICEF, 2004.

A framework for the protection, care and Support of orphans and vulnerable children living in a world with HIV/AIDS.

United Nations.

UN Convention on the Rights of the Child.

Useful resources

Useful websites

www.alp.org.za

The South African AIDS Law project website has a huge range of information about a wide range of legal issues.

www.crin.org

Child Rights Information Network website.

www.child-to-child.org

The Child-to-Child website has many useful resources on children's participation in health promotion.

Notes

To order Alliance publications, please email publications@aid alliance.org or write to:

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