

Building Blocks: Africa-wide briefing notes

Social inclusion



Resources for communities
working with orphans and
vulnerable children

Acknowledgements

What is the International HIV/AIDS Alliance?

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

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Background

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

- Education
- Health and nutrition
- Psychosocial support
- Social inclusion
- Economic strengthening



These briefing notes have been developed through a highly participatory process, guided by an international advisory board. During their development in English, French and Portuguese, they have been reviewed by more than 80 people across Africa. These people have read and commented on the papers, and have added examples and case studies from their own countries. One part of the review took place at a meeting in Uganda, attended by 20 people from Uganda, Malawi, Zambia, Zimbabwe, Kenya, Burkina Faso, Senegal, Mali, Mozambique and Angola. The people who attended this meeting then took the papers back to their colleagues in their home countries, who undertook a further process of review. Examples and case studies from this process have been noted in the text as coming from a "Member of the Building Blocks Development Group".

These briefing notes are divided into four sections:

INTRODUCTION

An overview that explains why programmes supporting orphans and vulnerable children need to address stigma and discrimination.

ISSUES

An outline of how HIV/AIDS-related stigma and discrimination affect children and why orphans and affected children may be more vulnerable to HIV infection.

PRINCIPLES

Guidelines for programmes aimed at tackling stigma and discrimination and promoting social inclusion of orphans and vulnerable children.

STRATEGIES

Possible ways of taking action to strengthen support for orphans and vulnerable children.

There is a growing evidence base for strategies that are effective in supporting orphans and vulnerable children. As the evidence base is not yet comprehensive, strategies in the briefing notes include both those that have been implemented together with suggestions for strategies based on the experience of people working with orphans and vulnerable children. As such, strategies are not given in any order of priority or relative effectiveness.

Introduction

DEFINING STIGMA AND DISCRIMINATION

- Stigma is an attribute that singles out an individual or a specific group of individuals as different. They are regarded in a negative and judgmental way because they possess this attribute.
- Discrimination is one of the ways in which stigma is shown. It occurs when a person or group of people is treated unfairly or unjustly on the basis of their belonging, or being perceived to belong, to a particular group. Stigmatised people are often discriminated against in laws, policies and social relations.

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HIV/AIDS is associated with taboo subjects such as sex, death and blood, and with behaviours such as commercial sex, drug use and homosexuality. This leads many people to stigmatise and discriminate against anyone with HIV or affected by HIV. Since AIDS was first recognised as a fatal disease, it has caused widespread fear, ignorance and denial, which have resulted in discrimination, abuse and violence not only against people with HIV but also their families.

Denial when a parent is dying and the sense of shame linked to an AIDS death is particularly harmful for children. They are especially sensitive to the damaging psychological effects of stigma. Stigma and discrimination can affect children with or without HIV in many ways. Even if they do not have HIV themselves, children may be stigmatised because a parent has HIV or has died from AIDS. Stigmatisation and discrimination create and reinforce the social isolation of those affected by the epidemic, including children. They engender rejection, hostility, isolation and human rights violations; for example, reduced access to health care, education and employment.

Stigma and discrimination can affect children if one or both parents has HIV or has died from AIDS. Sometimes children have to cope with hearing their sick and dying parents insulted by neighbours and relatives. Community members who fear that the orphans may also have HIV or think their families have shamed the community often discriminate against the children and deny them social, economic, emotional and educational support. This intensifies the harmful effects of HIV/AIDS on children.

HIV/AIDS also worsens the stigmatisation of already marginalised children; for example, the children of sex workers, street children, refugee children, children in detention and children using drugs. Some of these children, however, may be most at risk of HIV infection because of problems such as lack of information and emotional support, powerlessness and potential vulnerability to sexual exploitation and abuse.

Stigma also prevents people with HIV disclosing their status and getting access to available support and care services, as well as to information about HIV prevention that would help people (with or without HIV) to adopt safer behaviour. Stigma can suggest to people from discriminated groups that they are social outcasts and deserve to be punished.

Orphans, vulnerable children and their caregivers are often unaware of their rights and the laws intended to protect them from discrimination. Sometimes they are aware of their rights but are not able to demand better treatment from their caregivers or community. They may have no one to advocate on their behalf and lack access to legal advice.

Issues

While most people do their best to support and care for children affected by HIV, orphans and vulnerable children may be stigmatised and discriminated against in many different places and ways.

1 HOME AND FAMILY

Discrimination may take many forms at the household level. The majority of foster parents do their best to care for orphans in the same way as their own children. However, some foster parents may provide basic sustenance and shelter to some orphans, but favouritism and discrimination may determine how the needs of these orphans are met. Sometimes only the biological children receive clothing and the larger portions of food, while foster children have to work harder and for longer hours than the foster parents' own children.

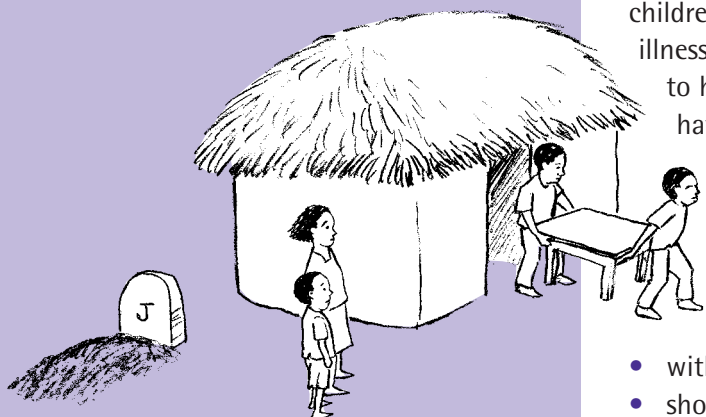
Sometimes the parents of children with HIV or affected by HIV may stigmatise and discriminate against their own children. For instance, in Uganda, widows have been reported to verbally abuse their own children because their fathers have died of AIDS. In the event of illness, some parents have been reluctant to take children with HIV to hospital, or to enrol them in school. In some cases, parents have diverted economic or educational support provided from external sources for a sick child to children who are considered healthy. This is because investing in children with HIV may be considered a waste of resources.

Stigma and discrimination at home can result in:

- withdrawal and depression of children with HIV
- shortened life span or increased illnesses in children affected by HIV because of neglect by caregivers
- rejection of orphans by extended families, leading to child-headed households in the community. Caregivers may feel that they are difficult children and a burden
- rejection by families, leading to exclusion from family gatherings and other social activities
- property grabbing by relatives when parents of vulnerable children die because the children are considered of no importance
- irregular school attendance and eventual drop-out
- verbal abuse (for example, regular reminders from relatives that they have been orphaned due to AIDS) and physical or sexual abuse.

2 SCHOOL

Children are especially vulnerable to stigma and discrimination at school, where social acceptance is so important to them. In some cases, children are teased or verbally abused by teachers and peers.



Relatives may grab property when parents die

Issues

In Uganda, despite being sickly, a child was forced to go to the garden to till the land and do other chores, while the other children in the home were left to play and attend school.

"Some of my happiest moments are when I'm playing in school, when I get a new dress, when I'm shown love by my uncle, such as when I do something wrong and he doesn't beat me. Some of the saddest moments are when my uncle shouts at me. I think so much about my mum and dad . . . I wish they had never died." Atoki, aged nine, Mbarara, Uganda

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In Uganda, a child with HIV who had a skin infection suffered discrimination at school by teachers and pupils. She was excluded from sporting activities and eventually refused to go to school. When the parents learnt of this, she changed schools.

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An orphan may not receive the same care and attention as another child

They can be described as children who could infect others, or who are not worth associating with as they are "walking corpses". Sometimes these children are excluded as they cannot pay their school fees promptly or buy the school uniform, even though they are often extremely poor and struggling to survive with little or no support.

Stigma and discrimination against a child can lead to:

- withdrawal and profound depression
- failure to concentrate in class and so poor performance
- a fear of infecting others
- a reluctance to go to school and irregular attendance at school
- eventual school drop-out
- the development of inappropriate or anti-social behaviour to get attention or get even with their oppressors.

See the Briefing Notes on education for more information.

3 HEALTHCARE FACILITIES

When seeking health care, orphans and vulnerable children may be stigmatised and discriminated against by health workers for a number of reasons:

- Sick children made vulnerable by HIV/AIDS may be considered of little or no importance, and that there is no need to waste scarce medical resources on them.
- Health workers sometimes fear being infected while treating affected children, so they treat them last or less thoroughly than other children.
- Caregivers of orphans and vulnerable children are often very poor and receive less attention from health workers. They are often treated badly, shouted at and handled without proper care.
- In order to protect them from further opportunistic infections, children with AIDS may be isolated from others in labelled wards or clinics; for example, AIDS clinics. While the intentions are good, this separation is stigmatising for children and their caregivers.

Stigma and discrimination by health services can result in:

- reduced or no access to health care. The negative or moralising attitudes of health workers can deter children and their caregivers from using the health services
- poorer quality care because of fear of HIV transmission prolonged illnesses and avoidable deaths of orphans and vulnerable children. Children will often be brought to a health centre when it is too late for anything to be done

Issues

A sick, six-year-old girl, whose parents had both died of AIDS, was admitted to hospital under her aunt's care. Knowing this background, the health workers advised the caregiver repeatedly that as there was no hope, it would be better if they returned home.

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"I need someone to look after me. I have problems getting enough to eat. I am always falling sick and have no money to go for treatment." Akello, aged nine, Tororo, Uganda.

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"Since father died, our neighbours mistreat me. They chase me away at meal times." A child affected by HIV in Uganda.

UNAIDS (2001)

"Our neighbours do not want us to join them . . . because we are identified as children whose parents died of HIV/AIDS, and there is a rumour that we are infected with the virus. People talk about us negatively and we feel ashamed."

A child affected by HIV in Uganda.

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"Since my parents died I have been treated like a slave. I wake up early to do the household chores while my aunt's children are sleeping. I do not have time to study."

UNAIDS (2001)

- isolation and separation from other patients, although sometimes this may be necessary to protect the patient from other opportunistic infections
- failure to respect confidentiality about HIV status
- an orphan not receiving the same health care and attention as a child who has not lost a parent to HIV "because she will soon die anyway".

4

COMMUNITY AND SOCIETY

Stigma and discrimination occur in the community in many ways, including:

- Rejection by friends and other children. Neighbours may not allow their children to play or eat with children who have HIV for fear of possible transmission. Children with HIV may be called names in the community or treated disdainfully.
- Lack of practical support because of fears of contracting HIV and from the belief that their efforts will be pointless. Often a household caring for someone with HIV will require home-based care and support from the community. This might mean help with household chores, agricultural work and/or nursing the sick. However, community members can be reluctant to nurse the sick for fear of infection.
- Social isolation. Households nursing people with HIV are less likely to be involved in ongoing cultural and traditional ceremonies and festivities. They are rarely included in the planning and implementation of these events. Consequently, when development programmes are being implemented these people are often invisible in the targeting and planning.

5

HOW STIGMA AND DISCRIMINATION MAY AFFECT CHILDREN

- Psychological and emotional distress. Fear, shame and rejection are added to the psychological and emotional distress of children already traumatised by parental illness or death.
- Social isolation. Children who are worried about being stigmatised or who have already experienced discrimination may isolate themselves from friends and neighbours, and avoid school and health services, both before and after a parent dies. They feel that everyone is judging them, and in extreme cases may commit suicide.
- Poor safety and support systems for affected children.

Issues

During the evaluation of the Families, Orphans and Children Under Stress (FOCUS) project in Zimbabwe, many orphans and vulnerable children said that they identified with a picture of a sad and isolated young boy being ignored by other children and adults.

Lee, T. (1999)

In Malawi, the orphans and vulnerable children who attend the Salima HIV/AIDS Support Organisation (SASO) Saturday group feeding sessions tell sad stories of how they are isolated and discriminated against in their communities.

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In urban Burundi, HIV/AIDS-affected households do not have access to credit.

Save the Children UK (2001)

A study (2002) carried out in Bubi, Zimbabwe, showed that more girls than boys fail to complete their secondary education. Drop-out rates for 1998 were: 22.4 per cent boys; 43.4 per cent girls. Rates for 1999 were: 12.5 per cent boys; 33.7 per cent girls.

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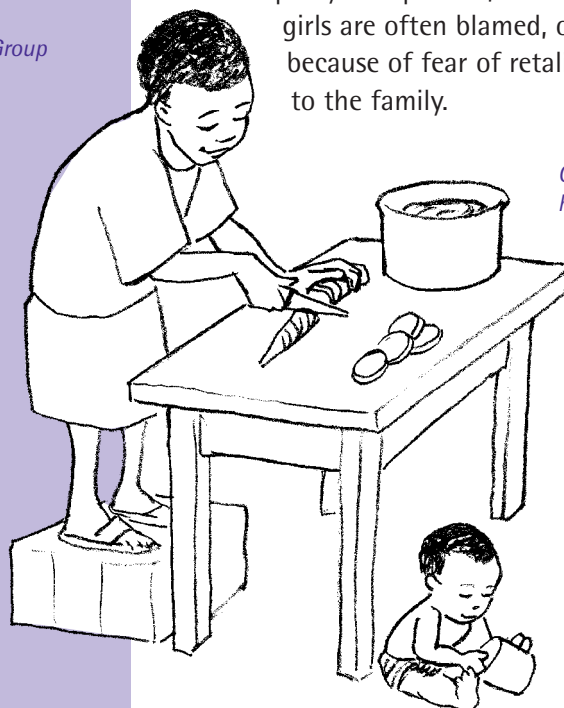
- Children may run away to towns or cities to escape unhappy home circumstances, neglect and abuse. They often end up living in the streets, without family or social support.
- Children of sex workers are often socially marginalised because of their mothers.
- Children may get involved in activities that increase their vulnerability to HIV including:
 - use of drugs, alcohol and glue
 - poor school attendance, leading to unemployment and crime
 - aggression and violence
 - early marriage for economic and social support
 - prostitution.

6

GENDER, STIGMATISATION AND HIV

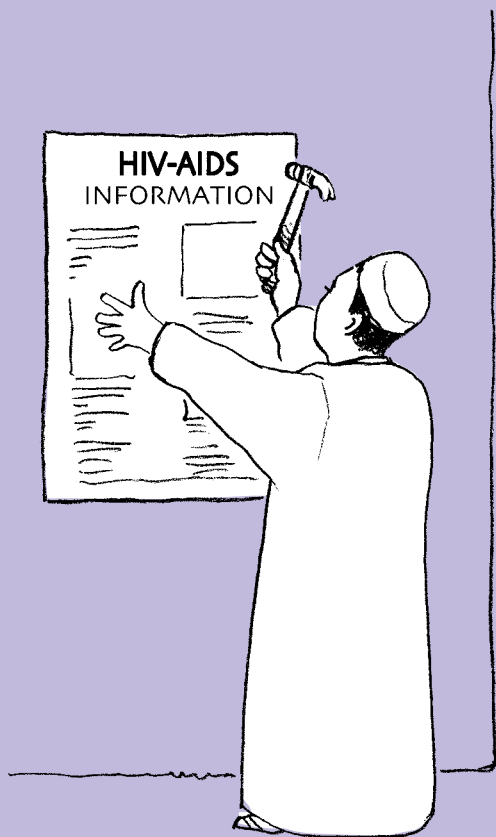
Various factors influence the different effects of stigmatisation on boys and girls affected by HIV. While girls may take on more household chores, and thus miss out on education, boys may be more likely to run away and live on the street, or become involved in crime. They may also be more likely to be used as child soldiers in areas where there is conflict. In these circumstances it is difficult for them to protect themselves from HIV.

Girls are more at risk of sexual abuse and exploitation. In cases of rape by a stepfather, the mother's partner or their employer, girls are often blamed, or they may keep quiet about it because of fear of retaliation or loss of economic support to the family.



Girls may have to take on more household chores

Principles



Traditional leaders should play a role

CHILDREN'S RIGHTS, SOCIAL EXCLUSION, STIGMA AND DISCRIMINATION

- Children should not suffer discrimination in leisure, sport, recreation or cultural activities because of their HIV status or that of family members.
- Children should have access to HIV/AIDS education, both in and out of school.
- Children's rights to informed consent, confidentiality and privacy with regard to their HIV status should be respected.
- Children should be protected from trafficking, forced prostitution, sexual exploitation, sexual abuse, drugs and harmful traditional practices that put them at risk of HIV/AIDS.

UN Convention on the Rights of the Child

1 PROMOTE A SUPPORTIVE LEGAL FRAMEWORK

Advocate for laws and policies that support the rights of children and that make stigma and discrimination illegal.

2 PROMOTE A SUPPORTIVE COMMUNITY ENVIRONMENT

Information can help to reduce stigma and discrimination. Ensure that communities are aware of laws and policies that support the rights of children, and that they have basic knowledge about HIV/AIDS and the modes of transmission.

3 PROMOTE PSYCHOSOCIAL SUPPORT FOR CHILDREN AFFECTED AND INFECTED BY HIV

See the Briefing Notes on psychosocial support.

4 TARGET INFLUENTIAL COMMUNITY MEMBERS

For example, teachers, health workers, traditional leaders, religious leaders and organisations – and encourage them to play an effective role.

5 PROMOTE CHILDREN'S PLATFORMS

Where their voices can be heard and they can express themselves freely.

6 PROVIDE NECESSARY TRAINING

For teachers and help other school children to become aware of how children affected by HIV might feel.

7 TARGET SUPPORT TO VULNERABLE HOUSEHOLDS AND CHILDREN

In areas where the majority of families are living in poverty, targeting assistance to children affected by HIV/AIDS can cause resentment and increase stigmatisation of these children.

8 HELP CHILDREN AND CAREGIVERS TO COPE WITH STIGMA AND DISCRIMINATION

Strengthen the ability in terms of skills and resources (capacity) of children and caregivers to challenge stigma and discrimination.

9 ENABLE CHILDREN TO PROTECT THEMSELVES FROM HIV INFECTION

Provide children with information, skills and the means to protect themselves.

10 TAKE A MULTI-SECTORAL APPROACH

To meet the needs of socially excluded children.

Strategies

This section outlines four strategies to address stigma and discrimination:

1. Creating a supportive legal framework
2. Promoting more positive attitudes
3. Encouraging community action
4. Empowering children and caregivers

1 CREATING A SUPPORTIVE LEGAL FRAMEWORK

Revise existing national policies to advocate for laws to protect the rights of orphans and vulnerable children and ensure that these are enforced.

2 PROMOTING MORE POSITIVE ATTITUDES

- Promote more positive attitudes towards the reduction and elimination of stigma associated with HIV/AIDS by providing basic facts about HIV/AIDS, training journalists and involving people living with AIDS, children and role models.
- Train caregivers in psychosocial support and counselling. See the Briefing Note on psychosocial support for more information.
- Support interventions in schools to promote tolerance and care for people with HIV/AIDS, using teachers or health workers. See the Briefing Note on education for more information.
- Discuss the impact of stigma and discrimination on children with health workers and provide training about non-discriminatory approaches to care and treatment, including practising universal precautions to prevent occupational transmission. See the Briefing Note on health and nutrition for more information.

Masiye Camp in Zimbabwe host an annual media advocacy day, where journalists are given an opportunity to discuss “live” issues related to HIV and AIDS, as well as listen to testimonies from orphans and vulnerable children. The journalist who has best covered issues relating to orphan and vulnerable children is given an award.

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In Zambia, Strengthening Community Partnerships for the Empowerment of Orphans and Vulnerable Children (SCOPE) has facilitated a media network to advocate for the rights of orphans and vulnerable children.

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In Uganda, a children's statute, formulated and rectified in 1998, provides a comprehensive legal and institutional framework for the protection of children and addresses the rights of children as stipulated by the UN Convention and the Organisation of African Unity (OAU). This was translated into six local languages, making it easier to implement locally. The statute provides for all the family members, and community officials must fulfil their obligations for all children, including vulnerable children. This document makes it clear that children's rights are not optional but obligatory for all children.

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In 1992, Malawi was one of the first countries to develop policy guidelines for care and co-ordination of assistance. By 2001, the Malawi government had produced a comprehensive national policy for orphans and vulnerable children.

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In Zambia, consultations about integrating policies concerning orphans and vulnerable children within existing child policies are currently taking place.

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Strategies

The South African Law Commission has developed a consultative paper, which sets out the following guiding principles for schools:

- Children with HIV/AIDS should not be unfairly discriminated against: any special measures taken should be fair and justifiable in the light of medical facts, school conditions and the best interests of the learner and other learners.
- No learner should be denied admission or attendance at school on the basis of his or her HIV status.
- Testing for HIV for school admission or attendance is prohibited.
- A learner's HIV status is confidential and may not be disclosed without his or her consent or that of a parent or guardian. HIV status does not need to be disclosed to school authorities.
- All schools should implement universal precautions to eliminate the risk of transmission of blood-borne pathogens, including HIV, in the school environment.
- While the risk of HIV in contact play and sports is insignificant, all schools should take measures to eliminate this risk. This includes universal precautions and prohibiting learners participating in contact sports with an open wound, sore, break in the skin or open skin lesion.

South African Law Commission (1998)

Some organisations in Uganda (for example, the Kamwokya Christian Caring Community) are encouraging influential members of the community to become involved in helping affected families. This encourages others to provide support, but also helps to reduce stigma and rejection.

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Save the Children UK is supporting Child-to-Child clubs in several primary schools in Uganda. Through drama, songs and poems, the children from these clubs teach their school and communities about HIV/AIDS prevention and management. These children also take part in annual anti-HIV/AIDS campaigns, world AIDS days and other events in their districts. Among other things, they discuss the problems of children affected by HIV and their needs for care and support. This has greatly helped to reduce stigma and discrimination against these children in their schools.

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The National Community of Women Living with AIDS (NACWOLA) have achieved a great deal in overcoming stigma and discrimination in Uganda. Women living with HIV openly discuss their status and challenge the stigma and discrimination so common in certain communities. As a result, many people have changed their negative attitudes towards people with HIV, who in turn have felt encouraged to accept their status and live positively.

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3

ENCOURAGING COMMUNITY ACTION

- Introduce community-based childcare centres in order to integrate socially excluded children and their families within their communities.
- Promote community awareness of children's rights and legislation against discrimination, building on traditional, religious and cultural strengths. Encourage community and religious leaders to promote acceptance, care and compassion for orphans and vulnerable children.
- Set up a programme of community visits to provide caregivers and children with moral support and regular social contact.
- Identify community volunteers to advocate on behalf of children and prevent discrimination within schools, health services and other institutions.
- Establish children's clubs to provide ongoing support and opportunities for social interaction.

The Malawi national orphans and vulnerable children policy, which emphasises community participation, has enabled over 3000 community support groups/organisations to be set up.

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In Zimbabwe, one family, in which an older sister takes care of several younger siblings, had been ignored until community leaders helped repair their house. The family now receives support from neighbours.

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Strategies

In a study carried out in Uganda, many local leaders agreed that their communities have a responsibility to take care of orphaned children, widows and other caregivers. They also agreed that one of the key roles of local communities and parish-level government is to strengthen the capacity of communities to respond creatively and effectively to the needs of orphans. However, they said that communities were only able to provide a small amount of support because of their limited resources. Efforts have been made to promote community-based care of orphans, but this approach is yet to be introduced in most communities.

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In Arua, Uganda, Save the Children UK supported the development of a peri-urban programme providing psychosocial support to children affected by HIV/AIDS. Community-based volunteers visit homes and provide counselling to affected families and children. They also refer these families to other organisations or institutions that can provide additional care, such as HIV testing and treatment of opportunistic infections. They have often mobilised the community to help reconstruct or repair the dilapidated huts of elderly caregivers, and organised meetings to raise awareness among communities about the rights of vulnerable children.

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The Farm Orphan Support Trust (FOST) programme in Zimbabwe has established clubs for all children so as to integrate orphans and non-orphans and discourage stigmatisation. Also in Zimbabwe, some community groups have established AIDS-awareness activities for orphans and vulnerable children involving students from school AIDS awareness groups, which helps to provide links between children who are in school and those who are not.

UNAIDS (2001)

4

EMPOWERING CHILDREN AND CAREGIVERS

Psychosocial and emotional support for orphans and vulnerable children should be promoted. Counselling is important for both adults and children. It allows children to cope with their grief and understand their parents' illnesses. It can also provide children with a comfortable space to discuss their HIV status, and can help prepare those who are soon to become orphans.

- Provide legal support and services for children, widows and grandparents, to advise them of their rights and help them obtain legal entitlements.
- Integrate counselling and support into existing home-based care and outreach programmes.
- Train caregivers in child rights, psychosocial care and counselling, so that they can deal with stigma and discrimination, and support children who experience them.
- Provide counselling services for children to help them deal with stigma and discrimination.



Children need emotional support

Strategies

- Establish support groups for caregivers and children, so that they can share their experiences and problems.
- Ensure that children are aware of their rights; for example, through the development and distribution of simple cards or leaflets, special sessions in schools, youth organisations, sports events, radio programmes, popular songs and drama.



Children promoting their rights on the radio

The NACWOLA memory project in Uganda addresses the needs and problems that orphans affected by HIV experience. Through training and counselling, it prepares children to cope better with parental loss. Parents are also empowered through training and psychosocial support to disclose their ill health to their children and discuss it with them. They are encouraged to make sound plans for their children's futures and document important family history and family values for them.

Member of Building Blocks Development Group

A Save the Children UK study in Uganda found that the community-based care and counselling available in several communities did not meet the children's needs. The counsellors often spoke only with adult caregivers or patients rather than with children, whether the children had HIV or were affected by HIV. The reason identified was their lack of specific knowledge and skills for counselling children.

Member of Building Blocks Development Group

- Discuss the risks of sexual abuse with children and what to do if they are abused, as well as how to deal with potentially exploitative situations.

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Useful Resources

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Save the Children (2002) *Children Living with HIV/AIDS in South Africa: A rapid appraisal*. Overview of experience and selected models of care and support, plus recommendations for action by government and civil society.

UNAIDS (1999) *Best Practice Case Study: Reducing Girls' Vulnerability to HIV/AIDS. The Thai Approach*. Available at: www.unaids.org/publications/documents/children/young/reducingcse.pdf

UNAIDS (2001) *Investing in Our Future: Psychosocial Support for Children Affected by HIV/AIDS. A Case Study in Zimbabwe and the United Republic of Tanzania*. Available at: www.unaids.org/publications/documents/children/children/JC606-InvFuture-E.pdf

UN Convention on the Rights of the Child. Available at: www.unicef.org/crc/crc.htm

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

Useful Resources

UNICEF (2001) *Child Workers in the Shadow of AIDS – Ethiopia, Kenya, Mozambique, Lesotho, Tanzania, Uganda.*

Webb, D. and Elliott, L. (2001) *Working Paper 23: Children Affected by HIV/AIDS Rights and Responses in the Developing World*, Save the Children UK. Includes examples of good practice drawn from programming experience and possible ways to integrate a children's rights framework into HIV/AIDS programming.

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Notes

Notes

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