

Circle of Hope

Children's rights in a world with AIDS



About Plan



Founded nearly 70 years ago, Plan is one of the largest child-centred community development organisations in the world. We work in 62 countries on projects and initiatives that address the causes of poverty and its consequences for children's lives.

This means working in partnership with children, their families and communities, and at national and international levels, to bring about sustainable change.

At a local level, we work directly with all groups in a community to identify the priority issues affecting children. We actively encourage children to analyse their own situations and raise their awareness of the fundamental rights to which they are entitled. We then support the community to build the skills and access the resources it needs to implement projects that will lead to positive change in children's lives.

We campaign for children to achieve their rights and work at national and international levels to influence policy decisions that will lead to improved resources for children and their communities. In this way, we create and maximise all opportunities for children to speak out on their own behalf and participate in decision-making that affects their own development.

By Josef Decosas and Wendy Davies, with Glen Williams

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Foreword

The global face of HIV

Last year, when I visited her in Eastern Uganda, Betty showed me the memory book she has put together for her children. Keeping memories alive helps both children and parents prepare for life after the death of one or both parents. Betty is a spirited, caring and strong woman. As well as caring for her own children, she has taken in children who have been orphaned by AIDS and is now looking after seven children. Betty is HIV-positive.

In Uganda, Plan supports community partners to deliver family therapy using memory books – an important part of succession planning. Here, at the sharp end, are remarkable people doing remarkable things in the face of daunting challenges.

Betty has also set up a post-test club for anyone who has taken an HIV test. Voluntary HIV testing and counselling is an important entry point to HIV-related services for those who test positive; for those who test negative, the service can be linked to effective reinforcement of protective behaviours. Plan's support of HIV testing is therefore never an isolated stand-alone effort. And this example reinforces our underpinning ethos — because the issues are complex, strategies to respond to HIV and AIDS need to be comprehensive, holistic and integrated. It is vital that Plan, as part of the international community, works with the international community, using our own special approaches and skills as one partner in a global coordinated response.

High mortality from AIDS or other causes, combined with poverty, rural-urban migration and other factors, often disrupt the family structure and leave children with inadequate care, guidance and support. As Plan exists to work on behalf of children, we believe it is essential that their needs and rights are considered as a priority.

In the global battle against HIV and AIDS, there are often more questions than answers. For instance, why is it that fewer than 5 per cent of HIV-positive children have access to treatment? And why do fewer than 10 per cent of children who have lost parents to AIDS get public support or care?

While it doesn't claim to have all the answers, the 'Circle of Hope' is a framework for Plan to develop programs that are appropriate to local social, cultural, political, economic and epidemiological contexts across the continuum of prevention, care, treatment and mitigation of impact – a framework that helps avoid short-term project responses driven by single high visibility issues.

At the centre of the Circle of Hope are boys and girls whose needs, rights and entitlements govern all Plan's responses to AIDS. Surrounding the children are the institutions responsible for protecting the rights of children and for delivering essential services. These institutions, from families to governments and global organisations, have a duty towards children, but they may also need assistance and support to be able to fulfil this duty.

Children and adolescents are not passive observers or 'victims' of AIDS. They have a primary role to play in the response. Reducing their vulnerability means giving them the opportunities and tools to develop their own leadership on an issue that will profoundly affect their own future.

Tom Miller

Chief Executive Officer, Plan

on Willi

Executive summary

A rights-based approach

Even if HIV infection ceased tomorrow, today's children would still live in a world with HIV for the rest of their lives.

AIDS is a reality faced by children every day. They may be looking after a sick relative, one or both of their parents may have died of AIDS, their schooling may be suspended because their teacher has died or they may themselves be living with HIV.

Poor households affected by AIDS generally become poorer. Their survival may already be precarious, and AIDS can push them to the brink of disaster. Children in households affected by AIDS are more likely to be malnourished, they are less likely to receive appropriate treatment when they are sick, they are less likely to be in school, they are more likely to be economically and sexually exploited, and they are ultimately at greater risk of becoming infected with HIV.

Plan's Circle of Hope framework is a child-centred community development model – a rights-based approach in which children, families and communities are active participants in their own development rather than passive recipients of assistance.

Plan's responses to HIV and AIDS aim to be gender-specific, age-appropriate and tailored to local contexts. They address the needs and entitlements of infants, young children and adolescents. For infants, this focuses on improving the safety of pregnancy, delivery and infant care. For young children, this focuses on child protection issues. And for adolescents, this focuses on promoting safe and fulfilling sexuality.

The Circle of Hope framework carefully balances several roles that define Plan's relationship to duty-bearers: the role of a service provider of last resort, to meet the urgent needs of children, families and communities; the role of building the capacity of local organisations to demand a government resource allocation that meets children's needs; the role of influencing and supporting governments to meet these demands; and the role of lobbying international organisations to provide more equitable and more effective development assistance.

Plan's programs deliver a continuum of prevention and care.

Plan strives to reduce children's vulnerability, championing their right to be protected from HIV infection. Strategies include reducing gender inequalities, promoting youth-friendly health services, ending child marriage and abolishing child trafficking.

Plan strives to extend the life of the parent-child relationship and improve quality of life. Strategies include preventing HIV transmission from parents to children, making antenatal services accessible and acceptable, improving nutrition and food security, emotional support and community mobilisation to eliminate stigma and discrimination.

Plan strives to strengthen community and family coping mechanisms and help prepare for transition. Strategies include planning for succession, promoting the legal rights of people affected by HIV and AIDS, universal birth registration, income generation activities, and education and vocational training which encourages self-reliance and economic empowerment, particularly for girls and women.

Developing youth leadership is another innovative approach by young people for young people. This demonstrates the potential of children not only to act as messengers among their peers, but also to develop messages and approaches that reach adults and that influence policies.



Introduction: a rights-based approach

Plan's response to AIDS starts with the life experiences of children and adolescents. The diversity of these experiences is often neglected in international AIDS programs. Yet, children and adolescents – and the way they relate to each other and to the adult world – will determine the future course of the HIV pandemic.

For many children in Uganda, like Jamalie (right), AIDS is a reality they face every day. They may be looking after a sick parent or relative, one or both of their parents may have died of AIDS, their schooling may be suspended because their teacher has died or they may themselves be living with HIV infection. In most of the 62 countries where Plan works, few children and young people have such direct contact with AIDS. They identify many other issues that affect their lives and their rights adversely. But most of these issues relate directly or indirectly to the vulnerability of young people to HIV infection.

Plan's program philosophy

Plan first adopted a policy for children affected by AIDS in 1996. As HIV epidemics continued to expand around the world, Plan's response grew in scale and scope. It evolved to reflect lessons learned at the community level, and it adapted to the increasing availability of effective medical treatment.

In 2006, Plan adopted a new framework for its response to AIDS called Circle of Hope. Central to this framework is a program philosophy that starts with the rights of children and addresses these rights in a manner that is both comprehensive and appropriate to the child's context. The Circle of Hope applies the practice of child-centred community development to the program response to AIDS. Child-centred community development is the overarching program philosophy of Plan. It defines Plan's role in international development.

"If you are an orphan, you don't have money to buy clothes, to pay rent for where you live, or to buy food, and you have young sisters and brothers to look after. You become the father or mother or both of the house. You go and look for jobs like working for builders to earn money for your family."

Jamalie, aged 14, Uganda

"The main problem in our community is poverty. Parents do not have enough money to send their children to school. Some parents use their children to increase the household income. They force their daughters to abandon school to do some petty trading in the market, or to get married. Sometimes they even send them abroad to do domestic work."

Children's opinions recorded in a focus group discussion in Togo

Child-centred community development

Child-centred community development is a rights-based approach in which children, families and communities are active participants in their own development rather than passive recipients of assistance. It enhances their capacity and opportunity to work together with others to address the structural causes and consequences of poverty at all levels.

A child-centred approach involves listening to what children have to say about their needs and concerns and what is preventing them from achieving their rights. It also means encouraging and enabling children to take an active and — where possible — leading role in finding solutions to the problems they face.

Children can only participate fully in community development when they are supported by their families and communities to do so. Plan therefore works with communities and national and international institutions to promote greater awareness and understanding of children's rights.



HIV and AIDS

The global face of HIV

We have become used to the large and ever-growing numbers associated with the HIV pandemic. This applies to statistics of people living with HIV infection, of people newly infected each year, of people who have died of AIDS and of children who have lost a parent to AIDS.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that at the end of 2005 more than 40 million people around the world, including more than two million children, were living with HIV.¹ These numbers remind us of the global dimension of the HIV pandemic; HIV has become a reality for all of us. Even if HIV infection ceased tomorrow, today's children would still live in a world with HIV for the rest of their lives.

Global statistics hide more information than they reveal. Although all countries in the world are affected by AIDS, the HIV pandemic is not sweeping the world in a predictable and uniform pattern. The profile of HIV epidemics and the factors that drive these epidemics differ widely from continent to continent, from country to country, and from community to community.

Sub-Saharan Africa has so far been regarded as the region most severely affected by AIDS. Yet there is enormous heterogeneity even in Africa. There are communities where every child has lost at least one close relative to AIDS, and there are many communities where children have never known a person who has died of AIDS, and may never know one. In other continents and regions where Plan works, HIV infection may be associated with specific behaviours or environments, such as intravenous drug use or the sex industry. In some communities HIV is spreading in a seemingly random pattern, in others the infection is concentrated in identifiable social or ethnic groups. In some places HIV infection is spreading rapidly, in others the infection rates have been on a decline for several years.

This local diversity of the HIV pandemic has profound implications on the development of a child-centred response to AIDS not only for sub-Saharan Africa but for global responses as well.

Children and HIV

All children today live in a world with HIV and AIDS. The overwhelming majority of children are not infected with HIV and will never be infected. But the presence of HIV in their communities influences how they conduct their lives and how they achieve their rights and entitlements.

All children in Plan's partner communities face the challenge of HIV prevention, but there is a need to pay special attention to those children directly affected by HIV and AIDS. These include children who are infected with HIV, children who have lost a parent to AIDS, children who are caring for a parent or relative with

¹ UNAIDS/WHO, AIDS epidemic update, December 2005, UNAIDS, Geneva, 2005

"I find it very difficult at school because of the way I feel now. When I am in class I don't feel so attentive because my parents are always on my mind. I feel very sad that I don't have them in my life any more."

Agatha, aged 16, Uganda

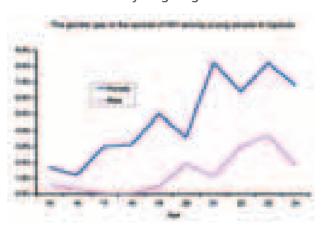
AIDS and children in families who are caring for orphaned children. In some communities where Plan works, all children belong to one or several of these groups.

Poor households affected by AIDS generally become poorer. Their survival may already be precarious, and AIDS can push them to the brink of disaster. Children in households affected by AIDS are more likely to be malnourished, they are less likely to receive appropriate treatment when they are sick, they are less likely to be in school, they are more likely to be economically exploited as child labourers, and they are ultimately at greater risk of becoming infected with HIV.

The illness and death of parents can have a devastating emotional impact on children. Many young people feel the emotional effects of being orphaned for a long time after losing their parents.

Women, girls and HIV

Where HIV infection takes root in a community, women soon outnumber men among those who become infected. There are biological reasons for this imbalance, because HIV is more transmissible from men to women than from women to men. But the social reasons are much more significant. Women throughout the world, and especially in sub-Saharan Africa, are at risk of HIV infection at a much younger age than men.



Source: Ministry of Health of Uganda, AIDS Control Program, February 2006

At the basis of this phenomenon are the pervasive gender inequalities found throughout the world. Women, especially young women, are much less likely to be in control of when they have sex, with whom and how. Many adolescent girls and young women are exposed to sexual coercion and sexual violence. Many young girls in agrarian societies are

married to men who are considerably older and sexually more experienced. In communities with generalised HIV epidemics, being married is often the greatest risk factor for HIV infection among young women.

When families are affected by AIDS, girls are more likely than boys to be taken out of school to care for sick relatives. In some communities which are highly affected by AIDS, school enrolment and completion rates among girls are falling. Stigma and discrimination against people living with HIV are more likely to be directed at women. Women often have less access to medical care than their male partners, and they have less protection against property theft by relatives after the death of their spouse.





The Circle of Hope

The Circle of Hope (left) is the conceptual foundation of Plan's response to HIV and AIDS. Initially developed by Plan Uganda, the model has since been adapted by several of Plan's country offices. It has also become the framework of the Hope for African Children Initiative (HACI), a pan-African partnership to strengthen support for children affected by AIDS in Africa.

The Circle of Hope applies Plan's corporate framework for child-centred community development to programs and initiatives responding to HIV and AIDS. It helps Plan and partner organisations define and understand issues related to HIV and AIDS from the perspective of children and their rights.

The Circle of Hope is a framework that facilitates Plan's country offices in Africa, Asia and the Americas to develop programs that are appropriate to the local social, cultural, political, economic and epidemiological contexts across the continuum of prevention, care, treatment and mitigation of impact. It helps avoid project responses that are short term and driven by single issues of high visibility. It reinforces the Plan practice of programs based on a comprehensive analysis of the needs and the rights of children, developed with the full participation of communities and children. It reinforces the need to mainstream AIDS into Plan's integrated programming, where support for sustainable community development and poverty reduction is an overarching objective.

Responding to children's daily experiences

At the centre of the Circle of Hope are girls and boys whose needs, rights and entitlements govern all Plan's responses to AIDS. Surrounding the children, like the layers of an onion, are the institutions responsible for protecting the rights of children and for delivering essential services. These institutions, from families to governments and global organisations, have a duty towards children, but they may also be in need of assistance and support to be able to fulfil this duty.

The four sides that frame the circle represent the continuum of strategic objectives that orientate Plan's work with children in a world with HIV. Within each of these areas, there are programs that have specific objectives, for instance to promote youth-friendly health and social services, to strengthen self-help groups of people living with HIV or to facilitate children's access to medical treatment.

Plan's integrated approach to HIV programming means that most programs involve more than one objective in the continuum. They all overlap significantly, and this is a function of the holistic nature of the Circle of Hope framework. Children living in a world with HIV do not experience the violation of their rights in terms of categories of services denied. They experience them as daily hardships, a lack of opportunities and a lack of freedom to decide about their lives. We need to appreciate the daily experiences of children in their entirety if we want to respond to them in a way that is centred on the child rather than on theories or technologies.

The children

Children are not a homogeneous group of people. Although their rights are universal, their entitlements and needs differ according to sex, age and social context. Plan's responses to HIV and AIDS aim to be gender-specific and appropriate to local contexts. In general, they address the needs and entitlements of children in three age-appropriate groupings: infants, young children and adolescents.

Infants

Infants are at risk of HIV infection at birth or through breastfeeding. HIV infection at birth has almost been eliminated in industrialised countries, but children in the developing world continue to be infected. These children rarely survive beyond their fifth year because they do not have access to appropriate medical treatment.

Globally, HIV infection is not the most important threat to child survival, accounting for less than one in 30 preventable childhood deaths.² In some communities, however, it is the most common reason why children die prematurely.

Preventing HIV infection at birth is part of Plan's work to improve the safety of pregnancy, delivery and infant care. Improving the treatment for infants living with HIV is part of Plan's child survival program.

Neither of these programs is ever applied as an isolated intervention with a single objective. All threats to maternal and infant health and survival have equal rank, and Plan's support to service improvement is based on a comprehensive analysis of the situation of children's health and the status of available services. The delivery of health services is generally undertaken by governmental or non-governmental partner organisations, while Plan aims to strengthen the systems and institutions that are necessary to deliver these services.

Young children

For young children up to the age of adolescence, issues of protection from violence, neglect and exploitation gain prominence. The child protection issues differ from community to community. Child trafficking may be a main issue in some places, in others it may be sexual abuse, or it may be a traditional practice involving cutting or scarification of the skin. Many types of abuse increase the vulnerability of small children to HIV infection.

In addition, early childhood is also the time when attitudes are formed and behavioural patterns are established that will determine future competence in living in a world with HIV and AIDS. Plan's programs therefore focus on education and on child protection issues, taking account of the distinct needs and entitlements of girls and of boys.

² WHO. World health report 2005. WHO, Geneva, 2005

Adolescents

During transition to adulthood, generally between the ages of 15 and 24, young people are at highest risk of HIV infection.³ This is particularly relevant for adolescent girls who are in the demographic group that is most vulnerable to HIV infection in many parts of the world. Sexual behaviours adopted during this period in the life cycle are key determinants of this risk.

In most communities where Plan works, adolescents have very narrow margins within which to determine or to choose their sexual behaviour. They often act under overwhelming social and economic pressures. Plan's programs therefore address the conditions that undermine their right to self-determination and a healthy, safe and fulfilling sexuality as much as they address the behaviours themselves.

This involves moving away from risk-based approaches to approaches that promote healthy, happy lifestyles. Examples include programs in child protection, for instance to prevent the practice of early forced marriage; initiatives to abolish sexual coercion and sexual violence; and programs to prevent sexual

exploitation of adolescent girls and boys. It also involves economic programs, for instance the creation of micro-credit facilities for young people. And it includes programs in education, in particular to support primary and secondary education for girls.

Adolescents between the ages of 12 and 18 make up about half of the children who have lost one or both parents to AIDS.⁴ These young people have special needs. Whether these needs are adequately met or not depends on the social structure, the HIV burden and the overall rate of orphaning in the communities where they live. Most communities with large numbers of orphans have serious problems meeting the needs and entitlements of these young people.



³ UNFPA. State of the world population, 2003: investing in adolescents' health and rights. UNFPA, New York, 2003

 $^{^{\}scriptscriptstyle 4}$ UNAIDS/UNICEF/USAID. Children on the brink 2004. UNICEF, New York, 2004

The families

Families have the most important role in protecting children and ensuring that their rights are respected. In many communities where Plan works, families are under stress. High mortality from AIDS or other causes, combined with poverty, rural-urban migration and other factors, often disrupt the family structure and leave children with inadequate care, guidance and support.

Plan recognises that the rights of children cannot be ensured unless there is adequate support for their families. The history of AIDS in Africa has shown that families are resilient and continue to carry most of the burden of care related to AIDS. New types of family arrangements are emerging, including families headed by grandparents, and families headed by adolescents. More and more elderly women and adolescent girls are assuming the responsibility to head households affected by AIDS. Many HIV-positive women continue to provide for their families, engaged in a daily struggle for personal and family survival.

The Circle of Hope framework is a reminder that families are the first line of duty-bearers responsible for the entitlements of children, be they related to HIV prevention or to mitigating the impact of AIDS. Supporting families is therefore a major component of Plan's response to HIV and AIDS.

The communities

Throughout the world, communities experience HIV epidemics in different ways. In some communities HIV spreads rapidly and unravels the social fabric; in others it spreads but there is little social impact; yet others appear to be almost immune to the spread of HIV. There is a growing body of evidence that suggests that more cohesive and more caring communities experience less severe HIV epidemics and less disruption as a consequence of AIDS.⁵ This quality of a community is summarised by the term 'community competence'. The social cohesion and overall competence of a community are determined by its institutions. These include local government, traditional government, religious institutions and civil society organisations. Among these are a wide variety of community-based groups, including women's and children's organisations and clubs.

Plan recognises the key role that functional local organisations play in creating community resilience to HIV infection and to the impact of AIDS. One of the main ways in which Plan works is to enter into partnerships with local institutions and organisations, and to assist them in their role as service providers and as advocates for their communities. Youth clubs and associations of people living with HIV are especially important partners in this context.

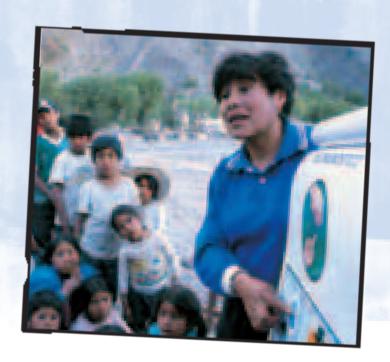
⁵ Decosas J. The social ecology of AIDS in Africa. Paper prepared for the UNRISD Project on HIV/AIDS and Development 2002. Accessed on www.unrisd.org May 2006

The State

The ultimate responsibility for providing the protection and services to guarantee children's rights and to meet the entitlements of children in a world with HIV rests with the State. It can never be the role of Plan or of any other international organisation to replace the State in its role as primary duty-bearer for its citizens.

In many countries where Plan works, the State lacks the means to fulfil this role. Even the sometimes inadequate services provided by governments are dependent on foreign development assistance. In other countries the means are theoretically available, but there are inequalities in allocation and service delivery problems. The result is that the rights of large numbers of children are violated.

Plan's work in the Circle of Hope framework carefully balances several roles that define the way we relate to the duty-bearers: the role of a service provider of last resort, to meet the urgent needs of children, families and communities; the role of building the capacity of local organisations to demand a government resource allocation that is more appropriate to the needs of children; the role of influencing or encouraging and supporting governments to meet these demands; and the role of lobbying international organisations to provide more equitable and more effective development assistance.



Advocacy in the Circle of Hope framework

The Circle of Hope framework guides Plan's advocacy agenda on HIV and AIDS from the local to the international level. It underpins Plan's commitment to promoting children's rights, including sexual rights and reproductive rights. Children have a right to be heard when priorities and targets for AIDS programs are defined, and they have a right to participate in national and international policy discussions on AIDS.

Governments and international agencies that provide services for children in the context of HIV and AIDS have to be accountable to these children. The needs and priorities may be complex and will differ from community to community. But Plan's advocacy message is clear and consistent:

Services, programs and policies for HIV and AIDS prevention and care among children should be developed in consultation with children, should meet the priority needs of the majority of children in the community, and should be delivered equitably and without discrimination.

Children from Uganda raise their voices

In May 2004, Plan organised a meeting by video link between eight young Ugandans and the UK Parliament's International Development Select Committee on AIDS Orphans. Four girls and four boys aged 11 to 16 exchanged their views on AIDS and discussed their priorities with seven Members of Parliament of the UK House of Commons.

The children talked about their hopes and fears. They discussed the stigma associated with HIV infection, and the hardships of life without parents. Prossy, a 16 year-old girl, recounted how relatives raided the properties of children left behind after the death of their parents. She talked about the sexual abuse of orphaned girls in the care of irresponsible relatives. Agatha, aged 16, talked about the sadness of losing her parents. All the children expressed their regret that their parents died sooner than they might have done because they could not afford anti-retroviral treatment. Job, aged 15, summed up the discussion:

"The drugs are available but they are expensive. If our parents could have had the drugs they would have lived longer and we would not have been discriminated against."

This initiative by Plan was part of a campaign by UK civil society groups to influence the formulation of UK government policy on AIDS and development. The outcome of this collective non-governmental organisation initiative was a three-year commitment by government to spend GB£150 million of the international development budget on programs for children affected by AIDS.

International partnerships

Advocating for the rights of children in international development practice and in the international response to AIDS cannot be done by Plan alone. It requires international partnerships, sometimes assembled on a one-off basis, to lobby for a specific issue or to influence a major policy decision, sometimes established for the long term to strengthen the institutional basis for a child-centred response to AIDS. Plan participates in many such partnerships. The Hope for African Children Initiative (HACI) and the Lesson for Life of the Global Movement for Children (GMC) are just two examples of initiatives in which Plan takes a leading role.

The Hope for African Children Initiative

HACI is a pan-African partnership that was created to address the challenges faced by children affected by AIDS. Established in 2000, the partnership brings together four major international humanitarian organisations working with children, a federation of religious organisations and two African regional organisations concerned with the response to AIDS: Plan, CARE International, Save the Children, World Vision, the World Conference on Religion and Peace, the Society for Women and AIDS in Africa and the Network of African People Living with HIV/AIDS (NAP+).

The partners are working together to increase the capacity of local communities to care for children affected by AIDS and their families. The HACI partners are already represented throughout Africa, and manage budgets that total more than US\$1.5 billion. Through the HACI partnership, they are sharing their experiences, systems and procedures to increase the efficiency of providing financial and technical support to community-based groups working with children affected by AIDS.

HACI has set itself a target of supporting three to five million African children affected by AIDS each year. HACI is trying to mobilise international funds amounting to US\$50 million annually to fund this work.

HACI has adopted Plan's Circle of Hope framework as a guide for its programs. HACI currently assists community groups in Cameroon, Ethiopia, Ghana, Kenya, Malawi, Mozambique, Senegal, Uganda and Zambia. Plan provides the administrative support for HACI in Cameroon, Ghana and Kenya.

"I was somewhat sceptical about Lesson for Life, but I am impressed by its success. Eight of the 11 Plan country offices in **West Africa** participated; three of them provided leadership to the national coalition. World AIDS Day has become an unavoidable institution for our country programs. Yet we have been somewhat frustrated by the traditional parades, shows and discussion forums that marked the occasion. **Lessons for Life** provided a framework to structure events around children that was much appreciated by our offices."

Plan staff, West Africa, speaking about Lesson for Life 2004

The Lesson for Life

The Global Movement for Children (GMC) is a worldwide movement of organisations, institutions and individuals that supports and promotes partnerships, discussions and activities that aim to build a world fit for children. In 2000, a group of organisations, including Plan, came together to create a convening committee to steer the activities of the GMC. In 2003, the committee identified the issue of children affected by AIDS as a priority theme and launched a three-year campaign to "mobilise the people and political will to protect the rights and ensure the well-being of children affected by HIV and AIDS". The Lesson for Life is the main global activity of this campaign.

The Lesson for Life is a public education and social mobilisation event involving millions of children around the world on or around World AIDS Day on 1 December. In both formal and non-formal education settings, Lesson for Life gives children a leading role in teaching others about HIV and AIDS. Most importantly, it allows children affected by HIV and AIDS to share their experiences, concerns and ideas.

Over its first two years, Lesson for Life has been highly successful in raising the visibility of children in the international response to AIDS, and in engaging children in the process. It has helped build many vibrant national networks and coalitions that have successfully mobilised children in schools and non-formal education settings. In 2005, over 12 million children participated in the Lesson for Life in 67 countries. In some countries, children asked their governments to deliver on their promises to ensure care and support to children affected by AIDS, and in particular to provide treatment for all children living with HIV.

The Circle of Hope program areas

Reducing children's vulnerability

Plan is fully committed to the rights of children affected by AIDS, and of their families and communities, to receive adequate care and support. At the same time, we have to acknowledge that the vast majority of children in this world are not directly affected by AIDS. They have the right to be protected from HIV infection — a right that often receives less attention in the international discourse on AIDS and development.

Rather than drawing up balance sheets of investments in HIV prevention versus investments in AIDS care, the Circle of Hope creates a convergence of common rights and entitlements in each of the four main program areas. Clearly, the area of 'reducing the child's vulnerability' includes most of the programs usually classified as 'HIV prevention', but it merges seamlessly into programs to support children affected by AIDS in a continuum of prevention and care.

This approach has been taught to us by children in communities affected by AIDS. For those who are directly confronted by HIV, the distinction between prevention and care is academic. Individual, family and community attitudes, behaviours and responses always relate to the imperative to prevent infections among those who are not infected; the need to care for those who are living with HIV; and the knowledge that all children in the community have a right to survival, development, protection and participation in decisions that affect them.

Another lesson Plan has learned from children and adolescents is that the link between vulnerability and HIV infection is often very indirect. It is important to know about HIV and about how to prevent infection, but the determinants of sexual behaviour are complex.

Lack of knowledge is rarely the main reason for children's vulnerability. Poverty, tradition, gender inequality and other social factors severely limit young people's margins of choice to adopt behaviours that protect them from HIV infection. On the face of it, Plan's programs sometimes appear to stray far from directly addressing the subject of AIDS, but they are nevertheless focused on reducing the vulnerability of children and their communities to this common threat.

"My friend (a 13 yearold girl) lived on her
own with her 11 yearold brother after their
parents both died. Her
uncle was a drunkard.
He went with a
drunken friend of his to
the children's house and
the friend defiled the
girl. She got pregnant,
and he also made her
HIV-positive — at only
13 years of age!"

Prossy, aged 16, Uganda

"We need to get together as a group and claim our rights. We want parents in our communities to stop abusing their children. We want them to give us the freedom to express ourselves. We need non-governmental organisations and we need the government to assist us. They should help us secure our rights, and they should develop programs that address our real issues. HIV prevention and sexual health promotion are only a small part of the problems we face as adolescents growing up in rural Benin.

"We want our government to be present in our communities. We want them to enforce the laws that protect the rights of children and young people. We want our government to work hand in hand with non-governmental organisations to create spaces for young people to meet, and to create services that meet the needs of young people.

"International donor agencies ... should support our education system so we have access to quality education. They should stop telling us what our problems are, and take us seriously when we tell them that our education, our health and our sexual health are at risk because we have to walk for hours to get to school, and we don't have anything to eat until we get home in the evening."

Sophie, aged 19, Benin

Program examples

The following examples illustrate the range of programs Plan supports in its attempt to reduce vulnerability to HIV infection. They are not an attempt to be all-inclusive, but rather an illustration of the range of activities that can be found in this program area.

Reducing gender inequality

In most societies, traditional gender roles and power relations place women and girls in disadvantaged situations relative to men and boys. For example, gender inequality limits women's access to the wage economy and leaves them in a position of economic dependence on men. Even where women work for wages, they have limited access to high salary positions and usually earn less than men for equal amounts of labour. Economic dependence limits women's ability to assert their rights or to negotiate for their health and safety. Women who are economically dependent are less able to negotiate for safer sex or to leave an abusive or unfaithful husband. Poverty and economic dependence leave women more vulnerable to sexual exploitation. In some communities, sex work may be the most economically promising option to escape the cycle of dependence and poverty. It is therefore a cruel irony that precisely this option is associated with an overwhelming risk of contracting HIV.



Gender roles are culturally determined and are not fixed. This is in contrast to sex roles that are biologically determined and do not vary over time. Men cannot give birth, but women can become President. The roles and the stereotypes that are at the basis of gender inequality are established during childhood. Plan works with children. It is therefore very appropriate that Plan places much emphasis on reducing gender inequalities in its effort to reduce the vulnerability of children to HIV infection and to AIDS. This involves work with children, their parents and the broader community.

Since its launch in Africa in 1995, the 'Stepping Stones' methodology – developed by Alice Welbourn for the Strategies for Hope project and ActionAid – has become widely recognised as an effective tool for community mobilisation and transformation on issues related to gender and HIV.⁶ Stepping Stones is a package of participatory training exercises that help groups of people of all ages analyse and overcome their difficulties in communication and relationships. It aims to create supportive and enabling environments, free of HIV-related stigma and discrimination. The introduction of Stepping Stones in communities has resulted in a reduction of family violence, less forced sex, fewer unwanted pregnancies, and better relationships between parents and children.

⁶ Welbourn A. 'Stepping Stones', Strategies for Hope Training Series No 1, ActionAid, London, 1995

"I always felt afraid and embarrassed to talk about such things. My husband didn't want me to go to the meetings. He said the people there were talking nonsense, that it made women cheeky and lazy ... But it wasn't like that ... I felt like I'd been living in darkness, but now I feel that I'm living in the light."

Participant in a Stepping Stones workshop in Ecuador Plan has already had a very positive experience with the Stepping Stones program in a number of countries in Africa. In 2004, Plan translated the manual into Spanish and adapted it for use in Latin America. The Latin American version of Stepping Stones, called Paso a Paso, was launched in 2005 in Quito, Ecuador. Plan then began to systematically introduce Paso a Paso in 10 countries in Latin America and the Caribbean. The methodology was tested among groups of primary school children, adolescents, parents and teachers throughout the first year.

In collaboration with a local non-governmental organisation, Plan collated the findings of this testing process and refined and adapted the manual to make it more relevant to regional issues and local cultures. This has resulted in a second edition of the Paso a Paso manual, launched in 2006 in Panama, it is supported by a video based on the life stories of people living with HIV in El Salvador. Plan is now working on a version of this educational approach to be used with children aged 7 to 12.

A different approach to reducing gender stereotypes and improving gender equality is being pursued by Plan in Togo. Studies among adolescents conducted by Plan and by partner organisations revealed a very low level of sexual health. Young people become sexually active at an early age, most sex is unprotected, sexual coercion and sexual violence are common, and many girls become pregnant in their teenage years. Communication between men and women and between children and adults on issues of sexuality is poor, and communities in general do not show much concern for the difficulties faced by adolescent girls and boys.

In response, Plan collaborated with a local association to help establish youth clubs in towns and villages in its program area. Each club has 20 to 30 members of both sexes, ranging from 13 to 19 years. The clubs choose their own names, for instance Hope Club, Brainy Club, Dynamic Youth Club, Future Club and Girls First. They develop their own activities, ranging from sports and entertainment to education on issues of concern to the young people and to incomegenerating projects.

The youth clubs have led to impressive changes in attitudes among young people. One 19 year-old girl reported: "Thanks to the club, I have gained self-respect and I know what I am capable of. I am proud to be a girl and to be involved in activities that help other girls."

Relationships between girls and boys have changed. Boys now treat girls with greater respect, and are much less likely to regard themselves as superior to girls. Both boys and girls find it easier to make friends with members of the opposite sex without entering into sexual relationships. Yet sex is not a taboo subject. It is openly discussed in club meetings, and many young people report that they are now able to discuss sexual matters with their parents. Headteachers in the towns where the clubs are active report a decrease in the number of pregnancies and abortions among schoolgirls.

Programs to reduce gender inequalities and stereotypes often focus exclusively on women. Men, however, are as much captive as women to the social norms that perpetuate these inequalities. Plan recognises the need to work with male adolescents to challenge damaging notions of masculinity. It seeks to create programs that treat young men as individuals and encourage them to explore the ways in which they were raised and how they are expected to behave.

In Brazil, Plan works with a local non-governmental organisation in an initiative known as 'Program H' (H for the Portuguese 'homen', meaning 'man'). Program H was developed in 1999 by a coalition of Brazilian and Mexican non-governmental organisations.

Using games, drama and group discussions, adolescent boys are encouraged to reflect on the socialisation they have experienced, the daily violence they suffer and the violence they themselves perpetrate. Groups of boys and young men meet weekly for three months. The groups explore common beliefs and attitudes, for instance that men have more sexual urges than women, that men have the right to decide when and where to have sex, that sexual and reproductive health issues are women's concerns, that men have the right to outside partners or relationships while women do not, and that child care and parenting are women's issues.

When the program started, the adolescents demonstrated little or no knowledge about sexual and reproductive health. The facilitators noted that physical violence was nearly always the first option taken when conflict arose. The adolescents' opinions and perceptions overwhelmingly reflected the prejudices of the macho culture within which they were growing up. By the end of the three-month program many of the boys spoke of how their perceptions, attitudes and behaviours had changed.

The boys of Program H

"Being part of this group has really helped me. Before, I spent all my time on the street getting into trouble and being chased by the police. Here in the group we talk about our lives. I can begin to see that I might be capable of more."

Augusto, aged 16

"Before, I used to feel embarrassed, but now I feel that I can talk about all I have learned here. Even at home things are better."

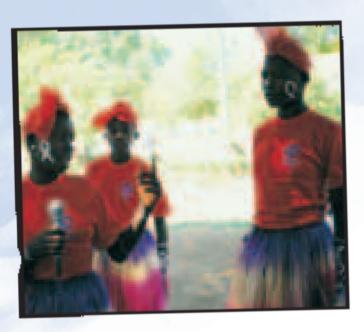
Paulo, aged 15

"All we used to do was fight and shout ... Now we can show that we care about each other ... I have learned to be more responsible and also to be less prejudiced against girls ... and I am not at all embarrassed to obtain and use a condom."

Junior, aged 16

Promoting youth-friendly health services

Each time Plan engages in a discussion with adolescents, we always hear the same story: health services in their communities are hostile to adolescents and young people. They are for adults, mothers and small children. Unmarried adolescents do not frequent them.



Adolescents do not have the money to pay the user fees. They do not trust the confidentiality of the services and often do not want to obtain the obligatory parental consent. When they have an issue related to their sexuality, be it a worry about pregnancy or concern about a genital discharge, they are hectored and insulted by the adult staff. Ironically, many national programs use health services to distribute condoms, promote family planning, and provide voluntary testing and counselling for HIV. These are services of specific relevance to adolescents, but often do not reach the intended audience.

Plan works with Ministries of Health, in most countries it works in, to make government health services more inviting and accessible to young people and to ensure that young people take part in defining and planning the services

they need. Most of this work is not captured in specific AIDS or sexual health projects. It nevertheless has a major impact on reducing children's vulnerability to HIV infection.

Many Plan programs actively support the establishment and promotion of facilities for voluntary HIV testing and counselling. Most Plan offices take a pragmatic approach, supporting services that are based in health facilities, while at the same time supporting services operated by community-based organisations outside the facilities. In both cases, accessibility to voluntary counselling and testing by adolescents and young people is the key to Plan support. Where national regulations prohibit testing below a certain age without parental consent, as for instance in Burkina Faso, Plan engages in national advocacy to change the policy.

Voluntary HIV testing and counselling is an entry point to HIV-related services for those who test positive. Plan believes that the testing services must be linked to an adequate offer of care, at the very least the offer of long-term support through a self-help group in the community. For those who test negative, the service must be linked to effective reinforcement of protective behaviours. Plan's support of HIV testing is therefore never an isolated stand-alone issue.

In Kenya, Plan works in fishing communities on the shores of Lake Victoria that are known for their high HIV prevalence. Although the level of knowledge about HIV in Kenya is high, uptake of services for voluntary HIV testing and counselling is very low. People are afraid of being tested and the benefits of knowing your HIV status are not appreciated, while another reason is the inadequacy of service provision.

To respond to this situation, Plan assisted the Ministry of Health to establish three sites for voluntary HIV testing and counselling. Youth volunteers who are trained as counsellors are present in all three sites. They work hand in hand with Ministry of Health staff to promote the services in the community.

Plan's support to voluntary HIV counselling and testing in this district is linked to a program of assistance to young people and children affected by AIDS. Because the community is very poor, there is a strong focus on livelihood support and income generation.

Developing youth leadership

Children and adolescents are not passive observers or 'victims' of HIV and AIDS. They have a primary role to play in the response. Reducing their vulnerability means giving them the opportunities and the tools to develop their own leadership on an issue that will profoundly affect their own future.

Plan's work with children and adolescents goes well beyond the universally accepted approach of 'peer education'. It is well established that knowledge transmitted by peers is more likely to be assimilated, and that behaviours supported by peer pressure are more likely to be sustained. Plan also respects the right of children and adolescents to define and to formulate the knowledge, attitudes and behaviours that they believe are important to transmit to their peers, and to support the development of skills among their peers that will permit them to make their own decisions.

This requires the development of leadership skills. In Benin, for instance, Plan worked with a group of 30 adolescents elected by youth clubs throughout the program area. Over the period of a year, the young people were trained in situation analysis and program development techniques. They conducted research and community consultations, and produced a project proposal to address priorities in sexual health as formulated by their peers. All of them are actively mobilising young people in their community to promote better sexual health.

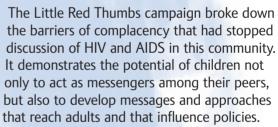
In a remote area of The Philippines, HIV was not considered an important issue. Only one case of AIDS had been reported in the entire province over a 10-year period. The Department of Education decree to incorporate AIDS education into the school curriculum was therefore not respected.

In collaboration with the Department, Plan organised youth health camps and health campaigns in schools. Over time, a group of youth advocates known as the 'Teen Health Vanguards' emerged.

To end the complacency about HIV infection in their communities, the Vanguards developed and launched an innovative campaign under the title 'Thousand Little Red Thumbs'. The concept was compellingly simple. Members of the group marked their thumbs with red ink. This aroused the interest of their peers, who wanted to know the reason and in turn encouraged a discussion about HIV and AIDS. More and more children started to sport red thumbs, indicating that they were informed about AIDS issues and ready to talk.

One of the participants described what happened when he arrived at school: "Everyone started to approach us, students and teachers ... That gave us the chance to talk to them personally." Others described how children came up to

> them in the street, and the way they joined in enthusiastically.





In Peru, Plan worked with a local secondary school in a very poor and marginalised rural community. The sexual and reproductive health of children was not considered a priority. Yet it was one of the communities most severely affected by AIDS in the country.

In partnership with the University of Peru, Plan developed a training program for teachers and a curriculum that was approved by the Ministry of Health and the Ministry of Education. The program emphasised how important it is for teachers to reflect on their own perceptions, attitudes and experiences.

Each grade in the secondary school then developed its own approach through a participatory process involving teams of teachers and students. The first grade decided to communicate about healthy lifestyles and healthy, responsible sexual behaviour through a newspaper mural. The second graders worked on strengthening their own communication skills in order to raise awareness about the importance of sexual health and of HIV prevention among parents. The third grade promoted the expression of ideas and information among peers by using community radio. The fourth grade strengthened skills for peer education and counselling. The fifth grade promoted interaction between young people and adults through community campaigns.

The key aspect of this initiative was the emergence of a dialogue between the generations involving teachers, students and parents. The interaction between teachers as facilitators and students as active participants fostered the idea that tasks and responsibilities could be shared. The program has had a marked impact on the personal and social development of the students, building self-esteem and promoting skills such as assertiveness, management of emotions, team work and negotiation. The students and teachers of this secondary school are now leading the way in their municipality on changing sexual behaviours and on advocating for the sexual health and rights of young people.

Throughout the world, Plan supports child media programs that enable children and adolescents to develop their skills and participate in discussions on matters that affect them. All these initiatives address HIV and AIDS issues directly and indirectly.

Some examples are children's newspapers such as Let's talk in Malawi, or Caja Magica in Colombia.

Plan's radio campaign in West Africa, 'I am a child but I have my rights too', covers seven countries, involving children between the ages of 6 and 18 in promoting children's rights. Based on stories adapted to each country's culture and produced by the children themselves in local languages, the radio shows prove that children can be eloquent and effective agents for change. The use of animal characters from the folklore of the various countries makes it easier for sensitive issues to be raised, and has proved popular among the audience. The children are not only involved in producing the five-minute stories, but also in subsequent debates, contests and interviews. Among the issues addressed in the broadcasts are AIDS, abuse and exploitation of children, genital cutting and child trafficking.

"This experience has been so useful to me. I have a brother who is infected... and now I can talk to my friends and colleagues at the school as well as in my community."

Deborah, teacher, Peru

"I can communicate better, I am more confident, my mother now feels really proud of me, of what I am capable of...she supports me..." Juancita, pupil, Peru

"When the story on early marriage was on the radio I told my father: 'This is my voice.' He listened and he understood what it was all about. He said: 'I will let you, my daughter, wait to marry until you are ready."

Child actor, aged 14, Guinea Bissau

"Caja Magica has taught me that it is not only adults who can write down their thoughts. Children can do so too."

Patricia, aged 11, a contributor to Caja Magica



Ending child marriages

By international convention, 18 years is the legal age for consent to marriage. Yet in many countries, girls are married at a much younger age, often against their will. If the current practice does not change, 100 million girls under the age of 18 will be married over the next 10 years, almost all of them to partners who are considerably older.⁷

Early marriage has many negative social and reproductive health effects on adolescent girls. It usually ends their schooling, it often isolates them from

their peers and it results in pregnancies at a young age, pregnancies that have very high rates of serious complications.

Of the generally recommended behavioural strategies for HIV prevention — abstinence, condom use and mutual fidelity — only the last remains an option, and it is beyond the control of the young bride. A study by the Population Council in 31 countries found that 80 per cent of unprotected sex by adolescent girls occurred within marriage. Other studies in Kenya and Zambia have found that married adolescent girls are more likely to be infected with HIV than their unmarried peers.⁸

Niger has one of the highest rates of child marriage in sub-Saharan Africa. To gain a better understanding of the issue, Plan entered into a partnership with a local non-governmental organisation to study the situation in a rural district of Dosso. Among women surveyed in this study, 68 per cent had been married before their first menstruation, 52 per cent had given birth before the age of 16, and 49 per cent had experienced complications during pregnancy or delivery.⁹

Yet, on the whole, men, women and children in Dosso district considered it appropriate for girls to marry between the ages of 14 and 16. Men regarded early marriage as a way of preserving the honour of their family. Women thought early marriage had magical attributes, and believed that a child born of a very young woman would be stronger, fiercer and more resilient.

⁷ Bruce, J. and Clark, S. The implications of early marriage for HIV/AIDS policy. Background paper prepared for the WHO/UNFPA/Population Council Technical Consultation on Married Adolescents. Population Council, New York, 2004

⁸ Glynn, J.R. et al for the Study Group on Heterogeneity of HIV Epidemics in African Cities. 'Why do young women have a much higher prevalence of HIV than young men? A study in Kisumu, Kenya and Ndola, Zambia', AIDS 15 (suppl 4), 2001

⁹ Brah, F., Soumana A., Mahamadou H., and Marou A. Early marriage in Niger. Presented at the International Conference for AIDS and Sexually Transmitted Diseases in Africa, Abuja, 2006

These findings formed the basis of a public education campaign using many different media and involving children, parents, religious leaders and traditional authorities. Community attitudes in Dosso have begun to change. Many parents now consider early marriage as a potential health problem for their daughters. With support from Plan, community schools have been opened where girls can continue their education, and a micro-finance program offers credit to young women to start their own business. At the national level, Plan advocates for the introduction of a law against early marriage.

The story of Lalmuni (Nepal)

When 14 year-old Lalmuni's parents decided she should be married, she knew it would be the end of her education. She was also worried about becoming pregnant and giving birth at such a young age. But her parents were adamant: the marriage would go ahead as planned.

In desperation, Lalmuni took her problem to her 'Child Club', one of 600 such clubs supported by Plan in Nepal. Her friends decided to meet Lalmuni's parents and to persuade them to change their minds. This was a highly unusual step for a group of young girls. Marriage in Nepal is a family affair. Outsiders, especially a group of teenage girls, have no say in such matters.

Lalmuni's parents listened to what her friends had to say but were unconvinced. Her father said: "We would have to give a lot of money in dowry if the girl marries at an older age. Are you going to give us this money?"

But the girls did not give up. They patiently explained the risks Lalmuni would face through an early marriage. They pointed out that although the family might save some money, this would be at the cost of their daughter's health and education, and it would affect her for the rest of her life.

Lalmuni's parents were profoundly affected by her friends' concern for her well-being. Eventually they changed their minds and let her continue her education. Today, Lalmuni is still attending school and is an active member of the Child Club.

Abolishing child trafficking

An estimated 1.2 million children worldwide are trafficked every year. ¹⁰ Child trafficking is a global problem, but it is particularly widespread in some regions, including West Africa and parts of South and South-east Asia.

In West Africa, large numbers of children are trafficked within countries and across borders to work under appalling conditions as farm labourers, domestic workers or in other menial jobs. They are often not paid, and they are subjected to abuse, including sexual abuse, on the journey with their traffickers or in the houses of their employers. Children are sometimes trafficked with the consent of parents who hand over their sons and daughters for small payments.

In Togo, Plan works in partnership with local organisations in an initiative called 'Stop Child Slavery'. The program raises awareness among children and adults of the dangers of child trafficking, strengthens community watchdog committees and mobilises youth groups to protect their peers. Plan and its partners have also set up shelters for intercepted and rescued children, and are providing counselling and other forms of support to survivors of trafficking.

In the booming sex industry in India's large cities, there is a high demand for child sex workers, not least because children are considered 'safer': in other words, less likely to be infected with HIV. As a consequence, many children in poor rural communities are abducted or lured into the cities where they are forced to work in the sex industry. These girls, and sometimes boys, are highly vulnerable to HIV infection.

The Child Trafficking and HIV/AIDS Project in Andhra Pradesh in India is an initiative of 21 local non-governmental organisations working in partnership with Plan to address this issue. Village-level vigilance committees have been formed, with members drawn from all occupational groups and castes. Each committee sets its own objectives and determines the best way to stop the trafficking of children from their communities. Clubs (sanghas) of adolescents and of younger children are raising awareness of child rights and human rights among the more than 20,000 girls and boys in the project's operational area. Some popular folk artists of Andhra Pradesh are volunteering their time to coach children in the skills and techniques of expressing themselves and delivering their messages through song and theatre.

The initiative is receiving much public attention. It has raised awareness about child trafficking among children and adults, and it has increased the vigilance of the community to stop the practice.

¹⁰ www.endchildslavery.org.uk

The story of Keerthi (India)

Keerthi, aged 13, lived in a poor and family in rural Andhra Pradesh. Her mother and stepfather showed her little affection. Perhaps to compensate for the neglect, she started to fantasise about a glamourous life in the city, and she became obsessed with cosmetics.

Vijaya, a 'friend', arranged for her to meet a man named Pandu, for whom she was acting as an intermediary. Pandu's offer of a job as a domestic worker in the city was enough to persuade Keerthi to go with him. But when she was deposited in a brothel in Mumbai, she realised how cruelly she had been tricked.

After 10 days of being forced to work as a prostitute, Keerthi managed to run away. She boarded a train without a ticket and almost reached home before being discovered by a ticket inspector. A community worker found her crying, and calling out for help in a rural railway station. She took her to a transit home for rescued children in a nearby provincial town.

Meanwhile, a local organisation working in partnership with Plan in Keerthi's home district contacted her family and the head of her village. Negotiations were held about the type of help and support the child would need. Keerthi was also consulted. She suffered from severe trauma and she needed professional help from a child psychologist.

Eventually she was able to return to her family. As with other returned children, the local organisation will follow her progress for at least six months.



Extending the life of the parent-child relationship

No program or initiative for the care and support of children affected by AIDS can replace the care of their parents. In some societies children are routinely raised by aunts or uncles and the concept of 'parent' is somewhat flexible. Yet, even in these societies, the premature death of parents and guardians is a threat to the rights of children to a family life as defined in the United Nations Convention on the Rights of the Child.

Plan therefore supports programs and initiatives that provide treatment and care to adults living with HIV. These programs are usually conducted in partnership with organisations that specialise in delivering medical services, most commonly the Ministry of Health.

Given Plan's profile and expertise, the most appropriate and useful contributions by Plan to this program area is through institutional support to organisations offering health care services, and by mobilising community support for HIV treatment. Drugs and laboratory tests are only a very small part of what is required to keep parents with HIV alive. Plan focuses on improving nutrition and food security, livelihood, emotional support and community mobilisation to eliminate stigma and discrimination. These important needs are often overlooked in the international discussion about access to HIV treatment.



Program examples

The following examples illustrate the range of programs Plan supports in its attempts to extend the life of the parent-child relationship. They are not an attempt to be all-inclusive, but rather an illustration of the range of activities that can be found in this program area.

Preventing HIV transmission from parents to children

In Uganda and in Benin, Plan supports the Ministry of Health in delivering services to prevent HIV infection among infants during pregnancy and delivery. This is a complex task, not just a simple question of providing a few pills during obstetric delivery.

The entry point for parents into these programs is the offer of voluntary HIV counselling and testing to pregnant women and their partners. In some communities, most pregnant women attend antenatal services. In others, it may be as few as one in three. Making antenatal services accessible and acceptable is therefore often the first hurdle that has to be overcome.

Women who test positive need psychological, social and medical support. In Uganda and Benin, Plan supports community associations and groups that provide much of the needed social and emotional support to these women. Both programs also support the delivery of enhanced health care services to women living with HIV. These services are provided by the government health facility. Through its support, Plan aims to achieve a systematic improvement in the care and services offered to pregnant women. This applies to those who are living with HIV and to those who are not.

If the father of the infant is not involved early in the program for HIV prevention, success will be very limited. This is why Plan refers to preventing parent-to-child transmission rather than preventing mother-to-child transmission. Both the programs in Benin and in Uganda emphasise the participation of men in the care and delivery of the infant. This is emerging as a very difficult aspect of all programs that are trying to achieve a reduction in paediatric HIV infections. It requires community consultations and an intensive effort of individual counselling and community mobilisation. This is an area of programming for which Plan is especially well equipped.

Malaria during pregnancy among HIV-positive women greatly increases the risk of infecting the infant with HIV. Preventing and treating malaria is therefore a major component of Plan's effort to reduce HIV transmission from parents to children.

The programs in Uganda and Benin are barely one year old. Within their first year, each helped provide services to between 200 and 300 pregnant women who tested positive for HIV. It is too early to report how many HIV infections among children have been averted because locally available diagnostic tests are unreliable for children under one year of age. But the main achievements of the programs can already be assessed in terms of improved quality and improved use of maternal health services, and of services to diagnose and treat HIV infection. These are the types of results that will help the effort to increase the life of parent-child relationships in communities affected by AIDS.

The story of James and Nyapendi (Uganda)

Forty-five year-old James lives with his two wives, Nyapendi and Nabwire, and their children in eastern Uganda. When Nyapendi became pregnant she agreed to be tested for HIV and found out that she was HIV-positive. But she was afraid to tell her husband. Instead, she agreed that the social worker would visit the family and talk to him.

James welcomed the social worker, and the discussion soon turned to the subject of AIDS. The social worker suggested that, these days, people should know their HIV status. James agreed, and the social worker asked him when he was planning to be tested.

James avoided answering the question until Nyapendi had left the room. Then he confided that he had already been tested in a neighbouring town, and had been found to be HIV-positive. However, he had not informed either of his wives because he was afraid they would desert him.

During subsequent visits, the social worker convinced James to disclose his HIV status to his wives. James and Nyapendi's baby was born with medical assistance and with anti-retroviral coverage during the delivery. The parents are now waiting for the baby to reach an age when she can be tested to find out whether she has escaped infection with HIV.

Supporting home-based care

In Haiti, Plan supports the work of the Maison l'Arc-en-ciel to deliver home care to children and families affected by AIDS in some of the poorest and most unstable neighbourhoods of Port-au-Prince. Initially, the home visits were conducted by a social worker and an auxiliary nurse. But the teams were soon expanded to include community volunteers, the 'Delegate Mothers' ('mères déléguées') who are themselves women living with HIV.

In 2003, the deteriorating security situation made it unsafe for outsiders to enter the poor neighbourhoods of Port-au-Prince. The visits of the professional home care teams had to be abandoned, but the Delegate Mothers continued their work. Today nine volunteers provide home care to 165 families with more than 500 children and adults.

The volunteers are elected for a term of six months. Many of them are re-elected at the end of their term. They are trained in primary care and other home care tasks, and are given a schedule of visits. They help with household chores and child care, check on the health status and well-being of the children, and ensure that medication is taken regularly. They arrange medical consultations and help parents when they have difficulties obtaining services at the hospital. They are more than home care workers — they are friends and the backbone of support for families living with HIV.

The Delegate Mothers take great pride in their work and keep to their schedule closely. They meet every two weeks with a social worker to give a verbal report on their activities, because most of them cannot read or write. They discuss what they have found during their visits, and work jointly on solutions to problems experienced by families in their care.

The program has been highly successful. The confidence of the Maison l'Arc-enciel in the Delegate Mothers has motivated them in their work, greatly increased their self-esteem and given them renewed hope in their own lives. The positive energy of the Delegate Mothers has proved to be infectious and is a source of renewed hope among families living with HIV in the poor neighbourhoods of Port-au-Prince.

Living positively and preparing the family for transition

In many communities where Plan works, children are being raised by parents who are ill or dying of AIDS. Recent advances in providing maintenance treatment for HIV infection have not yet reached most people living with HIV, especially in rural areas of Africa. Children of mothers living with HIV often find themselves in very difficult circumstances. This applies especially to adolescent girls. They may carry an enormous burden of family responsibilities; meanwhile they may not receive much external support because they are not 'orphans'.

Plan responds to this situation with initiatives that strengthen community and family coping mechanisms, and that help develop community-based structures and services that offer counselling and social support (relief and peace of mind) to families and children who have a loved one living with HIV or AIDS.

Program examples

The following examples illustrate the range of programs Plan supports in its attempts to help families affected by HIV to live positively and to prepare for the

possible premature death of a family member. They are not an attempt to be all-inclusive, but rather an illustration of the range of activities that can be found in this program area.



Supporting associations of people living with HIV

Self-help groups and associations of people living with HIV are a cornerstone of Plan's community-based response to AIDS. Wherever Plan supports services for voluntary HIV testing and counselling, there is a need to make sure that those who test positive have continued social, emotional, psychological and spiritual support. There are few, if any, government or other services for people living with HIV in most communities where Plan works. Self-help groups have many roles. They often fill an

urgent service gap for people living with HIV, they engage in community education and awareness-raising on issues related to HIV infection, and they are advocates for the rights of children and families affected by AIDS to receive appropriate services.

Associations of people living with HIV take many forms. Most of them also include members who are not HIV-positive. In communities where HIV infection is

stigmatised, the groups may be very discreet or they may present themselves under a different title, as for instance the 'post-test clubs' in some communities.

The groups may focus on delivery of home care services, on supporting children and families affected by AIDS, on income-generating activities for their members, on public education and awareness-raising, on encouraging people to go for voluntary counselling and testing, on operating or supporting voluntary HIV counselling and testing centres, or on managing a community pharmacy for the families of their members. Most take on several of these roles.

There are many self-help groups of people living with HIV that are supported by Plan. Most are in Africa and Haiti where there are larger numbers of people living with HIV and where they often play a pivotal role in helping families cope with the impact of AIDS. In communities where HIV infection is rare, and in sparsely populated rural communities, it is more of a challenge to facilitate the formation of self-help groups.

The story of Sophie (Zimbabwe)

"The change for me from being in the group is that I know now that I won't die immediately, I can stay alive and keep my children healthy and if possible keep them in school. I am now living positively. Before we joined, I was very angry with my husband, because I think he was unfaithful and brought me this thing, but we have had counselling from being in the group, now I feel sorry for him because he is sick too. I love him and I am focused on keeping us both healthy.

"I have been in the group for three years. The group is a godsend, I was bedbound and now because of better nutrition I am back on my feet. I manage to keep my house clean, I am mobile now, I can do things for myself. When I am sick the children help. When I have pain, I can go to the clinic. But often I just ask other group members to get me some paracetamol or give me advice. When I am bed-bound they visit frequently."

Reducing stigma and discrimination

The stigma associated with HIV and AIDS is a formidable barrier to effective prevention and care. Most agencies involved in the response to AIDS at national and international levels have adopted the objective of reducing stigma and discrimination. But there are many questions about how to do it.

Public education to reduce the fear of contagion by HIV may be useful, but it is insufficient to change ingrained beliefs and attitudes. Nevertheless, it is one avenue to pursue. Plan therefore entered into partnership with a popular Frenchlanguage youth magazine, Planète Jeunes, in 2005 in a campaign entitled 'My friend has AIDS, he is my friend'. The magazine targets young people of African origin in French-speaking countries of Europe, Africa and the Caribbean.

An elementary step for Plan is to avoid the creation of stigma in the first place. Plan programs are committed to avoiding any activity or message that reinforces existing beliefs that HIV infection is the result of immoral or socially reprehensible behaviour, or that link HIV infection with identifiable groups. In this sense Plan avoids reference to 'AIDS orphans' or to 'high-risk groups'.

Plan is committed to lead by example. Plan staff throughout the world have participated in a sensitisation program developed by Plan, with the assistance of HIV-positive educators, designed to reflect on our beliefs, prejudices and behaviours and the reality of living with HIV. At the international level, Plan has a staff AIDS policy that specifically protects HIV-positive employees from discrimination. This policy is restated at many of Plan's country offices, in the context of local employment legislation.

The most promising initiatives to end discrimination are being undertaken by people living with HIV or by support groups of people living with HIV. Plan assists such groups in many countries to engage in a dialogue with their communities at their own chosen pace in order to gradually reduce fear and stigma of HIV infection.

Finally, attitudes towards AIDS and towards people living with HIV are formed at a young age. Once established, they are difficult to change. Plan programs throughout the world work with children in and out of school. Our work with young children is carefully developed so that it does not instil fear and rejection in young minds. Reduction of AIDS stigma is a popular theme in Plan-supported children's radio programs, conceived and recorded by children in dozens of languages throughout the world.

The story of Nomalanga (Zimbabwe)

When 12 year-old Nomalanga attended a children's participation workshop organised by Plan, she was subjected to taunts and insults from other children: "Your father and mother died from AIDS," they said. Nomalanga felt humiliated and rejected. Later, in a tearful counselling session, she explained: "My friends say that because my father died of AIDS, this means he was an immoral person."

The workshop organisers responded swiftly, explaining to the other children why Nomalanga was so distressed. The children then decided to perform a drama on the theme of stigmatisation and AIDS. This time, however, the roles were reversed, with Nomalanga playing the role of one of the children taunting a child who had lost her parents to AIDS. In this way, Nomalanga's humiliation was turned into a positive learning experience for the whole group, who then staged it in other schools in the area.

Planning for succession

In 2001, a study in Uganda, conducted by Horizons in partnership with Plan found that more than one in five orphans and widows had lost all or part of their inheritance because of theft by relatives. Uganda's national law provides for the inheritance rights of widows and orphans, but many people are not knowledgeable about their rights or equipped to deal with disputes within extended families.

Plan therefore entered into a partnership with the Association of Uganda Women Lawyers (FIDA) to provide legal aid to people living with HIV and AIDS. Plan and FIDA aimed to raise awareness among women and children about their rights of inheritance, follow up cases of violation of these rights, and reinforce universal birth registration as an essential first step towards protecting the property rights of orphaned children in the future.

In Tororo, FIDA conducted community seminars on legal aspects of HIV and AIDS; provided legal counselling outreach sessions linked to HIV testing and counselling services and post-test clubs; produced and distributed information material on succession planning; trained volunteers to assist families in preparing wills; and provided dispute resolution



services. In the minority of cases where negotiated agreements could not be reached, FIDA took action through the court system on behalf of clients.

An evaluation after almost three years of the program in one district found a significant reduction of legal rights abuses. Women were more aware of their rights, and more confident about seeking redress when family members tried to deprive them of their inheritance. More and more people started to report cases of property grabbing to local courts, and there was an increase in inheritance disputes being settled through out-of-court dispute resolution.

¹¹ Horizons Program, Makerere University, Plan Uganda. Succession planning in Uganda: Early outreach for AIDS-affected children and their families. Horizons/Population Council, Washington, 2004

A letter for Evelyn (Uganda)

"My favourite memories of you go back to the day when you were born in 1990. When you came into this world vou were such a nice and lovable baby, admired by all. Christmas of 1998 is also a special memory. This was when you told me that you wished your daddy was still alive so that you and your sister could have received a pair of trousers, just like the other children in school. Needless to say, I scraped together everything I had and bought you and your sister new clothes for the New Year."

Written by Evelyn's mother, Christine, shortly before her death

The story of Joice (Uganda)

"I was one of the first people trained by FIDA. We received training in human rights, the rule of law, will writing, inheritance, and how to deal with cases of domestic violence, defilement and rape.

"People know that we are FIDA volunteers, and that we are there to help them. When someone has a problem they come to us. If the cases are difficult we refer them to FIDA. Most cases have been settled amicably.

"I know that people living with HIV and AIDS are suffering from the violation of their rights. You may find that when a man dies, clan members come and chase the widow away from the home. They grab all the property and even blame her for bringing the disease into the family. But since FIDA came and trained us we are living peacefully. People know that the law will deal with them if they violate our rights. This is good, we are happy."

Keeping the memory alive

In Uganda, Plan supports community partners to deliver family therapy using memory books.

The memory book, developed in the UK and pioneered in Uganda by the National Community of Women Living with HIV/AIDS, is a way to help both children and parents prepare for life after the death of one or both parents. The book is divided into about 30 sections, for example 'Your birth', 'As a baby, you ...', 'The story of your family', 'People who are special to you' and moves through to 'My hopes for your future'. Written by a parent, the book may also contain photos, drawings, postcards, certificates and letters from key stages of the child's life.

Keeping a memory book is part of succession planning and serves three main purposes: it opens the discussion between parents and children about the health condition of one or both parents; it helps parents and children plan jointly for the children's future; and it establishes a record of the family history and of important childhood memories as an anchor for the child in later life.



Ensuring the child's future

Plan's corporate vision is of a world in which all children achieve their full potential. This applies to children affected by AIDS as it applies to all other children. Ensuring the future of children means making sure that their rights to survival and development are respected in every sense.

The number of children orphaned by AIDS is a powerful indicator of the level of distress experienced by communities. But there is a consensus among all major international agencies working with children that targeting children orphaned by AIDS is poor practice. It is more efficient, effective and equitable to develop programs and policies that offer protection and deliver social services to all children in need. Some Plan programs assist children affected by AIDS by supporting the social safety net for all children. Others focus more directly on children who are at risk of slipping through this net. Sometimes this is directly related to HIV infection; at other times the relationship is less obvious.

Program examples

The following examples illustrate the range of programs Plan supports in its attempts to help ensure the future of children affected by AIDS. They are not an attempt to be all-inclusive, but rather an illustration of the range of activities that can be found in this program area.

Universal birth registration

Plan's efforts to promote universal birth registration are a good example of a general initiative for child rights that is of special significance in the context of AIDS. All children have the right to a legal identity, but children in communities severely affected by AIDS have specific and severe problems when their birth is not registered.

Many of them will be orphaned before they reach adulthood. Without proof of identity, and often without a responsible adult relative to vouch for them, they may encounter additional difficulties in claiming their rightful inheritance, and they may not be able to register in school. They may be more easily exploited, trafficked or forced into child marriages.



Universal birth registration is a global priority for Plan, pursued in almost all countries where Plan works. Children are active participants in national and local campaigns. They are often the best advocates, persuading their parents to register their brothers and sisters. They can also influence policy decisions at national and international levels.

In The Philippines, children's participation in a birth registration campaign helped overcome the opposition of traditional leaders. In a meeting of leaders from 110 different groups, the presence and the encouragement of children provided the incentive that finally unified the assembly to support the campaign.

Meeting livelihood challenges

In Machakos, eastern Kenya, Plan works with a local self-help group to revive the traditional occupation of goat farming in an impoverished community severely affected by AIDS. The Kamba goat used to be the principal source of income for the Akamba people. But over the last two decades the herds had almost disappeared. Today, hundreds of goats are again grazing the extensive pasturelands in the area.

The program started when the local partner organisation obtained a small grant to buy a herd of 55 goats. The goats were given to families living in severe poverty, most of whom were headed by elderly women looking after their orphaned grandchildren, who were encouraged to breed them. Kamba goats procreate on average every six months. They provide milk for domestic consumption, and meat and hide for income.

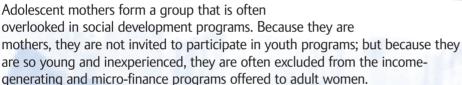
The initiative, entitled 'Goats for Growth', is closely linked to community education and mobilisation on HIV and AIDS issues, including the reduction of HIV-related stigma, and the establishment of a centre for voluntary HIV testing and counselling.

The Goats for Growth program has restored the hopes of many, according to the local coordinator. "We had almost accepted that we would have to co-exist with poverty. Then we saw that instead of suffering individually, we could change our lives by clinging together."

Education and vocational training

Two examples of programs for educationally marginalised children come from Guinea and Malawi, on opposite ends of the African continent.

In Malawi, Plan works with a community-based organisation to support vocational training of adolescent girls, including young mothers, in tailoring and tin-smithing. Both trades are considered to be a male domain, but with the high rates of HIV infection in Malawi, the barriers between male and female responsibilities are beginning to soften.





Stella is 17 years old. She dropped out of school after grade three when both her parents died of AIDS. Her older sister took her in. She was treated like a servant, and there was no question of her resuming her education. When she wanted to enrol in a Plan-supported program to learn tailoring, her sister did not approve. Her peers were also dubious. Why should she waste her time learning a trade reserved for men? But Stella persisted.

After six months Stella graduated and now has her own tailoring business. She makes school uniforms, girls' dresses and other garments. Stella is proud to be able to fend for herself. "Before I started this business I had no money even for basic items like soap or clothes, but now I am able to buy all these things, and even support my sister's family. My sister has changed her attitude and is very accommodating," observes Stella. "I have also opened a bank account so that I can continue to support myself when business is slack."

Besides running her own business, Stella is training another girl in tailoring. "I enjoy doing that," she says, "because I want to encourage the spirit of self-reliance and economic empowerment among other girls, especially those who have a background like mine."



In Guinea, Plan entered into a partnership with a local association to assist children who had dropped out of school because they were orphaned, lacked parental supervision or lived in extreme poverty. Initially, 106 boys and 94 girls entered the program; 150 of them enrolled in primary school and 50 in vocational training. After one year, only two children had dropped out of the program, and one had died.

The program pays the school fees, uniforms and supplies, and it provides tools for the apprentices. But it soon became clear that children entering the program suffer multiple deprivations. Many are sick or chronically under-nourished. If they have families, the entire family is often on the brink of starvation. Plan's partner organisation has therefore negotiated additional assistance for nutritional and medical support with other international agencies.

Medical care for children living with HIV

In Mali, Plan supports centres for voluntary HIV testing and counselling operated by community groups in remote areas. In 2003, the government of Mali adopted a policy of providing anti-retroviral treatment free of charge to children under the age of 15. The treatment, however, was only available in two central hospitals in the capital Bamako. It was inaccessible to the almost 100 children with HIV living in and around the Plan-supported HIV testing sites.

Plan therefore entered into a partnership with a private Malian foundation operating a paediatric hospital in Bamako. The two organisations set up a reception centre for HIV-positive children from rural areas in the vicinity of the hospital.

The reception centre provides transport for the children and their primary guardian to Bamako to fit in with their established treatment schedule. After clinical and laboratory examinations, and after the appropriate drugs are dispensed, the children return home. The local hospital and the community self-help group make sure there is medical and psycho-social support between visits to Bamako. Generally, the children and their primary quardian spend two to four days each month in Bamako.

The reception centre opened in April 2004 with its first 20 children. By December 2005, a total of 190 HIV-positive children had passed through the centre for assessment, and 82 were on anti-retroviral treatment.

At an estimated average cost of US\$650 per child per year, this program is expensive. This cost, however, is an indication of the real cost a family would have to bear for the medical treatment of their HIV-positive child, in a country where anti-retroviral treatment is 'free of charge'. This financial barrier is insurmountable for all but a very few families in Mali.

The objective of establishing the centre was to provide an interim solution while anti-retroviral treatment facilities were decentralised throughout Mali. By the end of 2005, two provincial hospitals offered anti-retroviral treatment, in addition to the two central hospitals in Bamako. Further expansion of services is planned. The clients of the reception centre constitute a critical mass of children on anti-retroviral therapy in the provinces. Without this group, decentralisation of services would be very difficult.

The story of Fanta (Mali)

Fanta is five years old and HIV-positive. She lives in a provincial town a day's journey from Bamako. Since the death of her mother nearly three years ago she has lived with a friend of her maternal grandmother, whom she calls Mah. Her father has no contact with her and is unaware that she is ill.

Mah describes Fanta as a survivor. The child was critically ill when her grandmother brought her to Mah, desperately seeking help. This is when she was diagnosed with HIV infection.

When the reception centre for children living with HIV opened in Bamako in April 2004, Fanta was one of the first children to be examined. She was found to have a CD4 count of only 50 and was swiftly put on anti-retroviral drugs. She was kept under careful medical supervision at the centre for a fortnight, after which she had recuperated sufficiently for the long journey back to her home town.

Fanta now comes to Bamako every two months for treatment, accompanied by a volunteer from a local self-help group of people living with HIV. Mah herself is not free to go as she is a market trader, and the sole provider for her family, consisting of her grandchildren, Fanta and herself.

To Fanta's delight, Mah has promised to enrol her in school next year, as long as she is well enough. Fanta is taking her medication every day and is making excellent progress.

Future directions

HIV epidemics around the world are evolving, sometimes in unexpected directions. The international response to AIDS is also changing in scale, focus and in its method of program delivery. Meanwhile Plan is also evolving as an organisation and exploring new approaches to effective programming.

This makes predicting future directions a very risky business. Change is often the only certainty in such an environment.

Nevertheless, some directions are emerging clearly. Internationally, the response to AIDS has experienced enormous growth. While children are still left behind in this response, they are increasingly being included. Plan sees its role as a key agency able to contribute to advocacy for the participation and inclusion of children in the decisions that govern the international response to AIDS. Plan shares this role with a number of non-governmental and United Nations organisations, and will continue to work in partnership with them in advocating with and for children.

With the increasing volume of international assistance to AIDS programs, we are seeing an increasing decentralisation of funding and decision-making to country level. At the same time, there is a call by international agencies to harmonise and coordinate assistance to AIDS programs in countries under the 'Three Ones' principles: one national action framework, one national coordinating authority and one national monitoring system.

Plan supports this initiative in principle. In Mali, for instance, Plan has changed its role from an organisation that mobilised funds and used them to provide technical and financial support to community-based groups, to an organisation that is contracted by government to provide technical support to governmental and non-governmental AIDS programs, with resources mobilised by the Government of Mali from multi-lateral sources. In several other countries, Plan has joined the government and civil society partners in submitting program proposals to the Global Fund to Fight AIDS, tuberculosis and malaria, and in implementing these programs within a national framework.

However, as this publication demonstrates, many of Plan's actions in response to AIDS are not typical 'AIDS programs'. Being child-centred means transgressing the boundaries of professional or thematic categories. Many activities supported by Plan will never be part of a national AIDS program, although they will have a profound impact on how children and communities experience HIV.

Plan's greatest strength lies in its flexibility and adaptability to children's needs and rights in different communities. It is the unique contribution that Plan brings to the international response to AIDS – a contribution that will be reflected in the lives of children rather than measured in curves drawn by epidemiologists and economists.







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