

Where prevention and care meet



Where prevention and care meet:

voluntary counselling and testing, and preventing mother-to-child transmission

Prevention and care are inextricable elements of an effective response. One without the other undermines the chances of success but, together, they create a powerful synergy. Voluntary counselling and testing (VCT) and the prevention of mother-to-child transmission (PMTCT) are examples of how effective critical HIV/AIDS interventions can be when integrated.

Voluntary counselling and testing

Voluntary HIV counselling and testing are key components of prevention and care programmes. In prevention, VCT helps people learn about how HIV is transmitted, practise safer sex, get a HIV test and, depending on the result, take steps to avoid becoming infected or infecting others. Within care programmes, HIV test results and follow-up counselling mean people can be directed, towards relevant care and support services, such as treatment for tuberculosis and sexually transmitted infections, family planning and, where indicated, treatment for opportunistic infections, treatment with antiretrovirals and prevention of mother-to-child transmission. In addition, wider access to VCT may lead to greater openness about HIV/AIDS and less stigma and discrimination.

Central to prevention

VCT is a proven preventive strategy that should become an integral part of HIV prevention programmes in all countries. For example, in a recent randomized trial of

individuals and couples in Africa and the Caribbean, a total of 3120 individuals and 586 couples in Kenya, Trinidad and Tobago, and the United Republic of Tanzania were randomly assigned to either a VCT group or a basic health education group, with the option of VCT provided as follow-up a year later. The VCT group self-reported a 35% reduction in unprotected sexual intercourse with both steady and casual partners during the year following the initial testing and counselling, compared with a 13% reduction in the group that received basic health information. Individuals in the comparison group who accepted counselling and testing at the first follow-up visit self-reported a drop in the level of unprotected intercourse, equal to that of the initial VCT group after one year.

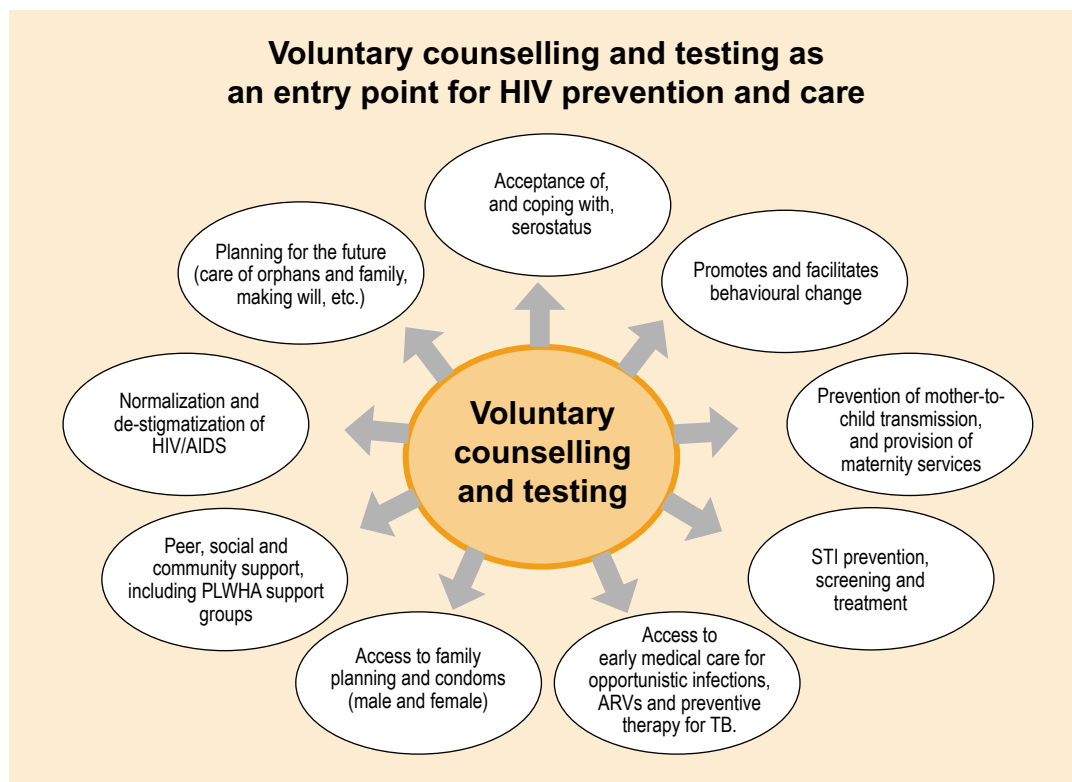
It should be emphasized that access to VCT is recognized as a critical strategy in responding to HIV/AIDS in low- and middle-income countries, as well as in high-income countries with advanced health systems. In the United States of America, where an estimated 25% of

HIV-positive people do not know their HIV status, the Centers for Disease Control and Prevention has made VCT a cornerstone of its 2001–2005 strategic plan for HIV prevention. The plan aims to increase the number of providers who routinely provide VCT in health-care settings (for example, sexually transmitted infection clinics, substance-use treatment programmes, family planning clinics, emergency rooms, community health centres), as well as in non-clinical venues (e.g., social venues, public assistance programmes, street outreach).

In view of the number and complexity of issues relating to HIV testing in UN peacekeeping operations, and in response to concerns expressed by members of the UN

Security Council, the UNAIDS Secretariat, in close consultation with the UN Department of Peacekeeping Operations, initiated a comprehensive review of United Nations policy in this area. The UNAIDS Expert Panel on HIV Testing in UN Peacekeeping Operations was established to assist in this effort. The panel unanimously recommended voluntary HIV counselling and testing as the most effective means of preventing the transmission of HIV, including among peacekeepers, host populations, and the spouses and partners of peacekeepers. The panel stressed that VCT should be provided to peacekeeping personnel within a comprehensive package of integrated HIV prevention and care programmes. The panel also noted that VCT has been shown to be

Figure 28



Source: UNAIDS (2002)

more effective than mandatory HIV testing in promoting safe sexual behaviour and reducing other risks involved in HIV transmission.

The main entry point to care services

As illustrated in Figure 28, VCT is the main entry point for care and support services. Furthermore, with plans for expanded antiretroviral drug access (both for treatment and prevention of mother-to-child transmission) in many countries, there will be an increasing need for hospitals and community care programmes to provide VCT. This stems from the simple fact that antiretrovirals are of little use unless people know their serostatus. In addition, ongoing counselling will be necessary to ensure that people taking antiretroviral therapy are supported, adhere to regimens and cope with possible adverse effects. Family and couple counselling will be particularly beneficial both for adherence and support in the context of preventing mother-to-child transmission. It is all the more important, therefore, to ensure that testing is supported by effective counselling with adequately trained counsellors, in user-friendly locales, and with guaranteed confidentiality.

Programme expansion is necessary and possible

While there are many examples of high-quality VCT services in low- and middle-income countries, most are concentrated in major urban areas, on a small scale. This means VCT is currently unavailable for the vast majority of people who could benefit from it. Expanding VCT services is therefore a cornerstone of the UN System Strategic Plan for HIV/AIDS 2001–2005, and the UNGASS

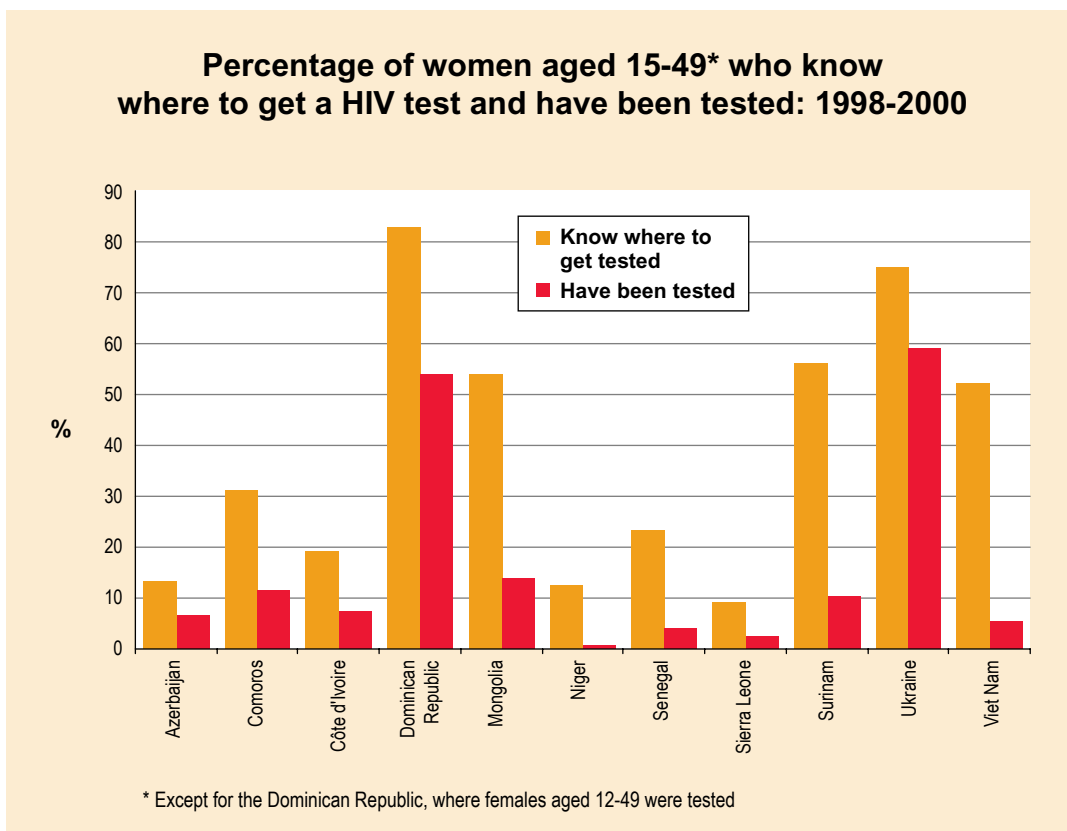
goals of reducing HIV prevalence among young people and infants by 2005.

In addition to expanding availability of VCT, people need to be encouraged to use those services where they do exist. As with other HIV prevention and care interventions, people living with HIV/AIDS have an important role to play in the design and development of VCT services, wherever they are implemented. As Figure 29 shows, only a tiny percentage of women in several African countries have been tested, despite the fact that a considerably larger percentage knew where they could go.

Rapid HIV tests are now available and can be carried out by staff with no formal laboratory training. This removes one obstacle to expanding services in rural areas and in small sites where laboratory facilities are not available. Many countries are now gradually expanding VCT as part of public health-care systems. However, external quality control and strong supervision to ensure high quality of testing remain essential.

An example of successful expansion is Uganda's AIDS Information Centre (AIC), which grew from a single site in 1990 to 51 in 2001, and which has tested more than half a million people. Since 1997, it has offered rapid testing with same-day results, along with related services such as syndromic management of sexually transmitted infections, tuberculosis preventive therapy, family planning, and referrals to and from other AIDS service organizations. Costs are subsidized and, for at least one day per week, VCT is free. The AIC has shown that couple testing can be implemented if approached carefully and consistently. The proportion of people requesting VCT as couples from AIC has

Figure 29



Source: UNICEF (2000) Multi-Indicator Cluster Survey 2

increased from 8% of all clients in 1992 to nearly a third in 2001, with about a quarter of these couples requesting HIV testing prior to marriage. Overall, male and female attendance rates are similar.

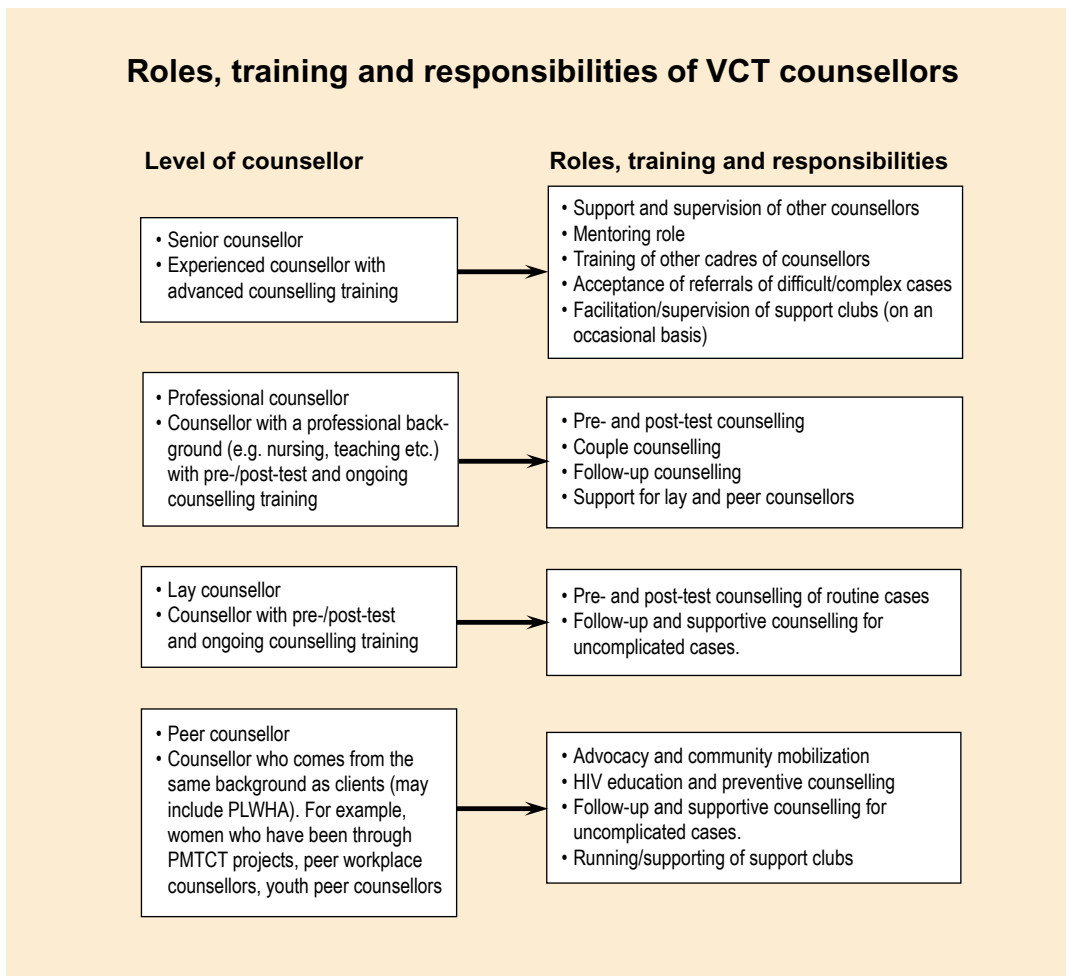
Strategies for expanding services

Finding enough trained counsellors can be a major challenge to the expansion of VCT services, but innovative approaches may help. In programmes for preventing mother-to-child transmission in Botswana, for example, clinic-based group counselling, video sessions and use of 'lay' counsellors and community-based counselling services are being used as a way

to reduce the length of the individual pre-test counselling sessions.

Staffing requirements should not be underestimated when expanding VCT services. The background, training, roles and responsibilities of people carrying out pre- and post-test counselling vary widely. In many VCT projects, most counsellors are nurses or social workers who have had additional HIV counselling training. However, due to a shortage of nurses and social workers, counsellors also need to be drawn from other walks of life. An example of a model for different roles, training and responsibilities is shown in Figure 30. It is useful to have senior counsellors that can

Figure 30



Source: UNAIDS (2001) Report from WHO/UNAIDS Technical Consultation on Voluntary HIV Counselling and Testing

provide support and supervision to the other counsellors and accept referrals of more complex cases. Ongoing support and supervision of counsellors, whatever their background, are needed if high-quality counselling is to be provided and burnout and a high turnover of counsellors are to be avoided.

One useful strategy is to link HIV-focused services with related services, notably those dealing with antenatal care, family planning, sexually transmitted infections (see

'Prevention' chapter) and tuberculosis. For example, effective tuberculosis treatment can dramatically enhance both quality of life and longevity, as well as help control the disease within the wider community. The World Health Organization's ProTEST initiative (which links HIV and tuberculosis programmes and general health services) promotes HIV counselling and testing as a response to tuberculosis in settings where HIV prevalence is high. Several successful

ProTEST sites have been set up in sub-Saharan Africa and others are being developed in Asia. Evaluation indicates that the approach is very effective. The Central District ProTEST in South Africa, for example, has found a 95% acceptability of HIV testing following pre-test counselling among all persons attending.

One of the most innovative recent approaches to delivering VCT services is through social marketing, in which 'social products' (notably condoms) are promoted. In Zimbabwe, for example, the New Start programme uses franchising to provide VCT services, and is creating a national VCT network with a common logo and name, which is promoted through media and information campaigns. The National AIDS Commission launched the New Start programme in 1998 with Population Services International (PSI) and USAID. High-quality counselling and testing services are offered at the programme's centres, with same-day results available at most of them. All sites use a standardized counselling and testing protocol developed in accordance with Zimbabwean Health Ministry guidelines. Free services are offered for clients unable to pay the standard fees.

Targeting VCT

Generalized VCT services are important, but cannot effectively reach all populations who need them. Targeted programmes—either using separate facilities or via communications campaigns—are necessary for specific groups, such as young people and couples, and for vulnerable populations, such as injecting drug users and sex workers.

VCT directed towards young people is being implemented in many countries (see 'VCT for

young people: Kara Counselling and Training Trust' box). A recent study from Kenya and Uganda showed that young people valued the counselling aspect of VCT. Most of the young people tested disclosed their test results to someone and intended to practise safer sex. The study also found that the vast majority of untested young people wanted to take a HIV test. However, young people's reasons for attending VCT and their needs following VCT can be different from those of other age groups. Training is needed to enable counsellors to communicate with young people and grasp their particular concerns associated with HIV infection and prevention. For young people under the age of majority, consent to testing and disclosure of HIV tests are issues that need to be addressed in the delivery of VCT services.

Care and support for sex workers is another important approach in HIV prevention (see 'Prevention' chapter). In Kinshasa, Democratic Republic of Congo, a programme offering VCT, screening and treatment of sexually transmitted infections, group discussions about prevention, and free condoms for sex workers has increased condom use and reduced the incidence of HIV and other sexually transmitted infections among sex workers. Other programmes have found it effective to use peer educators/counsellors to provide outreach counselling to other sex workers.

VCT can provide the opportunity for injecting drug users to know their HIV status and receive counselling about safe injecting practices and safer sex. In a study of 5644 attendees at a needle-exchange and detoxification centre in California, the factor most closely associated with not sharing syringes was use of VCT services.

VCT for young people: Kara Counselling and Training Trust, Zambia

Kara Counselling and Training Trust is a Zambian nongovernmental organization that started as a drop-in centre providing HIV information and counselling to the general public in 1989. It was also the basis for the first support group for people living with HIV in Zambia, which still plays an important role in HIV advocacy and education, and in challenging stigma and denial. In 1992, confidential VCT services were introduced at one of the Trust's facilities. Rapid testing with same-day results was introduced in 1996. The majority of the VCT clients are young people aged 18–29.

The Trust works to increase young people's use of VCT services, including post-test support services. To achieve this, the organization provides:

- youth-oriented outreach activities to educate and mobilize young people;
- access to partner and pre-marital counselling and testing for young couples;
- youth-friendly VCT services;
- ongoing counselling and youth-friendly post-test clubs; and
- operational research about VCT and young people.

The outreach activities often help young people decide to use VCT services. They alert people to the existence of the services, explain the process, and involve them in discussions about benefits and drawbacks. The Trust takes two approaches to community outreach by running an outreach programme with HIV-positive young people (targeted more at groups), as well as a community mobilization programme (targeted at individuals).

Mother-to-child transmission (MTCT)

An estimated 200 million women around the world become pregnant each year, of whom about 2.5 million are HIV-positive. One of the biggest challenges is that of enabling the nearly 99% of pregnant women who have not acquired the virus to remain HIV-negative. That challenge is integrally linked to the wide-ranging efforts to prevent HIV transmission to mothers and their children.

The internationally agreed approach to preventing mother-to-child transmission includes a number of strategies: (1) primary prevention of HIV among prospective parents; (2) prevention

of unwanted pregnancies among HIV-positive women; and (3) prevention of transmission of HIV from mother to child. The care and treatment of HIV-positive mothers in the context of mother-to-child transmission are now also recognized as an ethical imperative, and steps are being taken to provide such care alongside prevention interventions.

Preventing mother-to-child transmission and providing treatment and care to mothers and their infants can best be achieved by greatly increasing the access of women of childbearing age and their partners to HIV prevention

Declaration of Commitment

By 2005, reduce the proportion of infants infected with HIV by 20%, and by 50% by 2010, by ensuring that 80% of pregnant women accessing antenatal care have information, counselling and other HIV-prevention services available to them, increasing the availability of, and providing access for, HIV-infected women and babies to effective treatment to reduce mother-to-child transmission of HIV [...] (paragraph 54).

United Nations General Assembly Special Session on HIV/AIDS, June 2001, New York

services, reproductive health and family planning services, and antenatal/maternity clinics. Such services should ensure that women can choose whether or not to know their HIV status; to control their fertility; to terminate a pregnancy, where this is safe and legal; and to take advantage of MTCT drugs and other interventions if HIV-positive and having a child.

Cheaper and more easily administered antiretroviral drugs are available for use in resource-poor settings. These treatments have the potential of cutting HIV transmission by up to 50%. It is critical that provision of these drugs be expanded, given the fact that, in 2001 alone, an estimated 800 000 children were newly infected with HIV—almost all through mother-to-child transmission. Expansion should be possible, given the successes of small-scale projects and the increased commitment—both internationally and from governments in low- and middle-income countries—to MTCT interventions.

Reducing the risk of transmitting HIV to infants

Preventing HIV transmission from a HIV-positive woman to her child is feasible and rel-

atively inexpensive. Once a mother knows she is HIV-positive, intervention options include the use of preventive antiretrovirals, elective caesarean section, and replacement feeding. Another low-cost approach, which benefits all pregnant women and may reduce mother-to-child transmission regardless of whether HIV status is known, is the avoidance of unnecessary invasive procedures during labour and delivery.

Short-course zidovudine is widely used in MTCT pilot projects in low- and middle-income countries and better acceptance rates have been achieved in recent years than when the programmes first started. Recently, many programmes have been choosing to use nevirapine based on the results of the HIVNet 012 study in Uganda. Given as a single dose to the mother at delivery and a dose to the child within 72 hours of birth, nevirapine is similar in effectiveness to short-course zidovudine, offering up to 50% risk reduction among breast-feeding populations. Short-term safety and tolerance of single-dose nevirapine have been demonstrated in clinical trials. Research has shown no significant differences in serious toxicity or other effects between nevirapine and short-course regimens of zidovudine or zidovudine/lamivudine.

Breastfeeding and mother-to-child transmission

In the absence of any intervention, about one-third of HIV transmissions from mother to child are attributable to breastfeeding. It is also increasingly clear that breastfeeding undermines the protective effect of antiretroviral treatment to prevent mother-to-child transmission of HIV. The UN Interagency Task Team on Mother-to-Child Transmission of HIV recommends that when replacement feeding is acceptable, feasible, affordable, sustainable and safe, HIV-infected mothers should avoid all breastfeeding. Otherwise, exclusive breastfeeding is recommended during the newborn's first months of life.

Most countries with a national policy on HIV and infant feeding follow the UN guidelines, but adapt them according to local resources and conditions. The best policies are those that offer choices to mothers. In Botswana and Côte d'Ivoire, as well as in a number of pilot sites in South Africa, more than 70% of women choose replacement feeding when counselled on the various infant-feeding options. The women are provided with free formula. In Brazil and Thailand, all HIV-positive women are advised not to breastfeed and are offered free formula.

Unfortunately, replacement feeding is not a viable option in many low- and middle-income countries. The vast majority of women breastfeed their babies, either by choice or because they have no safe, acceptable or feasible alternative. Even when breast-milk substitutes are provided free of charge, serious obstacles may be present, such as lack of safe water and sanitary conditions, confusion as to appropriate use, and stigma from family or community (due to the association of formula feeding with HIV infection).

The nevirapine regimen requires minimal monitoring and is particularly beneficial to women who present late in pregnancy or who have taken less-than-adequate prenatal doses of zidovudine. Drug resistance has been reported among some women exposed to nevirapine and other short-course antiretroviral regimens used for MTCT risk reduction. The implications of such resistance are still uncertain and need to be considered in the context of increasing access to antiretroviral treatment for patients in developing countries. A WHO Technical Consultation in October 2000 concluded that the benefit of decreasing MTCT with these antiretroviral drug prophylaxis regimens greatly outweighed concerns related to development of drug resistance.

VCT within MTCT programming

VCT is a critical entry point to MTCT prevention programmes, but not enough programmes have taken this on board. A recent UNICEF report illustrates this, drawing on data from nine African countries (Botswana, Burundi, Côte d'Ivoire, Kenya, Rwanda, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe). In settings where prevention of MTCT has been integrated, an average of 62% of women attending care receive counselling, and about 70% of them accept testing. However, uptake of VCT varied greatly between countries and sites, ranging from 22% counselled and 65% tested in Zambia, to 82% tested in Rwanda and 100% counselled.

Many factors affect uptake. Some, such as staff training and supervision, are internal programming issues; others are societal and include stigma, minimal male involvement, partner violence, and rejection of HIV-positive women. Since men can play important roles in increasing acceptance and uptake, innovative ways must be sought to encourage their greater participation in VCT and in prevention of MTCT. A recent study of VCT in five settings indicated that encouraging more men to accept a HIV test is an important first step in getting them to take more responsibility for preventing mother-to-child transmission, including using condoms during the pregnancy and being supportive of HIV-positive women's infant-feeding choices. Finally, it is clear that where the emotional and health-care needs of mothers are addressed, uptake is increased.

Caring for HIV-positive mothers: 'MTCT-Plus'

Besides deterring women from participating in MTCT programmes, lack of care for HIV-positive mothers in the context of preventing transmission to their infants raises serious ethical concerns. Leaders of philanthropic foundations from around the world met in December 2001 with UN Secretary-General Kofi Annan and announced large-scale funding for a five-year demonstration project in Africa, Asia and Latin America. Dubbed 'MTCT-Plus', the initiative will seek to expand services for HIV-positive women, including basic care for prevention and/or treatment of opportunistic infections and, when indicated, treatment with antiretrovirals. The hope is that, eventually, MTCT-Plus will include the HIV-positive family members of participating mothers and children. Information campaigns aimed at raising international awareness are

to form part of the initiative, along with the purchase and distribution of drugs to prevent MTCT, advocacy for the elimination of laws and regulations that delay access to drugs, and education and training programmes. MTCT-Plus will begin as an extension of existing MTCT prevention programmes and will initially be concentrated in sub-Saharan Africa.

Expanding coverage of mother-to-child transmission programmes


Despite the complexity and logistical challenges of MTCT interventions, there is no longer any technical justification for restricting them to pilot or research settings. However, such interventions are only beginning to be incorporated into routine antenatal and maternity care settings in many low- and middle-income countries. Thailand, Brazil and Botswana (see 'Botswana national MTCT programme' box) are leaders in this respect, having made MTCT interventions available throughout the country. Countries that have started to expand coverage beyond pilot sites include Côte d'Ivoire, Honduras, India, Kenya, Myanmar, Rwanda, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe.

In South Africa, by April 2002, the provinces of the Western Cape and KwaZulu-Natal were expanding province-wide MTCT-prevention programmes. The historic legal case in South Africa brought by the Treatment Action Campaign and others is expected to result in similar expanded programmes commencing in other provinces. And although limited to two sites per province, South Africa's current national pilot programme for prevention of MTCT is perhaps the largest in sub-Saharan

Africa. Each month, the programme provides services (including treatment with nevirapine) to approximately 6090 women registered in antenatal clinics, which represents about 9% of the total countrywide. When these are added to those in a number of operational research sites and the provincial programmes, the national total for women accessing MTCT prevention is probably 12–15%. The rate at which women agree to be tested for HIV is currently 51% in the national sites, or about 3133 pregnant women being tested per month. However, the testing rate in the national sites varies greatly between provinces and sites, ranging from 17% to 90%.

In most sites in sub-Saharan Africa, the overall percentage of women reached and treated is currently very low—less than 20%. Among the few exceptions are Rwanda's Kichikura site and the sites supported by the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF). The Foundation's Call to Action Project, initiated

in September of 1999, has sites in 70 locations in 11 African countries and Thailand.) Overall uptake in Rwanda and in the EGPAF-supported sites in Africa is estimated to be 40%. In contrast, the overall percentage of women reached and treated in Brazil and Thailand is over 70%.

The UN and organizations such as EGPAF, *Médecins Sans Frontières*, the US Centers for Disease Control and Prevention, Family Health International and Population Council/Horizons are currently supporting the development and expansion of a large number of projects in low- and middle-income countries. In 2001, working through UNICEF, the UN Interagency Task Team expanded its support from 11 to 16 countries, with some 79 implementation sites. The World Bank now includes the financing of national prevention of MTCT programmes in all new Multi-Country HIV/AIDS Projects. 

Botswana's national MTCT programme

In 1999, Botswana became the first country in Africa to start an integrated VCT/MTCT programme using zidovudine for pregnant women testing positive in antenatal clinics. The programme was introduced in the cities of Gaborone and Francistown. However, when a 2000 antenatal sentinel survey indicated a prevalence of 38.5% (which translated into 26 newborns infected daily), the government decided to extend the programme countrywide to all health facilities offering maternal and child health services. Between April 1999 and November 2001, the programme reached 31 971 women, 17 732 (55%) of whom were counselled and 9422 (53%) of those counselled were tested.

By December 2001, the programme had been implemented in all 24 of Botswana's health districts. About 81% of women registering in public health facilities are currently counselled about MTCT; 57% of those counselled are tested and, of those found to be HIV-positive, 58% are started on zidovudine treatment. Plans to accelerate the programme call for training, management capacity-building, improving the quality of counsellor support, strengthening care and support services, and community and social mobilization. In addition, Botswana is studying further improvements, including combination antiretroviral therapy and various infant-feeding practices.

Focus:

AIDS and orphans

Declaration of Commitment

By 2003, develop and, by 2005, implement national policies and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including by providing appropriate counselling and psychosocial support, ensuring their enrolment in school and access to shelter, good nutrition and health and social services on an equal basis with other children; and protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance (paragraph 65).

United Nations General Assembly Special Session on HIV/AIDS, June 2001, New York

Living today are an estimated 14 million children who have lost one or both parents due to AIDS. Approximately 80% of these children—11 million—live in sub-Saharan Africa. However, the orphan crisis is not restricted to that region. There are an estimated 1.8 million orphans living in South and South-East Asia, 85 000 in East Asia and the Pacific, 330 000 in Latin America, 250 000 in the Caribbean, and 65 000 in North Africa and the Middle East.

As the number of adults dying of AIDS rises over the next decade, increasing numbers of orphans will grow up without parental care and love, and be deprived of their basic rights to shelter, food, health and education. Already, there are an estimated 1 million orphans living in Nigeria, for

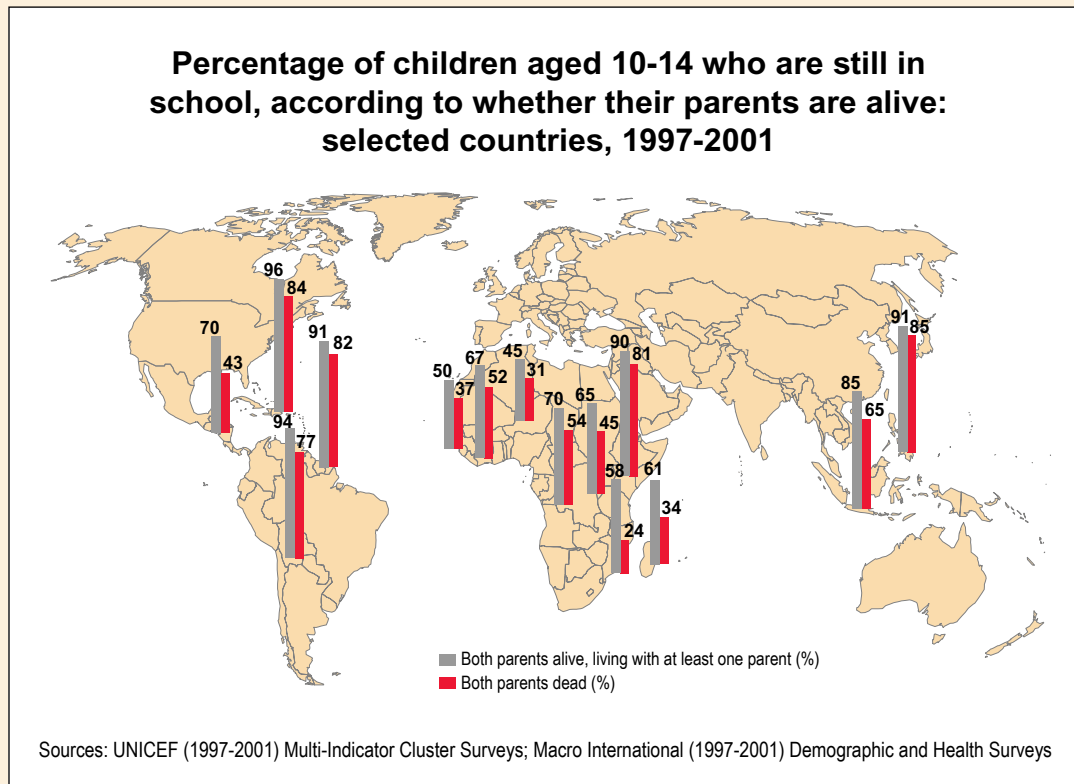
example, 890 000 in Kenya and 780 000 in Zimbabwe. Elsewhere in the world, huge numbers of children have also lost at least one parent to AIDS, as is the case for 290 000 children in Thailand, 200 000 in Haiti and 32 000 in Guatemala. Sadly, these numbers will increase as the epidemic matures. Forecasts indicate that the number of children orphaned by AIDS will rise dramatically in the next 10–20 years, especially in southern Africa. In South Africa alone, it is estimated that, by 2010, there will be 1.5 million children orphaned as a result of AIDS. In other countries, where epidemics are relatively new but growing rapidly, the impact of large numbers of orphans has yet to be felt. But the future cannot be ignored, and preparations must be made now.

Sensitive responses to complex needs

Programmes should not single out children orphaned by AIDS, since targeting specific categories of children can result in increased stigmatization and discrimination. However, to be orphaned by AIDS does create unique circumstances, not least because these children are more likely than other orphans to lose both parents, often in relatively quick succession. (Once one parent has acquired HIV, the other is highly likely to also become infected.) Very young children orphaned by AIDS may have acquired AIDS themselves; and children orphaned by AIDS are more likely than other orphans to encounter stigma and ostracism.

The vulnerability of children orphaned by AIDS and that of their family starts well before the death of a parent. The emotional anguish of the children begins with their parents' distress and progressive illness. This is compounded as the disease causes drastic changes in family structure, taking a heavy economic toll, requiring children to become caretakers and breadwinners, and fueling conflict as a result of stigma, blame and rejection. Eventually, the children suffer the death of their parent(s), and the emotional trauma involved. They then have to adjust to a new situation, with little or no support, or they may suffer exploitation and abuse.

Figure 31



As AIDS tears at the family fabric, assisting ill parents to live longer by providing appropriate medicine, food and care at home is one of the best ways to benefit children, particularly as many parents die of opportunistic infections that are treatable with inexpensive drugs. Home-based care for people living with HIV/AIDS is a means of addressing not only the health of those who are ill, but also the economic and psychosocial needs of their children.

Recent findings show that orphans who have lost both parents are even more likely to drop out of school and to be drafted into child labour than children who have lost one parent. Since the family is likely to have become more impoverished before the death of the parents, the children are often left destitute once their parents are gone. A situation analysis of children orphaned by AIDS in Côte d'Ivoire showed that traditional Ivorian family structures (which have proved capable of coping with many social and economic strains over the years) are facing serious problems with AIDS. Carried out by the World Bank, in collaboration with UNICEF and UNAIDS, the research shows that extended families find it harder to assign substitute parents to children orphaned by AIDS than to children orphaned by other causes, and to

cover the costs of their education and upkeep. In addition, the children are less inclined to accept family authority under these difficult conditions.

Moreover, the ability to stay in school—so crucial to a child's future—suffers significantly when a child loses one or both parents. In the late 1990s, a survey of 646 orphaned and 1239 non-orphaned children in Kenya found that 52% of the children orphaned by AIDS were not in school, compared to 2% of the non-orphans. Among the orphaned children, 56% of girls and 47% of boys had dropped out of school within 12 months of a parent's death. Girls often drop out of school because they assume the responsibility for caring for parents who are ill, or because they must look after household duties in the parents' stead, including that of caring for younger siblings. Other children leave school because they are discriminated against, are psychologically distraught, or cannot pay the school fees.

Many children appear to be slipping through social safety nets entirely, ending up in households with no resident adult, or as children on the streets. There is concern that they might come to constitute a 'lost generation' of young people who have been marginalized and excluded for much of their lives.

Declaration of Commitment

Ensure non-discrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of de-stigmatization of children orphaned and made vulnerable by HIV/AIDS (paragraph 66).

United Nations General Assembly Special Session on HIV/AIDS, June 2001, New York

The best solutions are close to home

In order to counter the stigma often directed at children orphaned by AIDS, efforts should address the needs of all vulnerable children in a community affected by the epidemic. Areas made vulnerable by HIV/AIDS can and should be targeted but, within these communities, residents and local government should provide assistance to the most vulnerable children and households, regardless of the specific causes of vulnerability. Experience shows that successful programmes are those that are child-centred, family- and community-focused, and respect and protect the rights of the child.

Growing up in communities disrupted by the epidemic, orphans are more likely to cope if they can live in surroundings that are as familiar, stable and nurturing as possible. The consensus is that orphans should be cared for in family units through extended family networks, foster families or adoption. At the very least, siblings should not be separated, and children should remain in, or close to, their

communities. Even child-headed households can be viable, although hardly ideal, options if given enough community and State support.

While Africa is still in the early stages of its orphan crisis, many children and many communities are coping, and their resilience and fortitude should not be underestimated. Millions of orphans have already been absorbed into extended family networks, even in the poorest communities. Formal and informal fostering arrangements are also common in some countries. Indeed, many societies in Africa have retained the structures and ethos of community-based orphan care—traditions that have helped them cope with previous calamities.

On the other hand, formal institutions, such as orphanages, have proved to be a tiny and inadequate part of a response. The financial costs of maintaining a child in one of these institutions outstrip that of other forms of care, making orphanages an unsustainable option. Furthermore, such institutions often

Better institutional care

'Step Forward...for the world's children' is a programme created and funded by the Abbott Laboratories Fund to help improve the lives of children orphaned and made vulnerable by AIDS around the world. It works in a number of countries in Africa and Asia, in partnership with nongovernmental organizations, local institutions and governments.

One of Step Forward's projects is in Romania, where many HIV-positive children have been abandoned and are growing up in institutions or health facilities. For example, abandoned children who live in the children's ward of the Constanta Municipal Hospital do not have a structured home life or attend school regularly. Through a Step Forward grant, a family-style group home was purchased and renovated, enabling 10 of the orphaned and abandoned children from the Municipal Hospital's Children's Ward to be housed in a more nurturing environment. The home, which opened in August 2001, allows for the children to be raised by 'social mothers' and to attend local schools.

leave children without the social and cultural skills they need to function successfully as adults. However, orphanages can be a last resort, either as a temporary solution, or one for children with no other alternatives. Where orphanages do operate, there should be proper registration of children and monitoring of standards of care.

Supporting extended families and affected communities

The extended family can only serve as part of the solution to mass orphanhood if adequately supported by the State, the private sector and the surrounding community. This need for support is desperate in the worst-hit regions where the capacities of families are being eroded by economic decline and deepening poverty. In Zimbabwe, almost all respondents in a recent study of AIDS-affected households said they found it more difficult than ever to cope with child support and other household needs following the death of a mother. Over half the urban respondents and more than one-third of the rural respondents blamed this on worsening economic

conditions. More than one-fifth said they were already battling to cope with the effects of illness and death. In the high-HIV-prevalence district of Kweneng, Botswana, an orphan-registration exercise conducted in mid-2000 found that only 22.1% of the people registered as caregivers for orphans were employed. The others lacked productive employment, and fully 40% of them were grandparents or elderly relatives.

But it is also clear that families are willing to take in an orphan if support is made available. Support to orphans and other disadvantaged children is a State obligation under the Convention on the Rights of the Child. Such support can take many forms: free health care and education (or subsidized school fees), food subsidies or supplements, enhanced access to microcredit, and other forms of financial support.

The World Food Programme is extending its existing school-feeding operation in various parts of Africa to support families and children made vulnerable in the context of AIDS. In Kenya's Mbeere District, an area of chronic food insecurity and very high HIV prevalence,

Helping communities and caregivers

The François-Xavier Bagnoud Institute provides support to orphans and vulnerable children, as well as to their caregivers, in Africa, Latin America, Asia and Eastern Europe. In Uganda, for example, the Institute's Project for Orphans and Children at Risk in the Luwero District helps place orphans in guardian families; barter with local primary schools to obtain free enrolment for these children (i.e., in exchange for goods that the schools need); and helps to set up income-generating projects, such as agriculture, bee-keeping or sewing, for guardian families. The project has so far helped over 3000 vulnerable children enrol in over 50 primary schools in their home area and has helped to establish more than 800 income-generating projects for guardian families. Through the barter system, schools have been provided with materials such as roofing timber, repair tools and supplies, and items required for school income-generating projects, such as raising poultry or cows, tailoring, banana/maize-growing and bee-keeping.

the Programme provides take-home rations for 90 000 orphans and their caregivers. This enables these children to continue school. Another approach is microinsurance. The ILO's STEP Programme (Strategies and Tools against Social Exclusion and Poverty) is working to extend this type of insurance to individuals and families affected by HIV/AIDS, including those who have taken on the care of orphans.

Partnerships between governments, nongovernmental organizations and private sector firms are also putting together innovative responses. In Burkina Faso, for example, the

Initiative Privée et Communautaire contre le SIDA au Burkina Faso works in partnership with the national government, the International HIV/AIDS Alliance and the Step Forward initiative. The Initiative's programmes in Ouagadougou and the city's outlying areas provide financial and technical support for community assessments. They also provide psychosocial support to orphans and vulnerable children through a network of community-based volunteers, and help meet basic needs through home-based care and support activities. In addition, insurance programmes strengthen the finances of affected families.

A part of the solution

Empowering affected children first of all means regarding them as active participants, rather than mere victims. Many children already function as heads of households and as caregivers. They are a vital part of the solution and should be supported in planning and carrying out efforts to mitigate the impact of

HIV/AIDS in their families and communities. For instance, the community-based organization Humuliza in the United Republic of Tanzania has an impressive programme called *Vijana Simama Imara* (Swahili for *adolescents stand firm*), which helps orphans not only gain skills but also utilize such skills in order

Memory books

In many countries, memory books have become an important way of opening channels of communication within families about HIV and, in particular, to help HIV-positive mothers tell their children of their serostatus. Terminally-ill parents and their children work together to compile the memory book, which is often an album containing photos, written anecdotes, and other family memorabilia.

In Uganda, use of memory books was pioneered by The AIDS Support Organization (TASO) in the early 1990s. Since 1998, the National Association of Women Living with AIDS has promoted this approach on a wider scale, with help from PLAN Uganda. The Association had found that HIV-infected mothers had great difficulty communicating with their children about their ill-health, and that memory books were good ways for the women to introduce the idea of HIV into their children's lives and discuss its impact. The book serves as a reminder to children of their roots so they do not lose their sense of belonging. The book also promotes HIV prevention, because the children witness and understand the ordeal the parent is going through and do not want to suffer the same fate.

to empower themselves for the future. The programme receives financial support from Humuliza but is entirely youth-run, with the elder orphans serving as a resource for the younger ones.

Children in households with ill parents should also participate in decision-making regarding their future foster care. This is crucial for succession planning, which helps parents (who know they are HIV-positive) prepare for the future and provide their children with the necessary care and support. So-called 'memory books' or 'memory boxes' offer valuable psychological benefits; usually containing important family information and memorabilia, these are often jointly created by parents and children.

Much can be done to ensure the legal and human rights of orphans and vulnerable children. Many communities are now writing wills to protect the inheritance rights of women and children. In Malawi, ongoing work by the CORE Group on the Wills and

Inheritance Act has involved countrywide consultations with widows, widowers, orphans, non-orphans, judges and other officials, and traditional leaders. Land- and property-grabbing (whereby unscrupulous adults attempt to rob orphans of their property once the children have no parents to protect their rights) is one of the practices being tackled.

An innovative community-based initiative has emerged in rural eastern Zambia whereby traditional inheritance customs protect women and children by allowing them to remain on their land after the husband or father dies. The Kanyanga Orphan Project set out to improve the farming skills and nutrition of families with vulnerable children by supplying seeds, fertilizer and tools. When it became clear that the families lacked the skills necessary to increase food production, the project hired an agronomist to improve agricultural techniques and yields. The project has surpassed expectations, and now provides an important source of family income, including funds for school fees.

Communities on the front line

The Salvation Army's Masiye Camp in Zimbabwe has been working for several years with children living with or affected by AIDS, with special emphasis on psychosocial support. Many of the children have poor life skills and exhibit psychosomatic disturbances, depression, very low self-esteem, disturbed social behaviour and hopelessness. The experiences of these children confirm that the death of a parent (or, worse still, both parents, as is often the case with AIDS) causes severe trauma and can stunt children's development.

However, the resilience and coping capacity of these children can be enhanced with relatively simple, direct and culturally appropriate psychosocial support. Since the project started in 1998, over 3000 children affected by AIDS participated directly in the life-skills camps at Masiye. Case-based documentation of children participating in these camps shows that the camps had a significant impact on children's coping capacity. Moreover, when young people are drawn in to provide psychosocial support and care for orphans, they themselves are likely to adopt safer behaviour.

Some governments are mobilizing for action (especially in southern Africa), and regional cooperation is also growing. The Regional Psychosocial Support to Children Affected by AIDS Initiative, a technical resource network, provides an important example of how regional successes can be shared and rapidly expanded. It began in mid-2001 by bringing together people and groups from five countries at the Salvation Army's Masiye Camp for vulnerable children in Zimbabwe. Since then, the project has mobilized millions of dollars for the development of resource materials (such as its *Teenage Parenting Manual for Child-Headed Households*), capacity-building work, programmes in youth development, joint advocacy and direct grants.

More generally, it is communities that are at the forefront of creating the scores of orphan-care programmes to ensure that vulnerable children have access to care and support. Most of these projects and programmes exist thanks to the efforts of women's groups, church-based groups and nongovernmental organizations.

The challenge ahead

The challenge of dealing with the rising numbers of orphans and vulnerable children (e.g., providing care to their HIV-positive parents) is beginning to be addressed on a wider scale. Such initiatives must be carefully executed, with maximum regard for the best interests of

the children and families concerned, as well as for the needs of society. In the past two years, the UN system, led by UNICEF, has developed a set of principles and strategies to guide programmes, while protecting the rights of orphans and vulnerable children. Among other things, these principles emphasize the need to:

- strengthen protection, care and coping capacities within extended families and communities;
- build the capacity of children to meet their own needs;
- pay attention to the roles of girls and boys, and address gender discrimination;
- ensure that governments provide essential services; and
- reduce stigma and discrimination.

UNICEF convenes regular consultations and discussions on these principles and on strategies to facilitate information exchange, collaboration and follow-up.

Caring and coping interventions for children and communities must take into account the long-term nature of AIDS-related problems and impacts. Millions of children have already lost at least one parent to the epidemic, and millions more will do so in the years to come. The challenge is to protect their rights and enable them to realize their potential. 