

TECHNICAL CONSULTATION OF GLOBAL PARTNERS FORUM ON CHILDREN AFFECTED BY HIV AND AIDS

Discussion Paper on the Impact of HIV and AIDS on Children in Lower Prevalence Countries

Mark Loudon, Consultant, UNICEF

The Framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS defines current agreement on programming strategies:

1. Strengthen the capacity of families to protect and care for orphans and other children made vulnerable by HIV/AIDS.
2. Mobilize community-based responses to support affected families.
3. Ensure equal access to essential services, including education, birth registration, health care, nutrition, psychosocial support and judicial assistance among others.
4. Provide government protection for the most vulnerable children through policy, legislation, standards and their enforcement.
5. Raise awareness to create a supportive environment for all children affected by HIV/AIDS.

However, UNAIDS makes the point¹ that there is no single HIV/AIDS epidemic – it assumes diverse forms in different regions and countries – and some programmers are questioning whether the *Framework* guidelines, based on the experience of Eastern and Southern Africa, are equally appropriate in all regions.

The answer may depend on whether children in different regions are affected in the same way by HIV/AIDS, and whether the implementation and outcome of similar programmes will vary in dissimilar social, cultural and economic environments.

This paper describes the primary challenges for children affected by HIV and AIDS across different regions and touches on regional differences relevant to programming in order to stimulate discussion and to motivate for a more robust inquiry into the subject.

REGIONAL OVERVIEW

Eastern and Southern Africa

Two thirds of all people living with HIV/AIDS are in sub-Saharan Africa, the majority of them in East and Southern Africa. The situation of the 12 million children who have lost one or both parents to AIDS, and the millions more who suffer increased poverty, risk and vulnerability as a result of the impacts of the epidemic, is described by UNICEF in Africa's Orphaned Generations.²

¹ AIDS Epidemic Update, December 2005, UNAIDS

² Revised version, December 2005 (in draft)

The fact that most of the world's children made vulnerable by HIV/AIDS live in this region has led to a growing national and international commitment to respond to the needs of children affected by the epidemic, accompanied by a significant scaling up of resources and increasing knowledge of what works. However studies on the impact of HIV/AIDS on children have tended to focus on orphaning rather than vulnerabilities which are caused or worsened by the epidemic.

Access to antiretroviral drugs is still very limited in most of the region³ so children continue to be very vulnerable to orphaning by AIDS and infection at birth, and the number of children affected by the epidemic is likely to increase.

West Africa⁴

UNAIDS says national prevalence has yet to exceed 10% in any West African country.⁵ Lower HIV prevalences also mean the statistical risk of infection, and therefore the risk that any given child will be affected by the epidemic, is lower.

However this also means that the epidemic is less visible to planners and decision makers. Intense poverty and other social crises such as wars and child-trafficking compete with HIV/AIDS for limited capacity and resources. Further, stigma is believed to be more intense than in higher-prevalence countries, acting as a disincentive to planning and interventions and as a barrier to individual response.

In West Africa, as elsewhere, there is an ongoing debate about “targeting” interventions for children affected by HIV/AIDS. Some programmers believe interventions should individually identify and help children and families directly affected by HIV/AIDS, while others believe interventions should target all vulnerable children, regardless of the cause of their vulnerability.

Those against targeting individual children affected by HIV/AIDS say it creates resentment among other children who are suffering even greater trauma or deprivation, albeit from other causes, and point out that people directly affected by HIV/AIDS often decline services directed at them alone, because accepting those services would expose them to stigma.

Those in favour of targeting children and families directly affected by HIV/AIDS say there are insufficient resources – financial and human – to address the needs of all vulnerable children. The usual compromise is to focus the resources which are available on all vulnerable children – regardless of cause – but in those communities hardest hit by AIDS. In other words: target the community, not the individual.

Latin America and the Caribbean

This region is second only to sub-Saharan Africa in terms of HIV prevalence, and AIDS is already the leading cause of death among adults aged 15-44 years⁶. However, access to treatment – particularly antiretroviral drugs – is improving rapidly, fewer babies are infected at birth, and adult mortality is beginning to fall significantly in countries like Bermuda and Barbados, which in turn means fewer children are being orphaned or made vulnerable when their parents fall ill.

³ UNAIDS says at best one-in-ten Africans who need antiretroviral drugs were getting it by mid-2005

⁴ And some countries of Central Africa – others feature HIV prevalences and social structures closer to East and Southern Africa

⁵ AIDS Epidemic Update, December 2005, UNAIDS

⁶ Ibid.

Although many governments in this region were not aware of the social impact of HIV/AIDS on children until recently, most appear willing to act decisively and a considerable amount of research and planning has been conducted in the last 12–18 months (most of it still in draft).

Stigma is a key constraint to planning and response, perhaps fuelled by the association of the epidemic with homosexuality, especially in Latin America. Single mothers who have children by a number of men are a strong feature of the Caribbean, which makes them particularly vulnerable both to infection and to family breakdown in the event that the woman is incapacitated or dies⁷.

A recent study in Central America and the eastern Caribbean⁸ suggests that planning and programming for children made vulnerable by HIV/AIDS is weaker than in Africa, while biomedical interventions such as PMTCT and paediatric AIDS treatment are stronger.

South and South Eastern Asia and the Western Pacific

Low HIV prevalence within huge populations translates to very large numbers of infected people. Despite the fact that the epidemic is clustered within high-risk groups such as injecting drug users and men who frequent commercial sex workers, more than 1.5 million Asian children have already been orphaned by the epidemic.⁹ There are methodological difficulties with producing accurate estimates of the number of children affected by HIV/AIDS, but it is clear that the numbers are large and growing.

Only one-in-seven Asians who needed antiretroviral therapy were receiving it in mid-2005¹⁰ which means more children are likely to be orphaned or made vulnerable by the epidemic in future.

Stigma is a major inhibitor to both planning and response. Many countries in the region do not track high-risk populations such as injecting drug users, men who have sex with men, and children and young people infected or affected by HIV/AIDS, and few East Asian countries are examining young people's risk behaviours or knowledge about HIV/AIDS. There is evidence that HIV/AIDS represents a significant barrier to essential social services – for example in Viet Nam 57% of children affected by HIV/AIDS are attending school, against a national average of 90%.¹¹

The debate over targeting of interventions continues in this region, too. In Cambodia the national coordinating body for orphans and other vulnerable children decided to focus on all vulnerable children, while in India, a national consultation and follow-up action has focused specifically on children affected by and vulnerable to HIV/AIDS.¹²

Organizations working with families affected by HIV/AIDS in India are increasingly confronted by children who do not have parental care, and are attempting to place these children in foster families, rather than institutions. Unfortunately the institutionalization of children whose families are unable to care for them appears to be common, although Human Rights Watch says many orphanages and other

⁷ A study of child vulnerability in Barbados, St. Lucia and St. Vincent & the Grenadines, UNICEF, 2005 (in draft)

⁸ Index of Programming Effort in Central America and the Eastern Caribbean, UNICEF, 2005 (in draft)

⁹ Brown, T & Walker, N. Regional estimates of children affected by HIV/AIDS in Asia and the Pacific, 7th ICAAP, Kobe, Japan, July 2005

¹⁰ AIDS Epidemic Update, December 2005, UNAIDS

¹¹ Viet Nam Ministry of Health and Save the Children UK, Socio economic impact of the HIV/AIDS epidemic on children in Viet Nam

¹² Providing support to children affected by HIV/AIDS and their families in the low prevalence countries of India and Cambodia: Programming issues – a discussion document. Linda Sussman, 1996 (in draft)

residential institutions are turning away HIV-positive children, or denying that they house them.¹³

Central and Eastern Europe

This region has two powerful characteristics relating to the impact of the epidemic on children which set it apart from other regions:

- Abandonment – a substantial proportion of children born to HIV-positive mothers in the Russian Federation are becoming “social orphans” as they are abandoned to state care by their mothers.¹⁴ This phenomenon feeds into the second characteristic, which is:
- Institutionalization. For the abandoned infants this can mean being warehoused in hospital wards for several years until their HIV status is determined while for infected children it may mean living in a specialized orphanage for HIV positive children – ostensibly to “protect them” from an intolerant society. There are concerns that as many as 1.3 million children in Eastern Europe are institutionalized, often in very poor conditions.¹⁵

Stigma and discrimination appear to be particularly strong in Eastern Europe, where children associated with HIV/AIDS are often prevented from entering kindergarten or elementary school, or refused treatment by doctors. Human Rights Watch says these actions are banned by Russian law, but many people living with HIV/AIDS are so frightened of revealing their status that they would rather suffer the consequences of discrimination than stand up for their rights.¹⁶

In addition, a comprehensive approach to mother-to-child transmission and paediatric follow-up is yet to be developed; many children born to HIV-infected mothers are not properly monitored by physicians, get late diagnosis, and are discriminated in their communities; and very few HIV-infected mothers receive ARV treatment, placing their children at considerable risk of orphaning.

There is little research into the social implications for children of parental HIV infection in this region.

Summary of differences between high- and low-prevalence countries

There is a huge difference across regions in the probability that a child may be made vulnerable by HIV/AIDS. This difference is mainly driven by three factors:

- HIV prevalence – statistically, children in Southern Africa are several hundred times more likely to be infected or affected than their counterparts in Asia or Latin America. Significant differences in the statistical risk also found between districts and communities within the same countries;
- Access to antiretroviral drugs – which can dramatically reduce the number of babies infected by their mothers at birth, help HIV-positive children lead

¹³ Future Forsaken: Abuses against children affected by HIV/AIDS in India. Human Rights Watch, 2004

¹⁴ Orphans and children made vulnerable by HIV in the Russian Federation: Briefing Note. UNICEF

¹⁵ Family Matters: A study of institutional childcare in central and Eastern Europe and the former Soviet Union. Richard Carter, 2005

¹⁶ Positively Abandoned: Stigma and discrimination against HIV-positive mothers and their children in Russia. Human Rights Watch, June 2005

relatively normal lives, and enable AIDS-ill parents to raise and provide for their children; and

- Poverty – child vulnerability is greatly influenced by the interplay between poverty and HIV/AIDS, to the extent that children in poor households and poor countries are more likely to be affected, and affected in more severe ways, than children in a middle-income setting.

Children in high-prevalence countries stand a greater chance of being affected by HIV/AIDS outside of their household – for example if their teachers are affected, or public services are disrupted by the epidemic.

On the other hand, there is anecdotal evidence that people living with HIV/AIDS, and their children, may be subject to (or at least more afraid of) more virulent stigma in low-prevalence regions, which has important implications for planning and service provision.

In low-prevalence countries the lack of visibility of HIV/AIDS has a number of consequences for programming, for example HIV programmes may not be considered a priority for human and financial resources, and the quality of interventions – including those for children made vulnerable by the epidemic – may not be as good as those in high prevalence areas.

Similarly, planners in low-prevalence countries may not recognize the social effects of the epidemic or its potential for escalation, and officials may (unwittingly) erect barriers for those living with HIV/AIDS to recognize their condition, or to access services to which they are entitled.

Finally the small proportion of children directly affected by HIV/AIDS in low-prevalence countries makes it much more difficult to attract funding and expertise, and much harder to show a return on the investment of those resources. Unfortunately a failure to invest now could mean considerably greater cost, both financial and human, in future.

PROGRAMMING IMPLICATIONS

If a child in a low-prevalence area is unlucky enough to be infected or affected by HIV/AIDS, it appears the manifestations of their vulnerability will be much the same as they are in high-prevalence regions: infection, illness and possible death; exposure to stigma and discrimination, emotional distress and material deprivation; separation from siblings, relocation to unfamiliar surroundings and loss of opportunities and entitlements; and heightened risks of further HIV infection in the family.

However, how their family and society responds to these threats will depend on a host of factors which vary across regions including:

- Poverty – which can force families affected by the epidemic into destitution and oblige communities to devote more time and energies to ensure their children are eating and attending school;
- Care-giving roles within a society – including those of fathers, grandparents and other relatives – and whether fostering or adoption of unrelated children or placing them in orphanages are commonplace;
- The capacity and willingness of government, civil and religious organizations and communities to support family care and protect the rights of children.

Returning to the question posed at the outset – whether the *Framework* guidelines are equally appropriate in all regions, it appears that they are, although like the ingredients of a cake they need to be mixed in very different proportions, depending on the needs and expectations of the intended beneficiaries.

However, a case could perhaps be made to expand the five guidelines to incorporate explicit reference to:

- The importance of medical treatment, care and support in both the prevention and mitigation of child vulnerability, and
- The need to overcome the stigma which causes so much misery to children, and makes it so much harder for everyone to respond appropriately to the issue.

Overall, it seems clear that programmes to mitigate the impact of HIV/AIDS on children everywhere need to include:

- Universal access to antiretroviral drugs and prophylaxis against opportunistic infections for parents and children, including nutritional support and treatment of paediatric AIDS;
- An effective and measurable prevention campaign focusing particularly on pre-adolescents and teenagers, and providing easy access to condoms and youth-friendly testing facilities;
- An effective public education campaign to overcome misconceptions about HIV/AIDS and challenge stigma, within the broad community and specifically among service providers;
- Guarantees that HIV/AIDS will not pose a barrier to the general health care, education and social protection services and other benefits to which all their citizens are entitled.

Beyond that, there is a strong case for programmes which focus on all vulnerable children in communities with high HIV prevalence, and which are developed in partnership with those communities – especially children and people living with HIV. These programmes should focus on reinforcing the capacity of families to care and provide for their children, generally and in the context of HIV/AIDS, and should enlist the support of all roleplayers.

ML 2/2/06