Children affected by HIV/AIDS in South Asia – a synthesis of current global, regional and national thinking and research, UNICEF Regional Office for South Asia, April 2007

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EXECUTIVE SUMMARY

More than 99 out of every 100 adults in South Asia are <u>not</u> HIV-positive, and this proportion is fairly stable. Nevertheless, somewhere between 3.5 and 10 million people in the region are living with the virus and most are clustered in small geographic areas. The vast majority have no symptoms as yet, and will only manifest AIDS over the next 10 years or more. Although South Asia is a low prevalence region, the true impact of the epidemic has yet to emerge.

South Asian governments have recognized the threat to public health and have responded with prevention campaigns among high risk groups and by rolling out anti-retroviral therapy (ART) for those who are already ill. In India, home to about nine out of ten people living with

HIV in the region, the National AIDS Control Organisation aims during 2007 to make ART available to everyone who has been diagnosed and is eligible for treatment.

Correctly used, ART is very effective, transforming AIDS into a chronic illness for adults and giving infected children a future. Similarly, the number of babies who are in fected by their HIV-positive mothers at birth drops from around a third to 10% or less with appropriate medical intervention. But the overwhelming majority of people living with HIV do not know their sero-status, and consequently their lives – and their children's futures – are at risk.

The impact of HIV/AIDS on children

More than 90% of people living with HIV in South Asia are adults, most are male, and most are parents. Their illness, if it is allowed to develop, will have a terrible effect on their children's wellbeing and prospects. It is absolutely critical that these fathers and mothers are diagnosed and treated, so they can provide for their families.

But diagnosis is a two-edged sword. When a person knows they are HIV positive, they can seek appropriate treatment – but it also means they and their families are at ris k of stigma and discrimination. There is now abundant evidence of the extent and severity of social exclusion due to HIV/AIDS in South Asia. Once infection is recognised or even suspecte d, many people living with HIV are disowned by their own families and excluded from services offered by their communities and governments.

Worse, it is widely assumed that children with positive parent s are themselves infected, and that they are likely to infect other children. The fact that these assumptions are wrong makes no difference to those children, many of whom are excluded from school, routine health care and important social rituals. Research is showing that it is often the most educated members of those communities – the teachers, doctors and community leaders – who are the instruments of this exclusion. The effect on many young lives is extreme and irreversible.

Global learning on impact mitigation

South Asia is not the first, nor the worst. AIDS has been wreaking havoc in sub-Saharan Africa for nearly two decades. In ten southern African countries more than one-in-ten adults are already infected. Around the world many mistakes have been made, and lessons learned, in protecting children from the fallout of the epidemic.

There are international fo rums which regularly review the learning from both high and low prevalence regions, and which offer advice and support to governments so they can fulfil the promises they have made to the global community on behalf of their children in general, and to HIV/AIDS-affected children in particular.

One of the most important lessons is that children affected by HIV/AIDS need to be raised by their own parents, within their own communities – and that this is more cost-effective for governments and more beneficial for the children.

We have also learned that, a part from a tiny minority of affected children who are themselves infected with HIV, these children need nothing that other children do not require. Efforts to identify, test, register, target, separate, institutionalise and counsel children simply because their parents are HIV positive or have died from AIDS are nearly always counter-productive.

Instead we now know that the first priority is to make sure that children who are affected by HIV/AIDS are not excluded from public services which are available to other children, or from the protection of their own parents and extended families.

In impoverished and disadvantaged communities it is often necessary to strengthen those public and private safety nets, and sometimes it makes sense to focus this kind of development work on communities which are particularly hard -hit by HIV/AIDS, but it is very rarely helpful to single out children because of the sero -status of their parents.

Regional action priorities for South Asia

The following actions are likely to have the greatest positive effect on the largest number of children affected by HIV/AIDS in South Asia:

1. **Make sure HIV-positive parents remain alive and productiv e** – find ways to diagnose more of the people living with HIV, especially parents, and ensure all have access to treatment, and remain on their treatment programmes

2. **Make sure public servants are part of the solution, not part of the problem** – re-educate government service providers, especially doctors, nurses, teachers and local officials, to overcome those myths and misconceptions which sustain stigma and discrimination, and establish and enforce standards of non -discriminatory treatment

3. **Make sure parents raise their own children, rather than getting rid of them** – establish/expand/strengthen the nation's capacity for family reconstruction and support, such as nutritional support, home -based care, skills training (parenting and income generation), through all relevant departments and drawing on communities and NGOs

4. **Make sure people don't exclude their own children from vital services** – educate the public on their rights, entitlements, and the services available to help them raise their children effectively, whether or not they are affected by AIDS

5. **Make sure everyone knows the truth about AIDS** – that it's no longer a sentence of death, that children of HIV -positive parents are not usually infected, that infected children won't infect other children, and that HIV affects (and infects) the innocent as well as those engaged in behaviour which society finds abhorrent

6. **Make sure protection failures are detected and corrected** – establish a mechanism (children's advice offices, child protection officers etc.) which is accessible to everyone to give real help to parents who are denied entitlements and children who are neglected or abused, and to refer cases to specialists where necessary

7. **Make sure children in orphanages don't stay long, and are treated well while they are there** – determine and enforce institutional standards, including measures to restore children to families (see #3 above) and to ensure their integration in local community life.

INTRODUCTION

This report brings together current research – much of it unpublished – into the impact of HIV/AIDS on children in the South Asia region. It presents an overview of the findings of studies in Bangladesh, India, Nepal and Pakistan. Limited information was available from the Maldives, Afghanistan and Sri Lanka, and none from Bhutan. Most research has taken place in India, so this synthesis is somewhat weighted toward that country. A list of the documents referred appears in Annex 3.

In addition this report extracts key messages from the latest global literature in rela tion to policy and programming for children affected by HIV/AIDS, and presents a series of recommendations for national action. It is intended as a background and discussion document for the forthcoming meeting of member states of the South Asian Associati on for Regional Cooperation to discuss strategies to respond to the needs and rights of children affected by HIV/AIDS.

The report was commissioned by the UNICEF Regional Office for South Asia, and compiled by UNICEF Consultant Mark Loudon, with the support of UNICEF ROSA HIV/AIDS Specialist Rachel Odede.

WHO ARE WE TALKING ABOUT?

Terminology and definitions

"Children" are defined internationally as people who are not yet 18 years old.

"Orphans" are children who have lost <u>one or both parents</u>. For statistical purposes, adults (older than 17 years) with a deceased parent are not counted as orphans.

"Vulnerable" is used in two distinct senses in the context of HIV/AIDS – children who are at heightened risk of HIV infection, and children whose human rights are threatened as a result of their link to HIV/AIDS. To avoid this ambiguity the term "children affected by HIV/AIDS" (or simply "affected children") is used for the latter group.

"Affected children" include:

- Children who are HIV-positive themselves;

- Children who have a parent (or two) who have died from AIDS;

- Children who have a parent (or two) living with HIV [1];

Young people who are particularly vulnerable to HIV infection are not "affected" unless they fall into one of the above categories. In sub-Saharan Africa many children are indirectly affected by HIV/AIDS due to the deterioration of services, weakening of social institutions and so on[2], but this is not considered significant in low prevalence regions.

Number of people living with HIV/AIDS

Estimates of the number of people living with HIV are notoriously imprecise. One of the main reasons for this is that most HIV-positive people live "submerged within the community, with a secret so terrible that they dare not reveal it even to those they love and trust."[3] Another reason is that the majority do not know they are, in fact, HIV-positive.

However, mathematical modelling gives us a good idea of the magnitude of the problem, and whether it is getting better or worse. The following table is a compilation of the latest data from UNAIDS[4] and the UN Population Division[5] for this region:

	PLWA* low estimate	PLWA high estimate	PLWA best estimate	Prevalence best estimate	Population (millions)	Fertility (children per mother)	Life expectancy (years)
Afghanistan	<2000			<0.1	27.1	7.07	43.8
Bangladesh	6,400	18,000	11,000	<0.1	158.7	3.52	64.1
Bhutan	<2000			<0.1	0.7	2.19	65.6
India	3,400,000	9,400,000	5,700,000	0.9	1,169.0	2.81	64.7
Maldives	<2000				0.3	2.63	68.5
Nepal	41,000	180,000	75,000	0.5	28.2	3.28	63.8
Pakistan	46,000	210,000	85,000	0.1	163.9	2.83	65.5

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[1] Sometimes this group is expanded to include children living in a household with any infected person – for example a sibling – or families which take in children orphaned by AIDS.

[2] An Assessment of Good Practices on Care and Support of Children Orphaned and Made Vulnerable By HIV/AIDS, Bina Pokharel, Save the Children UK, Office of South and Central Asia, March 2005

[3] Barriers to services for children with HIV-positive parents in six high HIV prevalence states of India (in draft), UNICEF, 2007

[4] 2006 Report on the global AIDS epidemic, UNAIDS/WHO, May 2006

[5] UN Population Division: World Population Prospects: The 2006 Revision

Sri Lanka	3,000	8,300	5,000	<0.1	19.3	1.88	72.4

*PLWA = people living with HIV or AIDS

UNAIDS says the situation in India is best described as a series of epidemics, widely varied in prevalence, risk factors and transmission patterns. Some of these epidemics appear to be stable or diminishing, while others are growing at a modest rate.

The UN Population Division recently downgraded their global projections of the impact of AIDS based on the assumption that antiretroviral therapy will reach more of those who need it, and that they will survive longer and be less infectious. However the agency cautions that this improved outlook depends on sustained commitment by governments to assure treatment for the infected, and to promote behaviour change among the uninfected.

The World Bank[6] stresses the heterogeneity of the epidemics in the South Asia region generally, and India in particular, with sex work being the critical driver of HIV transmission in some areas and injecting drug use in others. They list a diverse range of structural factors that amplify HIV vulnerability in the region including widespread poverty and inequality; illiteracy; low social status of women; a large sex work industry; porous borders; widesprea d migration; stigma and cultural impediments to sexual discussion; high rates of sexually transmitted infections and limited condom use.

Number of children affected by HIV/AIDS

There are no definitive data on the number of affected children in any country in South Asia. Research is currently underway in India to model the numbers, but the data were not available at time of writing.

However a draft report[7] suggests the numbers in India are somewhere of the order of 150,000 HIV-positive children (through peri-natal infection); two million children orphaned by AIDS and seven million children with HIV-positive parents. These numbers are purely indicative, and the categories are not mutually exclusive, but they provide a sense of proportion. Presented in graphic form, the categories look like this:
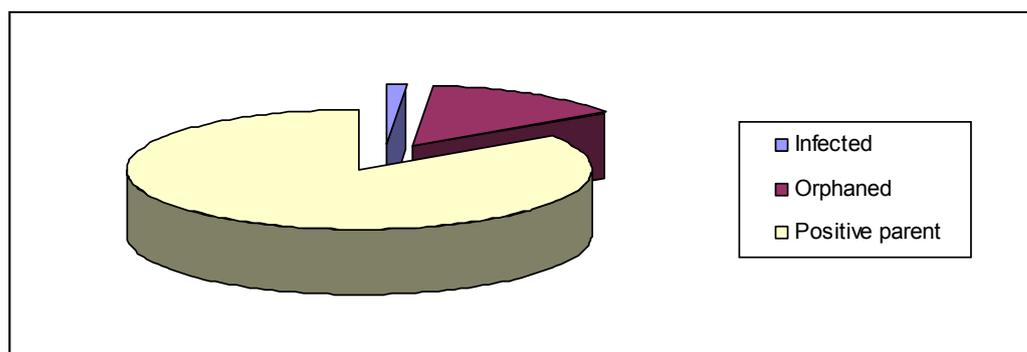
The important – and perhaps surprising – messages from this are, firstly,

- that only a tiny proportion of "affected" children are infected and, secondly,

- that the number of "affected" children is very large indeed – probably larger than the number of infected adults, and perhaps 2% of all children in India.

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[6] AIDS in South Asia Understanding and Responding to a Heterogeneous Epidemic, Stephen Moses et al, World Bank, 2006
[7] Barriers to services for children with HIV-positive parents in six high HIV prevalence states of India (in draft), UNICEF, 2007

WHAT ARE THE ISSUES?

HIV diagnosis and treatment

The vast majority of people living with HIV are not diagnosed. While they remain undiagnosed, their risk of illness and death is far higher. The survival prospects of both adults and children are dramatically improved if they are diagnosed and receive anti-retroviral therapy (ART) and treatment for opportunistic infections. [8] With appropriate treatment parents are likely to survive long enough to raise their children to adulthood, which means very few children will be orphaned by AIDS once ART is universal.

The National AIDS Control Organisation in India projects that the proportion of people living with HIV who are diagnosed will rise from 20% in 2006 to 80% in 2010, but says that 100% of those who are diagnosed and eligible for treatment will have access to anti-retroviral treatment from 2007. [9] This effectively means that almost everyone who knows they are HIV positive already has access to treatment. Clearly the greater challenge is to locate those who do not know they are infected.

Stigma and discrimination

In terms of importance for children affected by AIDS, overcoming stigma and discrimination is second only to keeping their parents alive and well.

According to India's barrier study[10], in many respects HIV/AIDS is just like other disasters which can befall a family, incapacitating parents and placing the future of their children in question, such as wars, natural disasters, and other illnesses. "However in at least one respect HIV infection is unusual, because the shame and fear attached to the virus often prevents those who are affected by it from accessing those services which would otherwise be available to them."

This thesis is strongly supported by other studies in India[11] and Bangladesh[12] and by current – but as yet unpublished – research in Nepal[13]. A UNDP study, for example, found 74% of employed people living with HIV/AIDS had not disclosed their status in their workplace for fear of losing their jobs, or being subjected to social discrimination. The same study found that the healthcare setting was the most frequent place of discrimination, followed by the family and community.

The Bangladesh study found that people living with HIV/AIDS were very aware of the myths surrounding their condition, such as the common belief that AIDS was the result of incest. Women with HIV were thought to have bad characters no matter how they contracted it. Both men's and women's groups reported severe stigmatization by health care personnel and difficulty getting treatment, even from health providers who had been trained in HIV/AIDS case management. They said that in general families and communities provide little assistance to any person with a chronic illness.

A recent study in Nepal found that people hesitate to eat food which is cooked by anyone living with HIV/AIDS, do not want to socialize with infected people, and exclude or ignore

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[8] A review of abstracts submitted to the XVI International AIDS Conference, Toronto, 2006, at http://www.aids2006.org/mainpage.aspx?pageId=265
[9] National AIDS Control Programme Phase III (2007-2012), National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India. November 2006 draft.
[10] Barriers to services for children with HIV-positive parents in six high HIV prevalence states of India (in draft), UNICEF, 2007
[11] Socio-economic impact of HIV and AIDS in India, Pradhan et al, UNDP, 2006
[12] HIV/AIDS-Affected Families and children and other vulnerable children in Bangladesh: A national assessment, Susan Hunter et al, UNICEF, December 2005
[13] A Rapid Assessment on HIV/AIDS-Related Community Coping Mechanisms with a Focus on Children and Families Affected by HIV/AIDS in Selected Districts in Nepal (in draft), New ERA, 2007

infected people and their families at social gatherings. Informants reported cases where infected people were not allowed to use public taps, and where nobody was willing to carry the dead body of an infected person.

The barrier study in India found a remarkable similarity between the experience of affected children and their caregivers across the country . The study interviewed the professionals responsible for the services from which affected children were excluded – including doctors, teachers and public representatives – and found that a majority of them were not aware of this exclusion. This could mean that exclusion is not as severe as the consumers of services suggest, or that service providers are not in touch with the experience of the ir consumers.

Self exclusion

People affected by HIV/AIDS avoid actions which may reveal their status and expose them to the kind of exclusion described above. This can lead people not to seek medical treatment – risking their lives in the process – or the help of family members or organisations to deal with loss of income or emotional distress.

But while there is plenty of evidence of self exclusion in the regional literature, there is also evidence of families and communities being supportive. The UNDP study in India, for example, found that of those who disclosed their status in the community only 10% reported discrimination, most of them in rural areas. The Nepal study found that over half of respondents said their community was "nice to them".

These positive experiences raise the intriguing possibility tha t in some cases, at least, exclusion is based on the fear of social exclusion, rather than the reality of it. But even if the fear is not always justified, the effect of self -exclusion on families is very real. This has important implications for programme rs, and should be considered for further study.

Myths and misconceptions

It is clear from the literature that exclusion linked to HIV/AIDS is based on fear, and that this fear arises from a set of false beliefs concerning the virus – such as that it can be transmitted through forms of everyday contact ; that children with HIV -positive parents are infected themselves; and that these children can infect others at home, school and in health centres. Neighbours tell their children not to have any contact with affected children, and teachers and doctors turn them away because they are concerned about the reaction of other parents.

It seems logical to undertake public education campaigns to overcome these myths, but this may be wasted effort as long as the ir role-models – doctors, teachers and community leaders – continue to indulge and reinforce those myths by their actions. A more logical starting point would be to educate the service providers, introduce regulations to prohibit discrimination, and establish mechanisms to detect and respond to breaches of these regulations.

The social safety net

Family and community

The first line of care for children everywhere is their parents and relatives. However it appears from the literature that this safety net is not strong in South Asia, particularly in poorer communities, and that it falls apart as soon as a child's predicament is linked to HIV/AIDS.

In Bangladesh[14] children are seriously affected when they lose the protection of their families and communities, particularly when either or both of their parents die. A large proportion of these women and children suffer repeated abuse and stigmatization until they voluntarily leave or are driven off. Once they have fallen outside the family and community, they are no longer entitled to its protection. Widowed fathers rarely take care of their children, placing

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[14] HIV/AIDS-Affected Families and children and other vulnerable children in Bangladesh: A national assessment, Susan Hunter et al, UNICEF, December 2005

them with relatives, in an orphanage, or abandoning them. If they do remain with their father until he remarries, their step-mother typically does her best to drive them out so they will not compete with her own children.

In comparison to children who are not affected by HIV/AIDS, children with positive parents in Nepal[15] get less support from those parents, and other adults are reluctant to take care of them, thinking they may have the disease and transmit it to others. Many children are burdened with immense responsibilities due to the illness or death of their parents, or their dread of illness[16]. UNICEF found that women's social exclusion in Nepal compounds the poverty and social exclusion of children[17], as it is traditionally the women who prioritise investments into children's education, healthcare and nutrition.

The picture is very similar in India[18] where relatives often send children away from their HIV-infected parents "for their own protection", or refuse to take them in for fear that they will infect other members of the household. Where affected children are taken into another household they may be treated as servants, denied schooling and subjected to physical and emotional abuse.

However, it is certain that the majority of children affected by HIV/AIDS are being raised by their parents, and that most orphans are still in the care of a surviving parent or relatives. The challenge is to reduce the number of parents and caregivers who feel they cannot raise these children, and that an orphanage will do a better job.

Institutional care

In South Asia placing children in residential institutions (ie: orphanages) has emerged as the main, and often the only, unchallenged response for children without parental care[19]. All South Asian countries face similar challenges – being too quick to place children in orphanages, allowing poor conditions in those institutions, and not offering alternatives.

It has been found that more than 85% of children in residential care in many countries such as Nepal[20] and Bangladesh[21] are not orphans but have at least one parent. The great majority of institutionalised children are there because of poverty, and could easily remain in their family if they were provided with basic services, particularly access to education. The decision to place children in care is taken by adults without considering the view of the child concerned.

In Pakistan[22] research is ongoing, but it is understood that government and private institutions are regularly evaluated and, on the whole, the Government views them as satisfactory.

In India affected children are reportedly[23] refused admission by many orphanages, who fear they are infected. However the Ministry of Women and Child Development is working with UNICEF and others to develop a set of minimum standards of institutional care, and to work towards a situation where institutional care is, indeed, a last resort.

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[15] A Rapid Assessment on HIV/AIDS-Related Community Coping Mechanisms with a Focus on Children and Families Affected by HIV/AIDS in Selected Districts in Nepal (in draft), New ERA, 2007

[16] Research proposal for rapid assessment on HIV/AIDS-related community coping mechanisms, submitted to UNICEF by New ERA, November 2006

[17] The Economic and Social Environment in South Asia 2006: Implications for Children, Gabriele Köhler and Mariana Stirbu, UNICEF ROSA, February 2007

[18] Barriers to services for children with HIV-positive parents in six high HIV prevalence states of India (in draft), UNICEF, 2007

[19] Children Outside Parental Care in South Asian Countries, UNICEF Regional Office for South Asia (ROSA), September 2006

[20] UNICEF Nepal (2004). Mapping and Assessment of Institutional Care for Children in Nepal (in draft)

[21] HIV/AIDS-Affected Families and children and other vulnerable children in Bangladesh: A national assessment, Susan Hunter et al, UNICEF, December 2005

[22] Assessment of Protection Risks and Failures for Children Vulnerable to and Affected by HIV and AIDS in Four Provinces in Pakistan; Literature Review, Andrew Dunn (in draft), 2007

[23] 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 (in draft). Linda Sussman, USAID/POLICY Project. 2006

Globally, as well as in South Asia, institutional care h as displayed its limitations and the negative impact it has on children. Placement in residential care is very rarely in the best interests of the child's development, nor is it cost -effective.

Several studies refer to the temptation by authorities to set up separate institutions to "protect" affected children from discrimination and cater for their "special needs". Fortunately there is a growing recognition that separating these children is itself highly discriminatory, and their needs are no more "specia l" than other traumatised, impoverished and marginalised children.

The tiny proportion of affected children who are HIV positive do need medical care, as do children living with other chronic illnesses, bu t this does not justify separating them from their families, or from other children.

Alternative care

All countries in South Asia have ratified the UN Convent ion on the Rights of the Child which commits them to ensuring that institutional care will be used only as a last resort. However family- and community-based forms of alternative care are little explored and promoted in this region[24]. In addition, the shift away from regarding children simply as the beneficiaries of welfare, and toward recognising them as citizens with the rights articulated in the Con vention, has still to be fully realised in any South Asian nation.

According to a 2004 policy document on children at risk in Afghanistan[25], the challenge facing that country is not the *re-building* of a child protection and family support system after decades of war, civil unrest and dislocation, but rather the *building* of such a system where none previously existed.

A review of alternative care systems for children in Pakistan[26] found that foster placement is not recognized under any law, and adoption is not permitted. However Islamic law provides for a very strong system of guardianship for the care of children without parents through the immediate and extended family.

In Nepal[27] the law also provides for the appointment of a guardian – usually a relative of the child – who is entitled to use income derived from any property inherited by the child for their maintenance, education and health care, but property grabbing and denial of inheritance are reported to be common.

However the Government of India is currently undertaking a major step towards guaranteeing the rights of children – including those affected by HIV/AIDS – through the proposed Integrated Child Protection Scheme. In their policy document[28] the Ministry of Women and Child Development says violations of children's right to protection are " massive, under-recognized and under -reported obstacles to child survival and development" with "consequences in loss in productivity and loss in quali ty human capital for the nation ."

WHAT SHOULD WE BE DOING?

There is now a considerable body of global learning on responding to the needs of children affected by HIV/AIDS. The literature is summarised in Annex 2. Some of the most important interventions are:

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[24] Children Outside Parental Care in South Asian Countries, UNICEF Regional Office for South Asia (ROSA), September 2006
[25] A better Future for Afghanistan's vulnerable children & their families – National Strategy of Action for Children 'at- risk'. Ministry of Labour and Social Affairs supported by UNICEF, November 2004
[26] Assessment of Protection Risks and Failures for Children Vulnerable to and Affected by HIV and AIDS in Four Provinces in Pakistan; Literature Review, Andrew Dunn (in draft), 2007
[27] A Rapid Assessment on HIV/AIDS-Related Community Coping Mechanisms with a Focus on Children and Families Affected by HIV/AIDS in Selected Districts in Nepal (in draft), New ERA, 2007
[28] The Integrated Child Protection Scheme, Ministry of Women and Child, Government of India. 27th draft, 27 December 2006

Focusing on all affected children, not only orphans

While many children orphaned by AIDS find themsel ves in difficult circumstances, there are also those who are well cared for. At the same time the research described above suggests that children with HIV-positive parents are often just as badly affected as those who are orphaned, and sometimes even worse.

Richter et al[29] describe the excessive emphasis on children orphaned by AIDS as one of two "major detours" in responding to the needs of children affected by AIDS [30] and conclude: "The preoccupation with orphans has meant that the plight of children living with sick parents has been overlooked. While we have been concerned with orphans, vulnerable children … have been largely invisible. "

It follows that orphaning alone is not a useful indicator. Programmes need t o focus on the needs of affected children, some of whom will be orphans. Our concern is for children whose survival, well-being, or development are threatened by HIV/AIDS.[31]

Supporting and strengthening families

HIV/AIDS is often connected to poverty, both as a cause and an effect. People living in poverty are much less able to hide their infection and to deal with the economic and social consequences of their illness. South Asian studies confirm that many affected households lose their income, deplete their savings, and borrow money to survive. Children are often withdrawn from school to supplement household income or tend to ill parents. Death from AIDS is often associated with the disinheritance and social rejection of widows and orphans.

While it is clear that anti-retroviral treatment will allow an increasing number of HIV -positive parents to be productive and to raise their children normally , the stigma and discrimination attached to HIV/AIDS can impoverish and destroy families, even if the health of fam ily members is unaffected by the virus.

Many programmes are designed to improve the economic resilience of affected families. The research consistently shows economically self -sufficient and nutritionally secure families are more likely to care for their o wn children, and to provide better care.

However the risks of targeting HIV/AIDS-affected families for such programmes are, firstly, that they can become islands of comparative privilege in an ocean of poverty and, secondly, that affected people may be reluctant to participate in such programmes, not matter how desperately they need help, because they fear public exposure and stigmatization. It is clearly unfair to put people in a situation where they must choose between stigma and starvation.

One solution lies in providing economic and nutritional support, and promoting income-generating skills and activities, to anyone in HIV/AIDS-affected communities, regardless of their HIV-status. Another solution is to ensure that anti -retroviral therapy is universally available without cost, and is actually used by all who need it. This not only allows family breadwinners to continue to support their families, but it also reduces household (and government) expenditure on medical care for opportunistic infections – and it eliminates the emotional trauma attached to AIDS illness and death .

Providing psychosocial support

In terms of the emotional wellbeing of children and families affected by HIV/AIDS, Richter et al[32] describe the excessive emphasis placed on psychosocial interventions as the second of

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[29] Where the Heart Is – meeting the psychosocial needs of young children in the context of HIV/AIDS, Linda Richter et al, Bernard van Leer Foundation, July 2006
[30] The other relates to psychosocial interventions, and is discussed later
[31] An Assessment of Good Practices on Care and Support of Children Orphaned and Made Vulnerable By HIV/AIDS, Bina Pokharel, Save the Children UK, Office of South and Central Asia, March 2005

two "detours" in the international response to these children (the first was the focus on orphans rather than vulnerable children, described earlier). They point out that when families are supported so they can care for their own children, very few of their children need specialised psychological or social programmes.

However, there will always be a few children who develop psychopathologies of one kind or another, and it is essential that they do have access to appropriate p rofessional support.

This support should include free e ducation, health and social services to address vulnerability, promote wellbeing, and build the capacity of those families. Governments, say the authors, need to match the vigorous responses that have, so far, been mounted by civil society.

It is also true to say that the source of children's emotional distress is often the abuse and ridicule which is meted out to them, once their parents' status becomes known, so overcoming stigma is an essential comp onent of psycho-social support.

Overcoming stigma

The most common recommendation[33] to overcome stigma and discrimination is to promote public awareness, particularly on the ways in which HIV is transmitted. However there is growing concern that some awarene ss campaigns actually reinforce stigma, particularly those that use fear, or link the epidemic to socially unacceptable behaviour.

It is clear that much of the fear surrounding HIV/AIDS is based on three misconceptions – that AIDS is a sentence of death; t hat children with positive parents are likely to be infected themselves; and that an HIV -positive child is likely to infect other children. It is essential to address these misconceptions while making sure that service providers and role -models – such as doctors and teachers – do not reinforce them in word or deed.

It is equally important to create public awareness of the rights and entitlements of all citizens, and of the mechanisms which are in place to deliver those services. By emphasising that children from HIV/AIDS-affected households have the same rights, and the same entitlements to services, governments can do a great deal to overcome discrimination and self -exclusion.

Protecting children's rights

Simply by ensuring that children affected by HIV/AI DS are not excluded from regular services and entitlements, and that their parents and extended families are encouraged and supported to care for them, governments will fulfil many of their duties to affected children. By strengthening the alternative care system they will satisfy even more children's rights.

However, there will always be exceptions – cases where children slip through the safety nets provided by families, communities and governments. It is essential that the adults responsible for those children, and the children themselves, have someone to turn to who can defend their rights. India's proposed Integrated Child Protection Scheme is one such model. South Africa's Legal Advice Centres are another. Child -lines are used in many countries, althoug h some lack the resources or mandate to make a real difference.

Such agencies need to be accessible to everyone, including children; have the authority and capacity to intervene across sectoral boundaries (education, health, welfare, justice..); and should avoid conflicting interests or bias such as affiliation to a particular religion, political party, or social cause – including HIV/AIDS.

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[32] Where the Heart Is – meeting the psychosocial needs of young children in the context of HIV/AIDS, Linda Richter et al, Bernard van Leer Foundation, July 2006
[33] Barriers to services for children with HIV-positive parents in six high HIV prevalence states of India (in draft), UNICEF, 2007

Providing alternative care

Alternative (to parental) care can take the form of formal or informal fostering, adopti on, guardianship, or placement in an institution.

The single most important action which governments can take is, once again, to keep parents alive and healthy, so that their children do not need to be cared for by anyone else. Household economic strengthening and ensuring their children have access to the same opportunities as their neighbours' children in education, health and social development will encourage more of these parents to keep their children, and to raise them well.

However there will always be a small proportion of children who find themselves without parental care and two strategies are needed to provide them with optimal care. The first is to establish and enforce minimum standards (and maximum stays!) for residential institutions, and the second is to establish the necessary resources to restore children to caring families through mechanisms such as guardianship, fostering or adoption.

These are not quick or simple solutions, and they must not be selectively applied – or denied – to children affected by HIV/AIDS.

Building partnerships and inter-sectoral coordination

One of the chief impediments for governments trying to mitigate the impact of HIV/AIDS on children is that it doesn't fit neatly into the traditional sectors of public and privat e service, nor into the divisions between health, education, social welfare and law enforcement. Another is that the needs of affected children clearly overlap with those of other children who are impoverished, neglected and abused. In short, it's difficult to know where to start.

But advances in social development, for example those measured by the Millennium Development Goals, and increasing international support – both technical and monetary – for HIV/AIDS programmes provide a window of opportunity to up lift all children. The new mantra in programming for affected children is universality[34] – provide education, health care and social benefits to all children, including those made vulnerable by HIV/AIDS.

What is needed is a clear plan, and someone to take r esponsibility. National action plans have been developed in many countries – including a few low-prevalence nations – and powerful coordinating bodies have been set up under the active leadership of the head of state, deputy president or first lady. Such bodies must also give an equal voice to civil society, including people living with HIV/AIDS and, directly or indirectly, children themselves.

CONCLUSION

The key messages from the regional research are:

- That a very large number of children – perhaps ten million – are affected by HIV/AIDS in South Asia. Fortunately, only a tiny proportion are infected themselves and medical treatment now offers them a future, if they are diagnosed early. Most affected children are at risk because they have a parent living wit h HIV, or have been orphaned by AIDS.

- That, without antiretroviral treatment for their parents, the prospects for many children are bleak – loss of education, inheritance, family support, and placement in an orphanage. In addition, if parents' sero-status becomes public knowledge, affected children often face exclusion, neglect and abuse by relatives, communities, health centres and schools.

- That stigma and discrimination are founded on widespread misconceptions, even among educated people, such as the beli ef that the children of HIV -positive parents are likely to

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[34] Eg: the recommendations of the Global Partners' Forum, London, February 2006 – see Annex 1

be infected themselves; that ordinary contact between HIV-positive people can infect others; and that HIV infection is a sentence of death.

- That governments in South Asia are not fully protecting the rights of their youngest citizens – especially those affected by HIV/AIDS – to the care and support of their parents and families; to freedom from discrimination, abuse and neglect; and to institutional care being used only as a last resort, and then only under strict conditions.

However, there have been major advances in global learning in relation to policies and programmes for children affected by HIV/AIDS, such as:

- That free, universal and sustained antiretroviral therapy for parents who need this treatment is unquestionably the most useful measure to protect the wellbeing of their children, and that ART for infected children not only gives them a future, but is essential to their families' economic and psychological wellbeing.

- That the "targeted" approach to programming, which relies on identifying children and families affected by HIV/AIDS and which assumes they all have similar needs, is giving way to a "universal" approach, which ensures affected children are included in public and community support systems which are available to all children.

- That children's rights are threatened by the HIV infection of their parents, or themselves. All young people and their caregivers need to know their rights and entitlements, and who to turn to if their rights are threatened. Children excluded from services as a result of HIV/AIDS must be helped to recover their rights and entitlements.

- That where ART is universal, the biggest remaining cause of suffering for affected children, and impediment to overcoming that suffering, is stigma. It now appears that stigma may be propagated by the very messages that are used to change risky behaviour, and by the professionals who are key to fighting the epidemic – the doctors and teachers.

ANNEX 1: INTERNATIONAL COMMITMENTS

This series of extracts is not intended to be exhaustive, but focuses on those instruments with the most direct bearing on national policy in relation to children affected by HIV/AIDS:

UN Convention on the Rights of the Child [35]

The government of almost every nation on earth has signed the United Nations Convention on the Rights of the Child (CRC) which provides wide-ranging rights to children and asserts that the best interests of the child should come first.

Children have the right to life, survival and development; freedom from discrimination; respect for their views; freedom of expression and access to appropriate information; protection of privacy and from torture and degrading treatment.

Children may not be subject to abuse and neglect; sexual exploitation and sexual abuse; sale, trafficking and abduction and other forms of exploitation.

Children are entitled to social services such as health; education; social security; leisure, recreation and cultural activities; and protection from economic exploitation.

Parental guidance and responsibilities are covered, as are separation from parents; deprivation of a family environment; family reunification; and recovery of maintenance for the child.

The protection of children's rights falls firstly to parents or, where applicable, the extended family. The State is obliged to help parents and guardians in this role by taking 'all appropriate legislative and administrative measures'.

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[35] See http://www.unhchr.ch/html/menu3/b/k2crc.htm

The State, for its part, must ensure children are protected from abuse and neglect. However, a child may not be placed in a residential institution simply to improve their access to health, education or other basic services. Instead the State should provide support to their family so they can take proper care of their child.

If a child is removed from the family the State must provide special care and protection such as guardianship within the extended family, foster care, adoption and, as a last resort, institutional care. Children in institutional care have the right to be re-integrated into the community as soon as possible.

The United Nations General Assembly Special Session (UNGASS) on HIV/AIDS[36]

At this meeting in June 2001 governments from 189 countries committed themselves to a comprehensive programme of international and national action to fight the HIV/AIDS pandemic by adopting the Declaration of Commitment on HIV/AIDS.

In relation to children orphaned and made vulnerable by HIV/AIDS, the Declaration commits governments to:

65. 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 psycho-social support; ensuring their enrolment in school and access to shelter, good nutrition, health and social services on an equal basis with other children; protecting orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance;

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

67. Urge the international community, particularly donor countries, civil society, as well as the private sector to complement effectively national programmes to support programmes for children orphaned or made vulnerable by HIV/AIDS in affected regions, in countries at high risk and to direct special assistance to sub-Saharan Africa.

Countries are required to submit information to the Secretary General on their progress towards attaining these goals – including conducting a situation analysis or study; holding a national consultation; developing a national action plan; establishing a coordinating mechanism; and reviewing policies and legislation.

The SAARC Convention[37]

The South Asian Association for Regional Cooperation (SAARC) [38] declared 2001-2010 to be the 'Decade of the Rights of the Child'. Reiterating their commitment to the UN Convention on the Rights of the Child, the SAARC Convention on Regional Arrangements for the Promotion of Child Welfare in South Asia was signed.

"Noting that a quarter of the world's children live in South Asia and many of them require assistance and protection to secure and fully enjoy their rights, and to develop to their full potential and lead a responsible life in family and society…"

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[36] See http://www.ecpp.co.uk/ungass.htm

[37] Extracted from Children Outside Parental Care, UNICEF Regional Office for South Asia, September 2006. For the text of the convention see http://www.tamilnation.org/humanrights/child/instruments_resolutions/saarc.htm

[38] Member States of the SAARC: People's Republic of Bangladesh, Kingdom of Bhutan, Republic of India, Republic of Maldives, Kingdom of Nepal, Islamic Republic of Pakistan, and Democratic Socialist Republic of Sri Lanka.

In the document state members recognise that the family, as t he fundamental unit of society and also as the ideal nurturing environment for the growth and well -being of children, should be afforded the necessary protection and assistance so that it can fully assume and fulfil responsibility for its children and comm unity.

The Convention reinforces political willingness to ensure the fulfilment of child rights among the member states by facilitating the exchange of information, experi ence, and practices, which have the potential to improve actual policies, laws and s ervices. It sets universal access to basic services (education and health care, with special attention to the prevention of diseases and malnutrition) as a regional priority.

However, the Convention does not give any direction on how to respond to specific issues like children outside parental care. In fact, the document has more of a declaratory than a strategic and operational character.

Instruments and Actions Taken in South Asia

	UN Convention on the Rights of the Child	The Hague Convention on Adoption	SAARC Convention on Child Welfare	Stockholm Declaration on Children and Residential Care
Afghanistan	√	-	√ (Accepted as member state in 2006)	√
Bangladesh	√	-	√	-
Bhutan	√	-	√	
India	√	√	√	√
Maldives	√	-	√	-
Nepal	√	-	√	√
Pakistan	√	-	√	-
Sri Lanka	√	√	√	√

ANNEX 2: POLICY AND PROGRAMMING GUIDANCE

The following extracts are presented in chronologi cal order

"The Framework"[39]

The Framework describes five key strategies to address the protection, care, and support of orphans and vulnerable children.

- Strengthening the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support;

- Mobilizing and supporting community -based responses;

- Ensuring access for orphans and vulnerable children to essential services, including education, health care, birth regist ration and others;

- Ensuring that governments protect the most vulnerable children through improved policy and legislation and by channelling resources to families and communities;

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[39] The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS. UNICEF, USAID, SCF-UK and others, 2004.

- Raising awareness at all levels through advocacy and social mobilization to create a supportive environment for children and families affected by HIV/AIDS.

Global Campaign[40]

Described four focus areas for national programming, namely:

- Prevent mother-to-child transmission of HIV

- Provide paediatric treatment

- Prevent infection among adolescents and young people

- Protect and support children affected by HIV/AIDS.

These focus areas have been dubbed "the four P's" and the mitigation of impact is often described as "the fourth P". The specific recommendations under the fourth P are the same as those in the Framework.

Global Partners Forum[41]

The Third Global Partners Forum was held in London, England in February 2006 and brought together over 150 representatives from 45 countries including bilateral and UN donor agencies, NGOs, faith-based organisations, research institutions and governments. For the first time the Forum was preceded and informed by a technical consultation of 130 technical experts from civil society, donors and governments.

Three themes central to eliminating barriers to providing effective services and protection for children affected by HIV and AIDS were highlighted:

1. Integration – reaching children and their caregivers requires that plans, resources, and support efforts be integrated across sectors and all levels of operation. Support for affected children needs to be integrated into services that benefit all children.

2. Coordination – is needed to ensure that human and financial resources from governments, donors, and the private sector address the myriad needs of all children affected by HIV and AIDS.

3. Scaling up – a paradigm shift is needed to address barriers to services, and exponentially expand essential services and programmes beyond current coverage rates.

The Forum identified seven areas where a greater focus on children affected by HIV and AIDS is needed, and prioritized actions within each:

1. Strengthen civil registration to promote child protection and services.

   - Advocacy campaigns for civil registration, especially birth registration:

   - Support governments to remove barriers to birth registration, including fees.

2. Develop social welfare systems with budgetary allocations.

   - Strengthen systems and human resources to deliver social welfare, including social transfers

   - International community to support those countries developing their social welfare systems

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[40] A call to action: children the missing face of AIDS. UNAIDS and UNICEF, 2005
[41] Global Partners Forum for Children Affected by HIV and AIDS – Priority Recommendations. DFID, UNICEF, WB and others, 2006

3. Accelerate the existing momentum towards education for all children through the Fast Track Initiative and other financial mechanisms.

- Eliminate school fees for all children
- Support effort behind Education For All to im prove quality education, promote gender equality and enhance school retention rates
- Enable girls to complete secondary school education

4. Integrate and provide routine HIV and AIDS prevention and treatment services for children.

- Integrate guidance on paed iatric treatment and care into child and maternal health
- Integrate the distribution of free cotrimoxazole to eligible children into health services
- Scale up PMTCT Plus
- Scale up prevention for young people
- Pediatric ART formulations and diagnostic availab ility

5. Integrate a multi-sectoral response for children affected by HIV and AIDS into development instruments, including Poverty Reduction Strategy Papers.

- Integrate action for children affected by AIDS into development instruments
- Strengthen national coor dination of actions for children affected by AIDS

6. Strengthen capacity, effectiveness and participation of civil society.

- Develop mechanisms for flexible funding to meet community needs
- Direct long-term financial support to the community level in order to scale up implementation of evidence -based approaches

7. Strengthen monitoring and evaluation to improve the accountability and performance of national plans through improving data collection for children.

- Ensure national monitoring disaggregates by sex and ag e and includes the core indicators for children affected by HIV and AIDS
- build capacity to ensure information is collected and used to improve practice and to ensure accountability increases around vulnerable children

Where the Heart Is[42]

1. Prioritise ever yday systems of care – families, schools and communities.

The most appropriate and sustainable sources of psychosocial wellbeing for young children come from caring relationships in the home, school and community. Supportive families and communities nurture and sustain children's resilience. All efforts to enhance the psychosocial wellbeing of young children must ensure the support of these natural systems of care in everyday life. Children under stress are calmed and reassured when their familiar surroundings and everyday activities are restored.

2. Invest long-term in integrated services to promote psychosocial wellbeing

The psychosocial wellbeing of children and their primary caregivers is best supported by integrated services that address economic, ma terial, social, emotional and spiritual needs.

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[42] Where the Heart Is – meeting the psychosocial needs of young children in the context of HIV/AIDS, Linda Richter et al, Bernard van Leer Foundation, July 2006

Long-term investments in community development, health, education and family support services are more sustainable and successful than short -term, crisis-driven interventions.

3. Realise the right of all chil dren to access these integrated services

Rights are fulfilled through state provisions to which all caregivers and their children are entitled. These include education, health and social services. Universal access also addresses many of the most pressing needs of very vulnerable children. Services and programmes must take account of the differing needs of younger and older children, boys and girls, and children living in a variety of settings.

4. Demand that more governments take the lead in guaranteeing this right

Governments must lead and resource a coordinated effort that matches the generally vigorous responses to support vulnerable children that have come so far from civil society. Systems to guarantee universal access to health and education must be strengthened. Social security underpins formal and informal, community -based, safety nets.

5. Earmark resources for applied research to expand the evidence base

We need to learn from experience and apply lessons learnt from other fields, rather than tre at HIV/AIDS as a special case in all respects. More evidence, including impact assessments, is crucial to guide and sustain appropriate and effective action.

"Companion paper"[43]

Social protection

- Implement social transfer programmes to ensure the most vul nerable families are able to meet their basic needs.

- Invest in family support services and ensure appropriate links with social assistance programmes for maximum impact.

- Engage and partner with communities in planning and monitoring social transfers and family support services.

Legal protection and justice

- Combat disinheritance, especially among orphans and widows, by amending legislation, sensitizing community leaders to existing laws, making the process of registering and executing wills easier, and prom oting public education on wills and trusts.

- Improve civil registration systems by eliminating fees, making civil registries more accessible through decentralization and linking birth registration with other commonly accessed services.

- Strengthen and/or dev elop specialized child protective services in police, justice and social welfare systems that provid e a safe environment and sensi tive procedures for children who experience abuse and exploitation.

- Strengthen, develop and implement legislation and enforcem ent policies on child labour, trafficking, sexual abuse and exploitation that are in line with international standards to protect children and criminalize and penalize offenders.

- Support community-based monitoring mechanisms that include building the capac ity of teachers, health and community workers, and youth organizations to identify children at risk, report on cases of a buse and exploitation, and pro vide referrals.

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[43] Enhanced Protection for Children Affected by AIDS – a companion paper to the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS, UNICEF, March 2007

Alternative care

- Develop effective means of supporting and monitoring informal care arra ngements to ensure children are protected in extended families and other settings where parents are not present.

- Improve the formal care system to reduce overuse, guard against protection violations, encourage appropriate permanency planning, and provide o pportunities for children and caregivers to express their preferences.

- Develop government and community-based protection and monitoring mechanisms that are supported by national guidelines and standards for care providers.

Address stigma related to HIV, ab use and exploitation

- Facilitate open discussion to promote community -owned social change for children and ensure appropriate participation.

- Sensitize the media to issues of HIV and protection risks, and develop guide - lines for reporting abuses.

- Train national and community leaders to stimulate discussion on child protection issues and HIV.

Strengthen the state's social welfare sector

- Increase budgetary allocations to government agencies responsible for social welfare, alternative care and protective serv ices within national frame - works, to a level adequate, at minimum, for providing statutory services and coordinating and regulating services provided by local government and non-governmental agencies.

- Invest in human resources within the social welfare sy stem to increase the size, competency and reach of staff from both government and non -governmental service providers.

- Develop regulations, guidelines and coordination mechanisms aimed at improving implementation of social protection policies and ensuring m ore effective service provision.

ANNEX 3: REFERENCES

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