



Irish Aid

Department of Foreign Affairs
An Roinn Gnóthaí Eachtracha

**Children Affected by
HIV and AIDS**

Briefing Paper

1. Objective

This paper aims to provide a synopsis of issues emerging within relevant literature in relation to children orphaned and/or vulnerable in the context of HIV and AIDS, while contributing to an understanding of the existing evidence base and identifying where some of the gaps in knowledge lie. This paper will further outline frameworks formulated to guide the international response.

Children affected by HIV and AIDS is a complex and multifaceted issue, and while certain cross-cutting issues cannot be ignored, the scope of this paper will preclude in-depth examination of those issues not directly linked to HIV and AIDS.

2. Overview and Definitions of Children affected by HIV and AIDS

2.1 Overview of Children Living with and affected by HIV and AIDS

It is estimated that 1,150 children become infected with HIV daily and 2.5 million children are living with HIV worldwide. Of those, 80% are born in sub-Saharan Africa and 90% of infections are acquired through Mother-to-Child (MTC) transmission. However, only one in ten HIV positive pregnant women are offered anti-retroviral treatment (ART), which can reduce the risk of MTC transmission by 40%. In some of the worst affected countries, AIDS is the biggest cause of death among the under 5's and yet only an estimated 10% of children needing antiretroviral treatment receive it. HIV progresses rapidly in children with an estimated one third of infants dying by the time they reach their first birthday. In 2007, an estimated 330,000 children died of AIDS-related causes; the vast majority of these deaths were preventable.¹

While not infected with HIV, many more children are affected and it is estimated that 15 million children under 18 years have lost one or both parents to AIDS, with the vast majority, 12 million, resident in sub-Saharan Africa. With the consequent loss in affection, support and protection, children are rendered more vulnerable to poverty, social dislocation, exploitation and abuse, while others may become responsible for the care of siblings and/or other ill adult members of the household. One in six households is caring for at least one orphan. The number of orphaned children as a result of AIDS is projected to exceed 25 million by the end of the decade², and the number of children in sub-Saharan Africa who have lost both parents to AIDS may rise to 8 million from 5.5 million in 2001, according to estimates³.

In Zambia data from 2005 show that 11.8% of children were vulnerable in that they either lived in a household with a chronically ill adult, or had experienced an adult death in their household in the last year.

Orphan hood is declining in other areas of the world, however in sub-Saharan Africa it is on the increase. In Zambia, 20% of all children were orphaned in 2005; over half due to AIDS⁴, while 15% were orphaned in seven countries within the sub-Saharan region. Double orphan estimates in sub-Saharan Africa suggest that 8% were between 0 and 5 years; 29% were between 6 and 11 years; and 63% were between 12 and 17 years⁵.

Almost half of all orphans and two-thirds of double orphans are adolescents aged between 12 and 17 years, while 40% experience death of a parent between age 10 and 14 years and 25% of these experience a parents death before age 5 years. Older

¹ UNAIDS/WHO, *AIDS Epidemic Update*, November 2007

² UNAIDS, *Orphans & Vulnerable Children Fact Sheet*, 2007

³ UNICEF, UNAIDS et al, *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, July 2004

⁴ UNICEF, UNAIDS, *Africa's Orphaned and Vulnerable Generations; Children Affected by AIDS*, August 2006

⁵ Ibid

orphans are at risk of missing out on education, of being subject to exploitative labour, sexual abuse and are consequently more vulnerable to HIV. The youngest orphans however, are the least resilient and have the greatest need for care and nurturing.

Projections based on HIV prevalence and current levels of ART coverage indicate that the number of orphaned and vulnerable children due to AIDS will continue to rise through at least 2010. Projections indicate that even if a full package of interventions is put in place including treatment prophylaxis, Prevention-of-Mother-to-Child-Transmissions (PMTCT) and primary prevention activities, the number of orphans will remain high for the next several years⁶.

2.2 Definition of a Child

The *United Nations Convention on the Rights of the Child*, 1979, defines a child as a person less than 18 years.

2.3 Definition of Orphans

Maternal Orphans are children under age 18 whose mothers, and perhaps fathers, have died (includes double orphans)

Paternal Orphans are children under age 18 whose fathers, and perhaps mothers, have died (includes double orphans)

Double Orphans are children under age 18 whose mothers and fathers have both died.⁷

It is estimated that 15.2 million children have been orphaned by AIDS⁸. Ordinarily, the death of one parent is not necessarily linked to the death of the other parent, but because HIV is sexually transmitted, the probability that both parents will die if one is infected is high⁹. Furthermore, research in Uganda has shown that HIV and AIDS has altered definitions of orphan hood; the Oxford English Dictionary defines an orphan as "One deprived by death of father or mother, or more generally, of both parents..."¹⁰ and in the past children who lost one parent were rarely considered orphans as it was common practice for a remaining parent to remarry. However, increased fear that the remaining parent may be infected, stigma and the impoverishment of households affected by AIDS have resulted in fewer remaining parents remarrying¹¹.

2.4 Definition of Vulnerable Children

The term 'orphans and vulnerable children' (OVC) was coined in order to signify and extend the discussion on disadvantage to other vulnerable children. Because the concept of vulnerability is often socially or contextually defined, reaching agreement on what constitutes a vulnerable child is particularly difficult. Hence, there is no means through which a reliable estimate of the number of vulnerable children as a result of HIV and AIDS may be calculated. This issue was discussed at some length and without resolution at the recent Inter Agency Task Team meeting on Children and HIV and AIDS in Washington in April 2007; some argued that for the purposes of research, monitoring and evaluation, and cross border data comparisons, it is necessary to agree a clear definition of what constitutes a vulnerable child in relation to HIV and AIDS, while others argued that vulnerability can only be understood in context. Currently then, consensual

⁶ Ibid

⁷ UNICEF, UNAIDS et al, *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, July 2004

⁸ Institut de Santé Publique, Epidémiologie et Développement (ISPED), Université Victor Segalen – Bordeaux 2, *Children and HIV/AIDS, From Research to Policy and Action*, Childhood and AIDS, October 2006

⁹ UNICEF, UNAIDS et al, *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, July 2004

¹⁰ Oxford English Dictionary, Second Edition, Clarendon Press, Oxford, 2004

¹¹ Deacon H., Stephney I., *HIV/AIDS, Stigma and Children; A Literature Review*, Kellogg Foundation and Human Science Research Council, 2007

agreement on what constitutes a vulnerable child continues to elude the international community, however the term *Children Living in Communities Affected by HIV and AIDS* is general and embraces the many different categories of children affected by HIV and AIDS including the following:-

- *Children indirectly affected by the AIDS pandemic*
In all countries with high HIV/AIDS prevalence, large numbers of children are indirectly affected by the epidemic because social institutions and services become overwhelmed and are further weakened when teachers, health service providers, civil servants and others become ill or are distracted by the responsibility for sick and dying relatives. For example, it is estimated that some 90% of children in Zimbabwe and in other countries with severe HIV/AIDS epidemics have suffered as a result of the impacts of HIV/AIDS.¹²
- *Vulnerable children affected by AIDS*
The term "children in especially difficult circumstances" was coined by UNICEF on the mid-1980's to describe the situations of particular groups of children that went beyond poverty. Children with disabilities, children living in and out of the streets, working children, children in institutions, children in conflict zones, and others, may all be considered vulnerable children living in especially difficult circumstances. Many of these children have very weak or no adult support. As a result of the HIV and AIDS pandemic, many of these children are doubly disadvantaged. Disabled children are more likely to be infected with HIV, to live with HIV-infected parents, or to be orphaned through the death of their parents from AIDS than other groups of children.¹³
- *Children in households that foster orphaned children*
The core response to orphaned and vulnerable children is through family fostering, a practice common in the Southern African region that pre-dates the AIDS epidemic. Crisis fostering occurs when families and neighbours or other guardians are obliged to take in children, instead of necessarily choosing to do so. This type of fostering which is more frequent as a result of the epidemic can be inappropriate or ill-matched resulting in exacerbated poverty levels in many fostering households due to increased dependency ratios. The standard of living of such households and the prospects of non-orphaned and orphaned children are adversely affected by crisis fostering.¹⁴
- *Children living with HIV+ parents and sick adults*
Around 80% of children born to HIV infected mothers are uninfected at birth. Nonetheless, studies show that uninfected children born to HIV positive mothers have higher mortality rates than HIV negative children in the community. In addition, it is reported that they have more attention, social adjustment and behavioural problems than comparison children do. Deepening poverty resulting from the diversion of household income to pay for the treatment of sick adults is inevitable. The loss of income, compromised parenting coupled with school absence and the physical and psychological burden on children living with and caring for sick and dying parents are contributing factors.¹⁵
- *Children living with HIV and AIDS*
In eight Southern African countries children living with HIV and AIDS represent between 2 and 4 per cent of the childhood population. In high prevalence

¹² Catholic Relief Services, 2004, from Richter L., Rama S., *Building Resilience; A Rights Based Approach to Children and HIV/AIDS in Africa*, Save the Children, Sweden, 2006

¹³ Save the Children, 2003, from Ibid

¹⁴ Richter L., Rama S., *Building Resilience; A Rights Based Approach to Children and HIV/AIDS in Africa*, Save the Children, Sweden, 2006

¹⁵ Ibid

countries, between one third and one half of all deaths of children under five years old are from AIDS. However, many deaths among children living with HIV and AIDS result from common diseases like bacterial pneumonia, diarrhoea, malnutrition and malaria rather than AIDS-related opportunistic infections.¹⁶

3. Issues Emerging and Recurring within the Literature

3.1 Child Mortality following the Death of a Parent; the Physical and Psychological Impact of Parental Illness and Death on Children

A survey in Uganda demonstrated that 26% of children living with HIV positive parents attended school less often, citing the need to stay at home and care for sick parents; they also reported increased household responsibilities and falling incomes¹⁷. Furthermore, children orphaned by AIDS are significantly more likely than non-orphans to experience hunger and are less physically healthy¹⁸. The death of a parent has a critical impact on early life and development and studies demonstrate that the survival of children less than 3 years is at stake particularly when mothers are dying or have recently died; children at this age are 3.9 times more likely to die during the two years surrounding a mother's death¹⁹. In countries with the highest HIV prevalence, AIDS has made a dramatic difference in child mortality rates; a cohort study undertaken in Uganda found an association between increased mortality rates in children within one year following the death of a parent²⁰.

While the research is not conclusive in any of these areas, there is significant evidence to suggest that children orphaned by AIDS are more likely to experience hunger and food insecurity; are significantly less healthy than non-orphans; are less likely to be in school during parental illness or to remain in school following the death of a parent; are at higher risk of child labour, and in the case of adolescent orphans, to sexual exploitation, and increasing vulnerability to HIV²¹.

Psychological distress is not confined to HIV and AIDS for orphaned and vulnerable children but may also be impacted by food insecurity, conflict, widespread unemployment or lack of essential services. Adolescents often experience emotions of anger, resentment, hopelessness and depression in the best of circumstances but losing a parent can heighten these feelings, resulting in a tendency towards risk taking behaviour, which in turn may increase vulnerability to HIV²². A study conducted in Bulawayo, Zimbabwe, found that orphaned and vulnerable youth, i.e. aged 14 to 20 years, 65% of which had lost one or both parents, reported high levels of exposure to traumatic events and daily life stress. While most youth showed signs of extraordinary resilience, a substantial minority, 31%, reported that they never feel able to cope²³. Social support for vulnerable youth was inconsistent and orphans scored lower in terms of access to social support than non-orphans; 46% reported never being supported by their community, or peers (23%), while 15% reported abandonment by family and

¹⁶ African Network for the Care of Children affected by AIDS, *from Ibid*

¹⁷ Gibbon et al, *from Maastricht Graduate School of Governance, UNICEF, HIV/AIDS and Its Impact on Children*, Policy Brief No.1, June 2006

¹⁸ Gerter et al, 2004,, *from Ibid*

¹⁹ UNICEF, UNAIDS, *Africa's Orphaned and Vulnerable Generations; Children Affected by AIDS*, August 2006

²⁰ Nakiyingi et al, 2003, *from Maastricht Graduate School of Governance, UNICEF, HIV/AIDS and Its Impact on Children*, Policy Brief No.1, June 2006

²¹ Maastricht Graduate School of Governance, UNICEF, *HIV/AIDS and Its Impact on Children*, Policy Brief No.1, June 2006; UNICEF, UNAIDS, *Africa's Orphaned and Vulnerable Generations; Children Affected by AIDS*, August 2006; Save the Children Sweden, *Missing Mothers*, 2006; Save the Children, *Building Resilience; A Rights Based Approach to Children and HIV/AIDS in Africa*, 2006

²² UNICEF, UNAIDS, USAID, *Children on the Brink*, 2004; Youthnet Programme, *Adolescent Orphaned and Vulnerable in a Time of AIDS*, Family Health International, 2005

²³ USAID, Population Council, *Orphaned and Vulnerable Youth in Bulawayo, Zimbabwe – An Exploratory Study of Psychosocial Well-being and Psychosocial Support Programmes*, February 2006

friends in times of greatest need.²⁴ Furthermore, females reported higher levels of psychological trauma, exhibiting in some cases worrying levels of depression and anxiety and orphan hood was associated with greater stress, isolation and psychological distress. Older respondents however, despite greater exposure to trauma and psychological distress, demonstrated signs of strength not evident in younger respondents. The study concluded that while psychosocial distress and well-being can co-exist, that there needs to be a greater emphases on the psychological needs of young girls including the need to build self esteem, while tailoring programmes to meet the needs of children's grieving processes in specific cultural contexts²⁵. Additionally, a study in Uganda found that children orphaned by AIDS had higher levels of anxiety, depression and anger, with a tendency towards inactivity, feelings of hopelessness and thoughts of suicide²⁶. More research is needed to understand children's grieving processes, and what factors enable resilience in young people post trauma.

3.2 Women and Children

There is a direct link between the well-being of women and of children; when women are healthy, educated and free to avail of life's opportunities, children also thrive. The consequences of women's exclusion from household decisions can be dire for children, whereas in families where women are key decision makers, the proportion of resources devoted to children is far greater than in those in which women have a less decisive role.²⁷ Women effectively increase nutritional status, and it has been shown that educating women improves survival rates for children while improving school attendance rates.

In countries with high HIV prevalence, the number of women dying from an AIDS-related illness is escalating²⁸. In sub-Saharan Africa, there are on average three women living with HIV for every two infected men. Mothers will soon exceed the rate at which fathers, who are older, are dying. Survey data from 2004 demonstrated that children who lose their mothers are less likely to live with the surviving parent, compared to children who lose their fathers²⁹. Furthermore, female headed households generally assume care of more orphans than male headed households; hence female headed households have a higher dependency ratio and are consequently at greater risk of poverty. While much research upholds the view that female headed households in low and middle income countries are at greater risk of poverty, some research demonstrates that women are more efficient household managers and may effectively mitigate the effects of poverty³⁰.

3.3 Family Structures of Care

When both parents die, analysis from 13 countries demonstrate that extended family typically care for double orphans and single orphans not living with the surviving parent. Children tend to express a preference for grandparents over other relatives, and studies conducted across ten countries in sub-Saharan Africa conclude that orphans living with grandparents fare better in school attendance than other relatives. The traumatic impact of the death of a parent/s on children is mitigated by the fact that grandparents frequently will have had a previous caring role. However, grandparent/s tend to have

²⁴ Ibid

²⁵ Ibid

²⁶ UNAIDS, *Africa's Orphaned and Vulnerable Generations; Children Affected by AIDS*, August 2006

²⁷ UNICEF, *State of the World's Children*, 2007

²⁸ UNICEF, UNAIDS, *Africa's Orphaned and Vulnerable Generations; Children Affected by AIDS*, August 2006; Save the Children, *Missing Mothers*, 2006

²⁹ Ibid

³⁰ International Food Policy Research Institute, *The Key to Food Security; Looking Into the Household*, 2000; Chant S., *Poverty Begins at Home? Questioning some (mis)conceptions about children, poverty and privation in female-headed households*, London School of Economics, Background Paper to *State of the World's Children* 2007, December 2006

fewer economic resources and there is also the risk that they will not survive until children reach maturity resulting in a second experience of loss and transition to new caregivers³¹.

While data on sibling separation is scarce, orphaned siblings can be placed among different relatives/neighbours as a way of distributing the burden of care. A study conducted in Zambia and Malawi revealed that sibling separation was a considered determinant of emotional distress for orphans in an urban sample³².

There are very few child-headed households (less than 1%); even in Zimbabwe where HIV prevalence and the proportion of orphans are particularly high the proportion of child-headed households was found to be only 4 per 1,000. Despite the low level of occurrence, such households are among the most vulnerable, with children at greatest risk of exploitation.

3.4 Diminishing Household Wealth

Several studies have documented the impact of AIDS on household income and wealth³³; with illness medical care and other expenses increase, while the capacity to work and generate income is diminished. In households affected by AIDS, more money is spent on those who are ill leaving less for children and of course poorer households have even less to begin with. A study in the Côte d'Ivoire found that in a family affected by AIDS, the proportion of household budget spent on medical care is twice that of the control group while income in the household affected by AIDS was half that of the control group³⁴. Also funeral expenses can impact on the household budget with funerals costing up to a third of annual household income.

As highlighted in section 3.1, households with orphans tend to have higher dependency ratios and it has been suggested that for each productive adult there are 1.6 people to be supported³⁵. Households that foster/adopt orphaned or vulnerable children need to provide basic necessities for additional children and support from extended family, neighbours or the community may not be sustainable on a long-term basis. Furthermore, there is increasing evidence of discrimination in resource allocation within poor households against children who are not direct descendents of the household head. A study in Malawi and Lesotho revealed that children living in another household because they had experienced death or illness of a parent reported being given different food from the other children in the household, being beaten and overworked, receiving inadequate clothing, while they were also less likely to attend school than the other children in the household³⁶.

3.5 Impact on Education

Research on the education experience of orphans is at best complex and findings are varied in that school enrolment for orphans compared to non-orphans differs across countries. There is nonetheless compelling evidence from research across several countries that show lower school enrolment rates among children living in AIDS impacted communities. After death the hazards of missing school are greatest for double orphans. A study from Mexico and Indonesia found that children with a deceased

³¹ UNICEF, UNAIDS, *Africa's Orphaned and Vulnerable Generations; Children Affected by AIDS*, August 2006

³² Ibid

³³ Béchu N., *The Impact of AIDS on the Economy of Families in the Cote d'Ivoire; Changes in Consumption among AIDS-affected Households*, European Commission, Brussels, 1998, pp342-343; Steinburg M. et al, *Hitting Home; How Households Cope with the Impact of the HIV/AIDS Epidemic*, Henry J. Kaiser Foundation, Washington, D.C., 2002

³⁴ Ibid

³⁵ UNICEF, UNAIDS, *Africa's Orphaned and Vulnerable Generations; Children Affected by AIDS*, August 2006

³⁶ Gillespie S., *Child Vulnerability and AIDS; Case Studies from Southern Africa*, International Food Policy Research Institute, September 2006

parent are more likely to drop out of school and are less likely to start school³⁷. Similarly a long-term impact study undertaken in a Northern region of Tanzania, shows that maternal death causes persistent impact on years of education of almost one year³⁸. Evidence shows that effects are largest for children whose mothers died, for young girls (under age 12) and for children with low basic academic performance³⁹. However, some researchers argue that orphans are not at particular disadvantage compared with non-orphans, and as noted by the World Bank in 2002, in low enrolment countries both orphans and non-orphans face considerable constraints.

While poverty is a significant factor determining school attendance it is not the only one. The relationship between an orphan and head of household impacts on school attendance; the closer the biological tie, the greater the chance the child will go to school⁴⁰. While a household may not be resource poor, the head of household may choose to privilege his/her own children over fostered/adopted children.

HIV and AIDS have devastating effects on the entire education system. In Zambia for instance, 40 percent of all teachers are HIV-positive and are dying at a faster rate than they can be replaced by new graduates⁴¹.

Finally, it is well established that children of HIV+ parents tend to reduce attendance or drop out of school with the onset of parental illness as documented above; one common strategy in HIV and AIDS affected households is to take children out of school because help is needed in the home and/or with decreased income, school fees/associated costs can no longer be afforded⁴².

3.6 Civil Registration

Registration of a child's identity is a fundamental human right, as stipulated by Article 7 of the Convention on the Rights of the Child. Registration enables a child to obtain a birth certificate, which is the most visible evidence of a government's legal recognition of the child as a member of society. A birth certificate is also proof of the child's relationship with parents and, generally, also determines nationality.

Birth registration may be needed for access to health services, welfare services or school enrolment. In sub-Saharan Africa two-thirds of all births go unrecognized, while in other low and middle income countries 55% of births go unrecognized⁴³. Countries particularly affected by HIV and AIDS tend to have especially low levels of birth and other forms of registration including marriage, which has particular implications for women, orphaned or vulnerable children leaving them at risk of abuse, exploitation and inheritance violations⁴⁴. Civil registration is crucial in determining the extent of child mortality or orphan numbers⁴⁵, but more importantly and particularly in the case of paternal or double orphans, registration can protect women and children from confiscation of property or other assets following the death of a parent.

³⁷ (Gertler et al, 2004), from Graduate School of Governance, UNICEF, *HIV/AIDS and Its Impact on Children*, Policy Brief No.1, June 2006

³⁸ (Beegle et al., 2005), from Ibid

³⁹ (Evans et al., 2005), from Ibid

⁴⁰ UNICEF, UNAIDS, *Africa's Orphaned and Vulnerable Generations; Children Affected by AIDS*, August 2006

⁴¹ (Daly et al., 2000), Graduate School of Governance, UNICEF, *HIV/AIDS and Its Impact on Children*, Policy Brief No.1, June 2006

⁴² Graduate School of Governance, UNICEF, *HIV/AIDS and Its Impact on Children*, Policy Brief No.1, June 2006

⁴³ UNICEF, *State of the World's Children*, 2006

⁴⁴ UNICEF, UNAIDS, *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, July 2004

⁴⁵ Grassly N. et al, *Comparison of survey and model-based estimates of mortality and orphan numbers in sub-Saharan Africa*, DFID Reproductive Health Work Programme, 2004

3.7 Stigma, Discrimination and Isolation

Stigma and discrimination can exacerbate the material and psychological problems children face in the context of HIV and AIDS, however, there is a dearth of systematic research illustrating the nature and extent of the problem⁴⁶. As noted earlier, the fact that HIV is sexually transmitted increases the likelihood that both parents are infected, which precludes remaining parents from marrying, even if they are HIV negative. The few studies of children's experience of stigma and discrimination⁴⁷ have argued that children affected and infected with HIV experience considerable psychological disadvantage as a result of HIV and AIDS-related stigma. Children whose parents are ill with AIDS or who have died of an AIDS-related illness, report being marginalized and isolated from other children, being teased and gossiped about, while presumed to be HIV positive, and not in receipt of care⁴⁸. There is significantly more evidence supporting the view that children infected with HIV experience stigma and discrimination and it may therefore follow that children presumed to be HIV positive following the death of a parent may experience the same. Overall however, the jury is largely out on this issue because it is difficult to separate causal factors for stigma and discrimination in societies where poverty or orphan hood are stigmatizing states in themselves.

3.8 Child Labour

One study found that although there are long existing patterns of child labour in South Africa, the HIV and AIDS pandemic and associated poverty seems to have increased the trend of young children engaging in paid and unpaid labour⁴⁹. Household poverty following the death of a parent or income earner to AIDS is one of the primary factors forcing children to drop out of school and enter the labour market. Girls are usually the first to be withdrawn from school in order to take up domestic positions that are oftentimes poorly paid and hidden from public view where sexual and other violent assaults and exploitation may be facilitated. Child labour is filled with numerous risks including sexual exploitation and HIV infection⁵⁰. When households lose productive members, incomes decline, at least over the medium term and productive labour is shifted from generating income or food to care for sick family members. At the same time, health-care costs increase followed by funeral expenses. There are widespread reports of families selling or renting household goods and assets (from clothing and utensils to livestock and land) to get needed cash. Grandparents or elderly guardians are likely to become primary caregivers for orphaned children and assume a heavy financial burden in the process. It is within this context that children are withdrawn from school (to save money) and/or encouraged to work (to earn money), either to assist their families or provide for themselves⁵¹. Furthermore, many orphaned and vulnerable children are forced into labour or sexually exploited for cash to obtain 'protection', shelter or food⁵².

The gender dimension in child labour is quite marked; a 1999 survey of working children in Uganda noted that orphaned girls often were "married off" by guardians if the household was too stressed, or if the girl was felt to enjoy better opportunities because the suitor was considered rich. Another study in Nairobi, Kenya, found that over one-

⁴⁶ Deacon H., Stephney I., *HIV/AIDS Stigma and Children; A Literature Review*, Kellogg Foundation and Human Science Research Council, 2007

⁴⁷ Clay et al, 2003, Strode & Barrett-Grant et al, 2001

⁴⁸ Deacon H., Stephney I., *HIV/AIDS Stigma and Children; A Literature Review*, Kellogg Foundation and Human Science Research Council, 2007

⁴⁹ Mturi & Nzaminde, 2003, *from Ibid*

⁵⁰ Rau B., *HIV/ AIDS and Child Labour; A State of the Art Review*, International Labour Organisation, Paper No. 6, 2003

⁵¹ *Ibid*

⁵² UNICEF, UNAIDS, *The Framework for the Protection, Care of Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, July 2004

third of orphaned children ended up as street children, commercial sex workers, casual labourers, or married as girl children⁵³.

3.9 Violence, Sexual Abuse and Child Marriage

Women and girls are particularly vulnerable to sexual violence which tends to be both a cause and a consequence of HIV. The *UN World Report on Violence against Children* (2006) reported that violence is common in schools, in institutions, within justice systems, communities, places of work and within homes. Children living with extended families, frequently following the death of a parent/s, are often subject to sexual violence from uncles, stepfathers and cousins⁵⁴. A study in Zambia revealed that as many as 32% of boys and 33% of girls reported that they had been physically forced to have sex⁵⁵. Experience of sexual violence at a young age can cause an increased tendency towards risk taking behaviour, thus increasing vulnerability to HIV and other STI's in later life.

Girls may be vulnerable to child marriage in AIDS affected communities, as parents may hold a belief that their daughters will be safer or financially better off if married early. However, this does not hold up under scrutiny and young girls in some regions are married to men twice their age, where the power differential is too large to bridge. In such circumstances young girls are subject to physical and sexual abuse and may be at increased risk of contracting HIV⁵⁶.

The *Enhanced Protection for Children Affected by AIDS* document highlights the need for more rigorous research and evidence-based knowledge on the connections between trafficking and child labour.

4. Treatment Issues for Mothers and Children

4.1 Prevention of Mother-to-Child Transmission (PMTCT)

Ninety per cent of children infected with HIV acquire the infection through MTCT, which can occur during pregnancy, delivery or breastfeeding. In the absence of any intervention the risk of such transmission is 15–30% in non-breastfeeding populations, however, breastfeeding by an infected mother increases the risk by 5–20% to a total of 20–45%⁵⁷. The risk of MTCT can be reduced to under 2% by interventions that include antiretroviral (ARV) prophylaxis given to women during pregnancy and labour and to the infant in the first weeks of life, obstetrical interventions including elective caesarean delivery (prior to the onset of labour and rupture of membranes), and complete avoidance of breastfeeding. With these interventions, new HIV infections in children are becoming increasingly rare in many parts of the world, particularly in high-income countries⁵⁸.

To date, nevirapine (NVP) single-dose regimen remains the most feasible and least expensive strategy in settings with the capacity to deliver only a minimal range of ARVs, with residual peri-partum transmission of at about 12%. Although the selection of NVP-resistant virus after the administration of a single-dose of NVP is frequent, this can be reduced by the addition to NVP single-dose of a short postpartum combination of ARVs

⁵³ Rau B., *HIV/ AIDS and Child Labour; A State of the Art Review*, International Labour Organisation, Paper No. 6, 2003; Population Council Presentation at Inter Agency Task Team on Children and HIV and AIDS, Washington D.C. 24th April 2007

⁵⁴ UNICEF et al, *Enhanced Protection for Children Affected by AIDS*, March 2007

⁵⁵ Ibid

⁵⁶ Ibid and Inter Agency Task team on Children and HIV and AIDS, Population Council Presentation, 24th April 2007

⁵⁷ World Health Organisation, *Antiretroviral Drugs for Treating Pregnant Women and Prevention HIV Infection in Infants, Towards Universal Access*, 2006 Version

⁵⁸ Ibid – Note: MTC transmission in Ireland is less than 1%

given to the mother. Among the post-partum interventions likely to contribute to PMTCT, observational evidence has shown that exclusive breastfeeding results in lesser postnatal HIV transmission than breastfeeding with other fluids (water, fruit juice) or solids (baby food)⁵⁹ in settings where refraining from breast feeding is neither viable nor safe.

However, in resource poor settings caesarean delivery is oftentimes not feasible and it is often neither culturally acceptable nor safe to refrain from breastfeeding. Other barriers to the PMTCT can include a preference for home/traditional birthing practices or resistance to HIV testing in pregnancy for fear of partner notification or rejection compounded by stigma and discrimination. Considerable efforts have been made to introduce and expand PMTCT programmes, which have been shown to be feasible, acceptable and cost-effective, yet despite significant progress they have not been implemented widely in resource-constrained settings⁶⁰. Up to 2006, only 10% of pregnant women living with HIV were receiving ARV prophylaxis for PMTCT. Also coverage varies between countries: in Botswana, for example, prevention services reach at least 50% of all pregnant women living with HIV and countries in Eastern Europe and Latin America have also achieved high coverage.

The Inter-Agency Task Team on Prevention of HIV Infection in Pregnant Women, Mothers and their Children organized a high-level Global Partner's Forum in Abuja, Nigeria in December 2005 to: (i) review progress towards the achievement of UNGASS targets for preventing HIV infection in infants and young children, and (ii) build consensus on priority action that global partners, national governments and all implementers could take to move faster towards achieving universal access by 2010. The Abuja Call to Action: *Towards an HIV-free and AIDS-free Generation* recognised the following:-

- evidence confirms that effective large scale programmes to prevent MTCT of HIV can be implemented in settings with limited resources
- 15% of new HIV infections each year are caused by MTCT and that elimination of HIV infection in infants and young children would serve to accelerate global HIV prevention efforts
- aggressive efforts to reduce mother-to-child-transmission of HIV and eliminate HIV infection in infants and young children would also help to hold families together, benefit communities and reduce the stigmatization of people living with HIV

and called upon other governments, development partners, civil society and private sector to join this Call to Action, and move swiftly towards supporting the measures needed to eliminate HIV in infants and young children and clear the way for a worldwide HIV-free and AIDS-free generation⁶¹.

Regionally, efforts are underway to identify obstacles to universal access in partnership with Governments, donor organisations and international agencies. One goal of the *Unite for Children, Unite against AIDS Campaign*⁶² is to provide PMTCT services to 80% of HIV positive pregnant mothers by 2010, and although not specifically stated in UNICEF's stocktaking report, there is no convincing evidence in existence to suggest that this goal will be met by that deadline. The PMTCT plus model of care uses PMTCT as an entry point to provide primary/secondary prevention, testing, treatment and support to

⁵⁹ Institut de Santé Publique, Epidémiologie et Développement (ISPED), Université Victor Segalen – Bordeaux 2, *Children and HIV/AIDS, From Research to Policy and Action*, Childhood and AIDS, October 2006

⁶⁰ World Health Organisation, *Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants, Towards Universal Access*, 2006 Version

⁶¹ Ibid

⁶² UNICEF, October 2005

families and can act as an incentive for pregnant mothers to access services. It is reported that PMTCT and PMTCT plus are making steady if slow progress, albeit from a very low base.⁶³

4.2 Children Born to HIV Infected Mothers and Paediatric HIV and AIDS

One thousand one hundred and fifty children are infected with HIV every day, the vast majority, 90%, through MTCT. In 2007, it is estimated that 420,000 children were infected with HIV and 330,000 died of an AIDS-related illness. The virus progresses rapidly in children with one third of infants dying by their first birthday and one half by their 2nd birthday⁶⁴. Without treatment, most children will die before their 5th birthday and while children account for only 8% of overall HIV infections, they represent 19% of all AIDS-related deaths⁶⁵. Over 90% of children infected with HIV live in sub-Saharan Africa, where there is least access to paediatric treatment. Estimates put the number of HIV-exposed and infected children at approximately 4 million, and this could be halved if all counties diagnosed HIV in infancy and cotrimoxazole was administered exclusively to infected children (although it is ideally recommended for all children born to HIV infected mothers – see below). In 2005, only 4% of children needing cotrimoxazole prophylaxis received it and only 10% of children requiring ARV's had access⁶⁶.

The medical care provided to HIV-infected children in low and middle income countries still consists mainly, in the management of opportunistic infections. Research has shown that children of all ages with clinical features of HIV infection should receive an antibiotic prophylaxis of cotrimoxazole in resource-poor settings, irrespective of local resistance to this drug⁶⁷. The cotrimoxazole is a highly effective prophylaxis that acts like an antibiotic preventing opportunistic infections occurring. It is further recommended that this drug be administered to all children born to HIV infected mothers until the status of the child is confirmed negative. Studies show a 43% drop in mortality when children had access to cotrimoxazole, which costs three cents of a dollar per child per day⁶⁸.

In low and middle income countries, one of the main challenges of paediatric HIV/AIDS care and treatment relates to the health system infrastructure, in particular the lack of health staff within existing health services or limited availability of laboratory facilities⁶⁹.

There is a need to develop simple and affordable diagnostic tests and fixed dose child appropriate ARV's. Some tablet formulations are only appropriate for adult consumption forcing physicians to chop or crush them for children and many drugs have adverse side effects that render administration to children more difficult. Resistance and intolerance to front line drugs compounds the problem of administration to children and cost is frequently a factor precluding second line drugs; these are 6 to 12 times more expensive than first line drugs in sub-Saharan Africa. Further research is also urgently needed regarding support to families who disclose HIV infection to the child, and the psychological development of children. The implementation of safe and adequate paediatric HIV/AIDS care is still a real challenge deserving further epidemiological, clinical and social research to accompany and guide programme implementation⁷⁰. In September 2006, the Governments of Brazil, Chile, France, Norway, and the UK launched UNITAID, which is a drug purchasing facility financed through levies on

⁶³ UNICEF, *Children and AIDS; A Stocktaking Report*, January 2007

⁶⁴ Ibid

⁶⁵ UNAIDS/WHO, *AIDS Epidemic Update*, 2007

⁶⁶ UNICEF, *Children and AIDS; A Stocktaking Report*, January 2007

⁶⁷ Institut de Santé Publique, Epidémiologie et Développement (ISPED), Université Victor Segalen – Bordeaux 2, *Children and HIV/AIDS, From Research to Policy and Action*, Childhood and AIDS, October 2006

⁶⁸ Global Movement for Children, *Saving Lives; Children's Right to HIV and AIDS Treatment*, 2006

⁶⁹ Ibid

⁷⁰ Institut de Santé Publique, Epidémiologie et Développement (ISPED), Université Victor Segalen – Bordeaux 2, *Children and HIV/AIDS, From Research to Policy and Action*, Childhood and AIDS, October 2006; Global Movement for Children, *Saving Lives; Children's Right to HIV and AIDS Treatment*, 2006

international travel and the Clinton Foundation will take the lead on continuing cost management of paediatric ARV's and focusing on extending coverage of paediatric HIV and AIDS treatment⁷¹. The UNICEF *Unite for Children, Unite against AIDS Campaign* further reports that single dose formulations are becoming ever more available. However, the report does not indicate how close or otherwise they are to reaching the campaign's second goal of providing paediatric ARV or cotrimoxazole or both to 80% of children in need by 2010⁷².

5. Frameworks to Guide the International Response

Guidelines to scale up Irish Aid's response to children orphaned and/or made vulnerable within the context of AIDS will be positioned within Ireland's commitments under: -

- UNGASS Declaration of Commitment on HIV/AIDS (2001)
- Political Declaration (2006)
- Dublin Declaration (2004) reinforced by the Vilnius Conference (2004)
- UN Convention on the Rights of the Child (1979)
- Communiqué from Gleneagles Summit 2005
- Review of the United Nations Millennium Declaration 2005

and An Taoiseach's announcement during the Irish launch of UNICEF's global campaign, *Unite for Children; Unite Against AIDS*, "When doubling our funding for these purposes {HIV and AIDS and other global diseases}, we will ensure that up to 20% of the increased funding now to be allocated will be invested in interventions that benefit children. This new commitment in regard to children represents a statement of policy" (An Taoiseach. Bertie Ahern, 24th October 2005, following the launch of UNICEF's Global Campaign *Unite for Children; Unite Against AIDS*).

However, Ireland's response is also shaped, planned and delivered within the context of *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* (UNICEF, UNAIDS 2004) and the *Enhanced Protection for Children Affected by AIDS* (UNICEF, 2007), which is a companion paper to *The Framework* document, while also reflecting the goals of the *Unite for Children, Unite against AIDS* UNICEF campaign. The *Inter Agency Task Team on Children and HIV and AIDS* is an important international structure, guiding and shaping the global response to orphaned and vulnerable children within the contexts of the aforementioned frameworks and Irish Aid maintains links with these international bodies in shaping and delivering its own response.

5.1 The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS (UNICEF, UNAIDS 2004)

The Framework represents a collaborative process between a wide range of actors including development practitioners, governmental and non-governmental agencies, faith based organisations, academic institutions, and the private sector. It aims to ensure that all actors work in a co-ordinated way with a common agenda to address the needs of orphaned and vulnerable children. It is pitched within the context of the Millennium Development Goals, the 2001 United Nations General Assembly Special Session on Children, the Declaration of Commitment 2001, and guided by the Convention on the Rights of the Child and other relevant human rights instruments⁷³.

⁷¹ UNICEF, *Children and AIDS; A Stocktaking Report*, January 2007

⁷² Ibid

⁷³ UNICEF, UNAIDS, *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, July 2004

There are five key strategies intended to target key action areas and to provide "...operational guidance to governments and other stakeholders as they respond to the needs of orphans and vulnerable children"⁷⁴. The five key strategies are as follows:-

- Strengthen 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.
How?
 - o improve household economic capacity
 - o provide psychosocial support to affected children and their caregivers
 - o strengthen and support child-care capacities
 - o support succession planning
 - o prolong the lives of parents
 - o strengthen young people's life skills

- Mobilise and support community-based responses
How?
 - o engage local leaders in responding to the needs of vulnerable community members
 - o organize and support activities that enable community members to talk more openly about HIV and AIDS
 - o organize co-operative support activities
 - o promote and support community care for children without family support

- Ensure access for orphans and vulnerable children to essential services, including education, health care, birth registration and others
How?
 - o increase school enrolment and attendance
 - o ensure birth registration for all children
 - o provide basic health and nutrition services
 - o improve access to safe water and sanitation
 - o ensure that judicial systems protect vulnerable children
 - o ensure placement services for children without family care
 - o strengthen local planning and action

- Ensure that Governments protect the most vulnerable children through improved policy and legislation and by channeling resources to communities
How?
 - o adopt national policies, strategies and action plans
 - o enhance government capacity
 - o ensure that resources reach communities
 - o develop and enforce a supportive legislative framework
 - o establish mechanisms to ensure information exchange and collaborative efforts

- Raise awareness at all levels through advocacy and social mobilization to create a supportive environment for children and families affected by HIV and AIDS
How?
 - o conduct a collaborative situational analysis
 - o mobilize influential leaders to reduce stigma, silence and discrimination
 - o strengthen and support social mobilization activities at community level

The Framework approach further underscores programming principles acquired over the years though small-scale and oftentimes ad hoc responses; these were first advocated

⁷⁴ Ibid

by the *Children on the Brink (2002) report* and are expanded upon within *The Framework* context: -

- Focus on the most vulnerable children and communities, not only children orphaned by AIDS
- Define community-specific problems and vulnerabilities at the outset and pursue locally determined intervention strategies
- Involve children and young people as active participants in the response
- Give particular attention to the roles of boys and girls, men and women, and address gender discrimination
- Strengthen partnerships and mobilize collaborative action
- Link HIV and AIDS prevention activities and care and support for people living with HIV and AIDS with support for vulnerable children
- Use external support to strengthen community initiative and motivation
- Monitoring progress towards goals

The Framework approach concludes by defining key actions that must be undertaken as a matter of priority including prioritization of support for orphans, vulnerable children and their families in national policies, actions and plans of affected countries and as per my report following the Inter Agency Task Team meeting on Children and HIV and AIDS in April 2007, this process is almost complete.

5.2 Enhanced Protection for Children Affected by AIDS

This companion to *The Framework* approach aims to help translate government commitment into practice and build on the strategies laid out in the original document. Specifically the paper articulates the vulnerabilities and protection risk of children affected by HIV and AIDS and proposes practical actions to address them. In order to ensure success the companion document suggests that these actions will need to be integrated into existing national plans of action, national poverty reduction strategies etc. Priority actions identified are supported within the text but for the purposes of this report are summarised as follows: -

Action Area 1: Actions for Social Protection

- Implement social transfer programmes to ensure the most vulnerable families are able to meet their basic needs
- Invest in family support services and ensure appropriate links with social assistance programmes for maximum impact
- Involve communities in the provision of social transfers and family support services

Action Area 2: Actions for Legal Protection and Justice

- Combat disinheritance by amending legislation, sensitizing community leaders to existing laws, making the process of registering and executing wills easier, and promoting public education on wills and trusts.
- Improve civil registration systems by eliminating fees, making civil registration more accessible through decentralization and linking birth registration with other commonly used services
- Strengthen and/or develop specialized child protective services in police, justice and social welfare systems that provide a safe environment and sensitive procedures for children who have experienced abuse and exploitation.

- Strengthen, develop and implement legislation and enforcement policies on child labour, trafficking, sexual abuse and exploitation that are in line with international standards to protect children and criminalize/penalize offenders.
- Support community based monitoring systems that include building the capacity of teachers, health and community workers, and members of youth organizations to identify children at risk, report on cases of abuse and exploitation, and provide referrals.

Action Area 3: Alternative Care

- Develop effective means of supporting and monitoring informal care arrangements, such as provided by grandmothers or in child headed households, 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 opportunities 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.

Cross-Cutting Issues are as follows: -

Addressing stigma related to HIV, abuse and exploitation:

- Facilitate open discussion to promote community-owned social change for children and ensure appropriate adolescent participation
- Sensitise the media to issues of HIV and protection risks and develop guidelines for reporting abuses
- Train national and community leaders to stimulate discussion on children's rights, child protection issues, and HIV and AIDS

Strengthening the state's social welfare sector:

- Increase budgetary allocations to government agencies responsible for social welfare, alternative care and protective services 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 system 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 more effective service provision.

5.3 Unite for Children, Unite against AIDS Campaign

The *Unite for Children, Unite against AIDS* campaign was launched by UNICEF in October 2005 with a goal of putting the “missing face”⁷⁵ of children at the centre of the global response to HIV and AIDS. One of the key objectives of the campaign is to improve understanding of the situation in relation to children and AIDS and to get a baseline for measuring progress. Hence, UNICEF and UNAIDS have been working in partnership with governments and partners to develop a core set of indicators that can be used to track progress of the four P’s, the goals of the *Unite for Children, Unite Against AIDS* campaign, at country level.

The goals of the *Unite for Children, Unite against AIDS* campaign or the ‘Four P’s’ are as follows:-

- **P**revent mother-to-child transmission of HIV – by 2010, offer appropriate services to 80% of women in need
- **P**rovide paediatric treatment – by 2010, provide either antiretroviral treatment or cotrimoxazole, or both, to 80% of children in need
- **P**revent infection among adolescents and young people – by 2010, reduce the percentage of young people living with HIV by 25% globally
- **P**rotect and support children affected by HIV/AIDS – by 2010, reach 80% of children most in need

The recent *Stocktaking Report, 2007*, which is intended to highlight progress since the outset of the campaign and note shortcomings, sheds little light on the overall landscape in relation to children and HIV and AIDS. Specific examples are cited where programmes targeting children under the four P’s are reporting success rates, but the bigger picture remains difficult to envisage. Very impressive percentages are quoted in relation to “support” extended to families in high prevalence areas but what specifically “support” entails is not apparent. The *Stocktaking Report* acknowledges significant gaps in progress in the areas of PMTCT and paediatric treatment as highlighted in section 4 of this paper, while further noting that the campaign has had little impact on school attendance and knowledge of HIV and AIDS for prevention purposes⁷⁶. The campaign has however proved successful in mobilizing a focus on children and has resulted in DFID and USAID pledging 10% of their annual budget on children, while Ireland has committed 20% of increased resources announced in 2005 to children. Notwithstanding those successes, other large donors have not specifically earmarked allocations for children. It is abundantly clear that the need to scale up responses in the Four P areas is paramount, as current levels of coverage will not meet campaign goals as outlined above.

6. Close

As identified at the outset of this paper, this is not a comprehensive literature review, but it has endeavoured to present a synopsis of a comprehensive list of issues as they arise within the literature. The information contained herein will act as a backdrop to the other phases of research and exploration identified to define Irish Aid’s response to children living with and affected by HIV and AIDS. Hence, this review is the first output from a comprehensive process identified to upscale Irish Aid’s response to children orphaned and vulnerable in the context of HIV and AIDS.

⁷⁵ UNICEF, *Children and AIDS, A Stocktaking Report, 2007*

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