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SYNTHESIS OF EVIDENCE

FOURTH GLOBAL PARTNERS FORUM ON CHILDREN
AFFECTED BY HIV AND AIDS

DUBLIN, IRELAND
6 – 7 OCTOBER 2008

UNITE FOR CHILDREN
UNITE AGAINST AIDS 

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ACKNOWLEDGEMENTS AND PROVISIO

UNICEF would like to acknowledge the seven working groups on the global Inter-agency Task Teams (IATT) on Children affected by HIV and AIDS as well as the regional Task Teams on children affected by HIV and AIDS for their contributions into this paper. In addition, UNICEF would like to thank the numerous authors of the papers cited herein for their contributions to enriching our understanding of the evidence around children affected by HIV and AIDS.

This paper's main aim is to synthesize recent existing evidence and outline the key messages that will improve understanding of the situation of children affected by HIV and AIDS. It is intended to stimulate a wider dialogue among policymakers, practitioners, researchers and donors.

ACRONYMS

ARV	Antiretroviral
CEE-CIS	Central and Eastern Europe – Commonwealth of Independent States
DFID	Department for International Development
DHS	Demographic Health Survey
GDP	Gross Domestic Product
GPF	Global Partners Forum (on children affected by AIDS)
IATT	Inter-Agency Task Team on Children affected by HIV and AIDS
ILO	International Labour Organisation
JLICA	Joint Learning Initiative on Children and HIV/AIDS
M&E	Monitoring and Evaluation
MICS	Multiple Indicator Cluster Survey
NAP	National Action Plan
NGO	Non Government Organisation
NPA	National Plan of Action
OPPEI	OVC Policy and Planning Effort Index
OVC	Orphans and other vulnerable children
PMTCT	Prevention of mother to child transmission
POS	Programme of Support
QAP	Quality Assurance Project
SAARC	South Asian Association for Regional Cooperation
SCF	Save the Children Fund
USAID	United States Agency for International Development
UNICEF	United Nations Children Fund
UNAIDS	The Joint United Nations Programme on HIV/AIDS
USD	United States Dollars

EXECUTIVE SUMMARY

Responses in the worst-affected areas

- In impoverished areas greatly affected by AIDS, all children become vulnerable and AIDS-sensitive responses should be community wide
- While orphanhood and AIDS do impact negatively on children and families, other factors are also important in determining wellbeing. In several studies asset ownership, household wealth status, and education level of adults in the household were more heavily correlated with vulnerability than orphan status or AIDS affectedness.
- Gender and age are contributing factors to vulnerability of children.

National responses for children affected by HIV and AIDS

- Strong, committed and involved government leadership is essential to ensuring that national responses are properly resourced, coordinated, implemented and monitored.
- There is no 'one size fits all' national response for children affected by HIV and AIDS. Some countries are implementing specific National Plans of Action while in other countries the response is integrated into social protection frameworks, national development instruments, HIV/AIDS or other sectoral plans.
- Regular, predictable cash transfers can have a long-term positive impact on AIDS affected children
- Family support services and policies, non institutional alternative care and case management of children in institutions are essential aspects of social protection for vulnerable children, including those affected by HIV and AIDS.
- Community level involvement is essential to any response and building capacity of local organizations, including faith based organizations continues to be key to reaching vulnerable children and their families.
- Stigma, denial and discrimination continue to be a barrier to all aspects of the AIDS response.

Scaling up

- The main government institutions responsible for the coordination and implementation of the response to vulnerable children are often Ministries which are under resourced and with little capacity.
- There is a dearth of systems, structures and frameworks to support scale up of programming for children affected by HIV and AIDS such as child protection legislation, monitoring and evaluation systems and poor resource mobilisation in the worst affected countries in the world.
- Scaling up for children affected by HIV and AIDS needs to be linked to prevention and treatment including ensuring access to education, provision of Antiretroviral therapy to parents and caregivers and early diagnosis and treatment of HIV and opportunistic infections among children.

ORPHANS AND CHILDREN AFFECTED BY HIV AND AIDS: THE EVIDENCE BASE FOR AN INCLUSIVE RESPONSE

In 2007 there were an estimated 15 million children who had lost one or both parents to AIDS (11.6 million in sub-Saharan Africa)¹. Additionally, millions more children are orphaned and/or vulnerable due to other causes. Orphanhood from all causes exceeds 5 per cent in many countries. Although the majority of global orphans are in Asia, on a per capita basis Africa is impacted more by the incidence of orphaning. The sub-Saharan Africa region also has the most children who are orphaned due to AIDS.

Vulnerability and the impacts of HIV and AIDS

The results of a secondary analysis of global population household surveys across 36 countries² show that in the majority of countries analysed, orphans were worse off than non-orphans but this result cannot be generalised across all countries. For example countries with overall high levels of wasting such as Ethiopia, Somalia and Mali did not have significant differences between orphans and non-orphans and in countries where school attendance was generally high, both orphans and non-orphans attended school in similar proportions³.

Wealth status appeared to be more important across countries in determining school attendance than orphan status.⁴ A review of DHS studies in 11 countries in eastern and southern Africa found a similar result (Campbell et al. 2008)

HIV and AIDS also impacts on child wellbeing but not in all cases and not for all outcomes. For example the global household study found that the presence of an HIV positive adult or chronically ill adult in the household worsened school attendance rates in every country except Côte d'Ivoire.

Notably, single orphans are more at risk of losing another parent; the global household population survey provides inferential evidence that children who have already lost one parent are more likely to experience parental death (a second time) than are children who have lost no parents.

AIDS affectedness and orphanhood is not always a good measure of vulnerability; not all vulnerable children are orphans or AIDS affected and not all AIDS affected children or orphans are vulnerable. Across thirty-seven potential indicators of vulnerability drawn from population based surveys, the markers that best reflected vulnerability consistently were asset ownership, household wealth status, and education level of adults in the household⁵.

These effects are influenced by gender. In Cameroon, Mali and Zimbabwe the odds of wasting are significantly higher if a child's mother has died. Children living in households where the head of household or the eldest female had a primary education or higher, were more likely to attend school in nearly all of the country regressions.

¹ UNAIDS (2007) Global Epidemic Report.

² Four criteria were used in the decision to include a survey in this report: The country has an orphan prevalence greater than 8 percent; The adult prevalence of HIV exceeds 1 percent; An AIS or DHS has been conducted since 1995 or a MICS round 3 survey has been conducted; And the data were available previous to June 15, 2008

³ Futures Institute, MACRO and UNICEF (2008) Identifying measures of vulnerability for children less than 18 years old. DRAFT

⁴ Ainsworth M, D Filmer (2002) "Poverty, AIDS and children's schooling: a targeting dilemma," World Bank Policy Research Working Paper, Report No. WPS-2885.

⁵ Futures Institute, MACRO and UNICEF (2008) Identifying measures of vulnerability for children less than 18 years old. DRAFT

Girls in sub-Saharan Africa are 50 per cent more likely than boys to be sexually active before the age of 15, putting them at greater risk of HIV infection. For adolescent girls, early marriage increases the risk of being exposed to HIV for example in Kisumu Kenya, 33 per cent of married adolescent girls are HIV positive compared to 22 per cent of unmarried sexually active girls. (Glynn JR, 2001). Relationship to head of household also makes a difference; where the household head was not a parent or a grandparent more girls were having sex before the age of 15 years⁶.

Targeting Orphans and Children Affected by HIV and AIDS

The Inter-Agency Task Team (IATT) on Children and HIV and AIDS commissioned a paper on targeting (Gulaid, 2007), which points out that in hyperendemic countries where HIV prevalence exceeds 15 percent most children are directly or indirectly affected by AIDS. In these situations, it makes more sense to programme more broadly for all vulnerable children since the errors of inclusion will be small in relation to the number of affected children. For example, pilot cash transfer schemes from Zambia and Malawi utilise criteria of poverty, high dependency ratios, and/or limited labour capacity to identify eligible households. Approximately 70 per cent of households reached are directly affected by HIV and AIDS.⁷

Both the IATT and the Joint Learning Initiative on Children and HIV/AIDS (JLICA)⁸ studies show that using the term 'AIDS orphan' as a criteria for targeting is confusing, stigmatizing and at times a poor proxy for high levels of need. In addition, it is creating tension between guidance provided at the global, regional, and national levels and programming practices.

Linking financial benefits to target specific children (rather than households) can create inappropriate incentives and undesirable results. For example, in programmes where support depends on the presence of orphans creates financial and other incentives for taking in orphans. This may result in exploitation and inequitable treatment of orphans within households. (Greenblott and Greenaway 2007)

The evidence on targeting has led to calls for expanding the current definition of children affected by HIV and AIDS to include other vulnerable children in both generalised and concentrated epidemics. The current definition of children affected by HIV and AIDS (UNICEF and UNAIDS) are those under 18 years of age who:

- Are living with HIV,
- Have lost one or both parents due to AIDS or
- Whose survival, well-being or development is threatened or altered by HIV.

The JLICA⁹ propose that in poor communities with high HIV prevalence this definition should expand to include:

- Children indirectly affected by HIV and AIDS because they are living in communities heavily burdened by HIV and AIDS, and
- Children especially vulnerable to exposure to HIV due to their circumstances.

Broader targeting is called for and appropriate in settings where the majority or in some cases all children are more vulnerable because of the direct and/or indirect effects of AIDS.

⁶ Futures Institute, MACRO and UNICEF (2008) Identifying measures of vulnerability for children less than 18 years old. DRAFT

⁷ Gulaid, L (2007) Targeting AIDS mitigation resources to children: a review and recommendations for the IATT on Children and HIV and AIDS. Inter-Agency Task Team on Children and HIV and AIDS Steering Committee Working Paper.

⁸ Richter L, Sherr L, Desmond C (eds) (2008) JLICA Learning Group 1: Strengthening Families: Integrated report. Synthesis paper for the Joint Learning Initiative on Children and HIV/AIDS (JLICA). DRAFT

⁹ ibid

The States of the South Asian Association for Regional Cooperation (SAARC) developed a framework for children affected by AIDS in 2008, to which eight member states committed. The SAARC Framework promotes a universal approach so children affected by HIV and AIDS have access to the same public and social support systems available to other children, rather than being separated or singled out. However, within this universal approach the Regional Framework calls for additional and specific measures to overcome the stigma that surrounds HIV and AIDS and to intervene on behalf of children who suffer from discrimination¹⁰.

While the evidence supports an inclusive approach to targeting HIV and AIDS resources, it is still recognised that children affected by HIV and AIDS do have specific needs, such as access to prevention and treatment programmes as well as protection against stigma and discrimination. This implies that closer links are needed between programmes addressing prevention, treatment and protection of HIV and AIDS affected families and children.

NATIONAL RESPONSES TO ORPHANS AND CHILDREN AFFECTED BY HIV AND AIDS

There are many different types of national responses to children affected by AIDS. Some countries have opted for stand alone National Plans of Actions (NPA) for orphans and vulnerable children and children affected by AIDS, while others have integrated these issues into social protection frameworks or broader sectoral and/or developmental plans. The impact of different approaches varies.

Gulaid (2008)¹¹ found that stand alone orphans and vulnerable children NPA's in Kenya and Tanzania brought more attention to children and resulted in the integration of vulnerable children issues into ministerial plans and other key sectoral and development documents¹². In Kenya this led to a national budget line for vulnerable children, which increased from USD 0.7 million (2005) to USD 2.5 million in¹³ The Zimbabwe NAP has also focused attention on needs of children affected by HIV and AIDS and generated significant donor funding of USD 84 million over four years.

Taylor (2008) found that integration of vulnerable children into sectoral plans, as well as national AIDS frameworks, has clear short-term benefits for vulnerable children. Integration has led to more domestic contributions and improved access to education and health services that are sensitive to vulnerable children. In Zambia, vulnerable children were reflected in the Education and Social Protection plans which were later integrated into the Fifth National Development Plan (2006-2010). The Plan sets aside USD 38 million of the social protection allocation for the elderly, orphans and vulnerable children. Later, components of the development plan were pooled into the National Action Plan for Vulnerable Children and linked to the Zambia Council for Children to provide a legislative framework.

A revised orphans and vulnerable children Policy and Planning Effort Index (OPPEI) was developed in 2007 by UNICEF, USAID and the Futures Group to measure the national response by countries in Sub-Saharan Africa to orphans and other vulnerable children (2007). The OPPEI shows that the greatest improvements between 2004, when the first

¹⁰ SAARC (2008) Regional framework for the protection, care and support of children affected by HIV/AIDS

¹¹ Gulaid, L (2008) National responses for children affected by AIDS: Review of progress and lessons learnt. Developed for the IATT working group on NPA's

¹² Such as the Tanzania Multi-Sector Strategic Framework on HIV/AIDS 2008-2012, the Social Protection Framework and the Kenya National HIV/AIDS Strategic Plan 2005/6 - 2009

¹³ Taylor, N (2008) Orphan and vulnerable children and national development instruments: Lessons learnt from successful integration. UK Consortium on AIDS and International Development, Orphan and Vulnerable Children Working Group.

OPPEI was conducted and 2007, were the development of national situation analysis, policy and national action planning, while monitoring, evaluation, legislative review and resource mobilisation scored lowest. Supporting this finding, Campbell et al (2008)¹⁴ found monitoring and evaluation are persistent challenges for NPA's in eastern and southern Africa, including collecting baseline data and aligning national and global programmatic and monitoring indicators.

The IATT and UNICEF collected evidence on some of the key success factors for mounting and sustaining a national response. These include:

- High level government ownership and sustained leadership
- Donors with good understanding of local politics and the policymaking process
- Involvement of and support by civil society organisations
- Accountability and political pressure
- Committed, dynamic individuals
- Broadly consultative, technically sound process of development
- Availability of resources

There is no "one size fits all" recommendation to guide what form national responses to children affected by HIV and AIDS and other vulnerable children should take. The diversity of context across regions, countries and districts makes generalization impossible and inappropriate. Wide variation across countries calls for more refined guidance from global and regional stakeholders.

Stigma and Discrimination as a Barrier to Effective Response

Despite efforts to care and protect the most vulnerable children, exclusion, stigma, and discrimination of children affected by HIV and AIDS continues to be common challenges in most countries. Stigma (self/internalized, perceived, or actualized) has been cited as a reason for children not being enrolled in school or not being served by national support programmes in low prevalence countries.¹⁵ According to a review of evidence in India, 20 per cent of children from households with an AIDS death reported having been discriminated against, versus 2.8 per cent in households with a non-AIDS death, and 3.5 per cent from households with no death. In Haiti and Brazil, infected teens reported experiencing violence and peer-fighting in schools as a response to teasing about their HIV status.¹⁶

UNICEF carried out a synthesis review in South Asia finding that children affected by HIV and AIDS are more often stigmatized and excluded from services and programming than children made vulnerable by other causes. There is a misconception that children living with an HIV-positive adult are automatically infected themselves and can infect others through casual contact.¹⁷

Monitoring and surveillance of HIV-related stigma is an element of 'knowing your epidemic,' and tools to track HIV-related stigma have been developed. However, UNAIDS reports that

¹⁴ Campbell, P. et al. (2008) A review of monitoring and evaluation in support of orphans and vulnerable children in east and southern Africa. UNICEF

¹⁵ Quality Assurance Project, USAID Health Care Improvement Project and UNICEF. (2007) The evidence base for programming for children affected by HIV/AIDS in low prevalence and concentrated epidemic countries. Published for UNICEF and the U.S. Agency for International Development by the USAID Health Care Improvement Project Bethesda MD: University Research Co., LLC

¹⁶ Ibid

¹⁷ UNICEF Regional Office for South Asia (2007) Children affected by HIV/AIDS in South Asia: A synthesis of current global, regional, and national thinking and research

by 2008, only 33 per cent of countries have indicators to measure changes in HIV-related stigma and discrimination.

The Enhanced Protection Framework for Children Affected by HIV and AIDS shows that stigma and discrimination are challenges that contribute to a host of abuses faced by children, increasing their vulnerability and risk of further exploitation. Fostering open discussion can help reduce HIV-related stigma, making these violations less hidden and less acceptable.

Monitoring and Evaluation

There is an increasing amount of data available on orphans and vulnerable children, but in many cases it remains under analysed and under utilised at country level. With the increasing number of countries launching national responses to children affected by HIV and AIDS, as well as an increasing number of global partners requesting accountability, the lack of monitoring and evaluation capacity and systems is an urgent challenge.

Global information needs often differ significantly from national and community level needs. There is a lack of clarity about what data should be collected through government services, through population based data collection, and through community and child level monitoring systems. Additionally, national baseline information is often unreliable with unclear denominators, and fluid definitions and targeting parameters, leading to a lack of information on the scope and coverage of responses¹⁸.

Since 2006, efforts have been made to enhance data availability. For example, additional Multiple Indicator Cluster Surveys (MICS) and Demographic and Health Surveys (DHS) have become available, the survey designs improved, and there are efforts to strive for consistent methodologies to make it possible to combine data from various surveys. The Progress Report for Children Affected by HIV and AIDS¹⁹ includes data from five strategic approaches taken from the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS²⁰. But there are major gaps in data collection on basic global indicators. For example, in Asia only Thailand and Cambodia officially report on the estimated number of children infected with HIV and no country in Eastern Europe and Central Asia reported on this indicator in the 2008 UNAIDS Global AIDS Epidemic Update.

Taylor (2008) found that there are a number of key challenges in monitoring programming at a community level. The first is tracking the domestic and external resources that actually reach community based initiatives. The second is monitoring the coverage, quality and impact of these community based responses on the lives of vulnerable children. Often the monitoring of efforts through community initiatives is not captured in national monitoring systems making it difficult for governments to track coverage, identify gaps and learn lessons which can be replicated elsewhere²¹.

In Zimbabwe, the Government, civil society organisations and donor partners developed a conceptual framework to monitor the NAP. The monitoring and evaluation system is based on data flow, data collection and training and technical support. Activity books were

¹⁸ Ibid

¹⁹ UNICEF (2008) OVC Progress Report

²⁰ These include: strengthening the capacity of families to protect and care for children; mobilizing and strengthening community-based responses; ensuring access to essential services; ensuring that governments protect the most vulnerable children; and raising awareness to create a supportive environment

²¹ Taylor, N. (2008) The role of international donors in supporting community responses to vulnerable children in countries severely affected by HIV and AIDS. An issues paper for the IATT on communities.

developed containing a harmonised set of core output indicators that implementers reported on monthly. This data is submitted to the social welfare authority at district level and to the NAP secretariat nationally. Evaluation of the system suggests that it is robust and replicable.²²

Fragmented monitoring and evaluation efforts and lack of coordination between governments, implementers, and partners makes it difficult to get a complete picture of the national responses. These challenges undermine efforts to plan, monitor, and evaluate national and sub-national responses in support of vulnerable children.

SUPPORTING FAMILIES TO CARE FOR CHILDREN

Nearly all children who have lost one or both parents are living with families. Using data from Tanzania, Uganda, Zambia, and in other countries in east Africa, Subbarao & Coury (2003) found that approximately 90 percent of all orphans had been taken in by family members²³. Evidence demonstrates that children who lose one or both parents in heavily AIDS affected countries are no more vulnerable than a child with both parents alive²⁴.

In contrast to popular perceptions, only a small percentage of the children orphaned by AIDS are on their own. Widespread informal child fostering (kinship care) within family networks is very common in sub-Saharan Africa. In Zimbabwe, for example, 98% of children who have lost one or both parents are living in a family setting.²⁵ 'Family' has expanded throughout sub-Saharan Africa and no longer implies blood relation – families are often comprised of a wider social network and maternal relationships are more frequently called upon to care for children than paternal connections.²⁶

The vast majority of children who have lost one or both parents, including in countries with high HIV prevalence, are living in families. Extended families and communities are playing a critical caregiving role but they are not sufficiently supported.

Family capacities are being stretched by the increasing burden of care, especially for the large number of household headed by grandparents caring for orphans and vulnerable children in sub-Saharan Africa. Additionally the Quality Assurance Project (QAP), USAID and UNICEF (2007) found that families affected by AIDS have lower income and lost productivity than those that are not affected.

Despite these concerns, the evidence suggests that little is being done to support caregivers, and when support is provided, coverage and access are limited. In 18 countries where household surveys were conducted between 2003 and 2007, the proportion of households with orphans and vulnerable children that received basic external support such as education assistance, medical care, clothing, financial support or psychosocial services was low. Support ranged from 1.3 per cent in Sierra Leone to 41 per cent in Swaziland, with a median value of about 12 per cent.²⁷

²² UNICEF Zimbabwe; Ministry of Public Services Labour and Social Welfare, Zimbabwe; National AIDS Council (2008) A partnership making a difference. Zimbabwe's Programme of Support to the National Action Plan for Orphans and other Vulnerable Children

²³ Subbarao K, Coury D. (2003). Orphans in sub-Saharan Countries: A Framework for public action. World Bank Africa Region (Human Development) and Human Development Network (Social Protection).

²⁴ Futures Institute, MACRO and UNICEF (2008) Identifying measures of vulnerability for children less than 18 years old. DRAFT; this statement is true except in the case of young children, who are more likely to experience wasting if their mother dies than if their mother survives.

²⁵ UNICEF (2006) Collecting Data for National Indicators on Children Orphaned and made Vulnerable by AIDS: A Methodological Report

²⁶ Mathambo, V Gibbs, A. (2008) Qualitative accounts of family and household changes in response to the effects of HIV and AIDS: A review with pointers to action (DRAFT)

²⁷ UNICEF (2008) OVC Progress Report,

Family centred support

To effectively support vulnerable families, the JLICA findings²⁸ emphasize that a comprehensive package of services can provide assistance to prevent family separation and promote access to essential services.

This includes:

- Early childhood care and development services
- Community-based assistance in accessing entitlements and services (e.g. health care, education, civil registration, child grants, cash transfers)
- Legal aid (e.g. protection of inheritance rights and succession planning)
- Family tracing and reunification services
- Parenting skills, livelihoods and life-skills training for youth,
- Psychosocial support, including support for elderly or young caregivers
- Investment in basic services to ensure increased demand from social protection support can be met
- Assistance to prevent HIV infection and access treatment for family members.

JLICA also highlights the importance of linking prevention, care and treatment in family support programmes. For example prevention of mother to child transmission (PMTCT) prevents children from becoming infected. 33 per cent of HIV-positive mothers in low and middle income countries receive antiretroviral (ARV) prophylaxis in PMTCT programmes.²⁹

10 per cent of all orphaning worldwide is attributed to AIDS, and recent analysis of household survey data from 47 countries indicates that orphaning is higher in countries with greater HIV prevalence compared with countries with lower HIV prevalence (MACRO and UNICEF 2008). Treatment for adults directly benefits children by keeping parents alive, healthy and productive.

The Challenges Facing Children Outside of Family Care

Although most children are living with families, there are still some living outside of family care. Pilot surveys based in Kingston (Jamaica) and Blantyre (Malawi) found that less than 1 per cent of the population under the age of 18 years lived outside of households³⁰ They may be in the greatest need of protection.

According to a study by QAP, USAID and UNICEF (2007) 1-3 per cent of orphans worldwide reside in institutional care. Extensive evidence shows that children placed in orphanages (whether HIV-infected or not) fare significantly worse than those children with their families or in foster settings (Tobias, 2000; UNICEF/SCF, 2007; Deininger et al., 2001). A comprehensive review of the substantial scientific literature on child institutionalization documents that, compared to home care, children under five years in institutions are especially vulnerable to infectious disease transmission and inadequate cognitive development (Frank et al., 1996).

Institutional care is also expensive. The World Bank in Tanzania found the estimated annual cost for one child in institutional care was six times the cost of supporting a child in foster care and while institutional care is globally considered the last resort for children outside of

²⁸ Richter L, Sherr L, Desmond C (eds) (2008) JLICA Learning Group 1: Strengthening Families: Integrated report. Synthesis paper for the Joint Learning Initiative on Children and HIV/AIDS (JLICA). DRAFT

²⁹ WHO/UNICEF/UNAIDS (2008): Towards Universal access Scaling up priority HIV/AIDS interventions in the health sector. Progress report 2008

³⁰ Guide to monitoring and evaluation of the national response for children orphaned and made vulnerable by HIV/AIDS (2005)

family care, institutions are proliferating. A study in Namibia found that from 2002 to 2008 the number of children's institutions has expanded from 9 to 42 representing an increase of over 400%³¹.

Evidence also shows that the majority of children living in residential care have one or both parents alive. In Belarus, Brazil, Kyrgyzstan, Sri Lanka, Tajikistan, for example, over 80 per cent of children in residential care have a living parent, with around 50 per cent or more children in a similar situation in Afghanistan and Zimbabwe. This fact is a powerful reminder that viable alternatives exist, and that few children living in residential care lack options.³²

Children who live in the streets also face increasing risks of abuse and exploitation, and may engage in behaviour that puts them at high risk of HIV infection. A seven-country project in Central and Eastern Europe³³ studied adolescent risk behaviour in the region. The report found that in Ukraine, children and young people living or working on the street had all been subject to some form of serious trauma, such as violence, abuse and sexual or labour exploitation. This further underlies the need to respond to risk and vulnerabilities of adolescents for effective HIV prevention³⁴.

Where families do not exist to care for children, alternative arrangements must be in the best interest of the child. There is an urgent need to invest in better alternative care options such as kinship and foster care as alternatives to institutions, and domestic adoption as a way of facilitating permanency.

A programming tool is available to guide the protection of children affected by HIV and AIDS, the Enhanced Protection Framework for Children Affected by AIDS (2007). This provides detailed guidance on programming in social protection; legal protection and justice; and alternative care.

In countries where formalised non-institutional alternative care is limited, evidence shows that children are better monitored and cared for in residential care institutions that are regulated, have consistent case management and where the first priority is the reintegration of children back into families wherever it is in the best interest of the child. Short term residential care is sometimes needed to provide emergency care for abandoned, abused, exploited or neglected children. Contact with family and community should be encouraged and reunification efforts supported whenever appropriate³⁵.

Government oversight of all alternative care providers is essential including the development, enforcement and monitoring of standards, guidelines and regulations³⁶.

SOCIAL PROTECTION

In many countries, social protection is rising within the policy agendas of governments, donors and civil society organizations. In these countries with weak administrative capacity, various social protection interventions that provide some degree of social assistance or

³¹ Dunn, A. (2008) Capacity to manage alternative care. Assessment report for Namibia. DRAFT

³² Children in Institutional Care: The Status of their Rights and Protection In Sri Lanka, Save the Children (Sri Lanka); Stockholm Country Reports (Afghanistan, p. 6; Belarus, p. 18; Kyrgyzstan, p. 110; Tajikistan, p. 118); Report to the Committee on the Rights of the Child, 2005 (Brazil); Children in Residential Care (Zimbabwe).

³³ Conducted by the London School of Hygiene and Tropical Medicine and UNICEF.

³⁴ UNICEF and AIDS Foundation East West. (2006), Children and Young People Living or Working on the Streets: The missing face of the HIV epidemic in Ukraine.

³⁵ The Enhanced Protection Framework for Children affected by HIV and AIDS

³⁶ UN (2007) UN Guidelines for the Appropriate Use and Conditions of Alternative Care for Children. DRAFT

social insurance are being adopted where social security systems are not yet developed. This momentum is partially generated by the ways that AIDS exacerbates poverty.

Social protection is described as 'public and private initiatives that provide income or consumption transfers to the poor, protect the vulnerable against livelihood risks, and enhance the social status and rights of the marginalised; with the objective of reducing the economic and social vulnerability of poor, vulnerable and marginalised groups'.³⁷

The IATT definition of social protection in the context of HIV and AIDS includes the integration of three broad elements:

- Support services (child and family support services, child protection and alternative care)
- Social transfers (cash, food, vouchers)
- Social policies and legislation including necessary guidance and administrative structures

A Focused Look at Cash Transfers

Well designed cash and income transfer programmes alleviate poverty and positively impact vulnerable children. Although targeting AIDS affected families is not recommended, the JLICA found that targeting income assistance using criteria such as poverty and labour constraints is highly AIDS sensitive.

Adato and Bassett reviewed the potential of cash transfers to strengthen families affected by HIV and AIDS (2008 JLICA). Their report shows how social protection protects children and families affected by HIV and AIDS and how cash transfers secure basic services and reduce poverty whilst also protecting the human capital of children – specifically their education, health and nutrition. The review provides strong evidence that cash transfers have increased food expenditure and consumption when they are regular and predictable. Cash transfers impact positively on AIDS affected families by:

- Securing basic subsistence for families where illness prevents them from securing a livelihood
- Keeping children from leaving school because of inability to pay fees or labour needed at home
- Enabling people to invest in small income generating activity
- Increasing the agency of communities where local organizations participate in targeting, monitoring or service delivery.³⁸

Cash transfers are also effective in keeping families together and preventing family separation thereby reducing the need for alternative care services³⁹.

A UNICEF paper analysing cash transfers in eastern and southern Africa shows that on economic grounds, transfers enable productive investments that increase current income, consumption and health, as well as investments in children's human capital development, leading to increases in future income and breaking the inter-generational cycle of poverty. (UNICEF, May 2008)

Strong evidence shows that cash transfers have a positive impact on alleviating household poverty and impacting positively on vulnerable children.

³⁷ Devereux, Stephen and Rachel Sabates-Wheeler (2004) Transformative Social Protection, IDS Working Papers 232, Institute of Development Studies, p. 9.

³⁸ Adato and Basset (2007) What is the potential of cash transfers to strengthen families affected by HIV and AIDS?? A review of the evidence on impacts and key policy debates. Technical paper of the Joint Learning Initiative on Children and HIV/AIDS (JLICA), Learning Group 1

³⁹ Tolfree, D. (2005) Facing the crisis: Supporting children through positive care options, Save the Children UK, London.

Scaling up social protection

Temin (2008) studied different models for institutionalising national social protection systems. In Latin America, systematic scale-up of nationally owned social protection systems is ongoing, especially in Brazil, Chile, and Mexico. In Central and Eastern Europe, reform of the state social welfare system is leading to increased efforts to provide families with the support they need to stay together, while investing in alternatives to institutional care for children⁴⁰.

Increased evidence around the gains from investment in social protection, primarily in the areas of poverty relief and uptake in school attendance, is driving increased investment. In Africa, several countries are in the process of developing national social protection policies in line with the March 2006 Livingstone Call for Action on Social Protection. Many countries are also implementing pilot projects, mostly focusing on cash transfers to the poorest.

There is a clear commitment to social protection but there are a number of challenges that are posing barriers to scale up. Institutions responsible for social protection do not have sufficient capacity to ensure that the delivery of cash transfers is accompanied by the undertaking of other core functions such as child protection, case management of institutional care, and support to family based alternative care (Temin 2008).

In most generalised and hyperendemic countries more local and international funding is needed for scale up of comprehensive social protection including for: cash transfers; child protection; social work case management; and alternative family-based care.

Strengthening Government and Civil Society to Deliver Comprehensive Social Protection

Social welfare sectors are most often responsible for coordinating social protection services for vulnerable children and families. In Namibia, the Ministry of Gender Equality and Child Welfare supports social welfare functions including the oversight and management of child welfare grants, adoptions, custody and control cases and advocacy of children's rights across national, regional and community level⁴¹. Yet, welfare sectors often have insufficient budgets, human resources and authority to effectively coordinate and oversee the full range of family support and child protection services that fall within their mandate.

Strengthening systems to respond to vulnerable children poses significant political, administrative and programming challenges. The intricate linkages between protection and other systems need to be well defined in order to fulfil all preventative and protective functions. Establishing inter-ministerial partnerships and collaboration is one important function for promoting a continuum of care for children. Temin (2008) recommends that more effort is needed to bring Ministries of Finance and Planning on board as an effective way to increase the profile of child vulnerability and mainstream social protection in poverty reduction plans. With these important stakeholders, arguments based on the economic benefits of social protection may be more effective for advocacy than humanitarian and rights arguments.

⁴⁰ Temin, M. (2008) Expanding social protection for vulnerable children and families: learning from an institutional perspective. Prepared by the IATT working group on social protection.

⁴¹ Ministry of Gender Equality and Child Welfare Namibia (2007) A Human Resources and Capacity Gap Analysis. Improving child welfare services.

The growing momentum on social protection is a key opportunity to address the capacity and organizational weaknesses of social welfare sectors charged with protecting the most vulnerable. Some countries are taking steps to improve welfare sector capacity. For example, the need to reduce fragmentation and duplication in the social welfare system in Brazil led to institutional changes and the creation of the Ministry of Social Development. In Chile, the President created a comprehensive social protection system, Chile Solidario, leading to strengthened investments in social work capacity and reorganization of the delivery of social programmes and services to improve access to poor families.

Intersectoral coordination between Ministries responsible for child welfare is important to ensure that protection of children is linked to prevention, treatment and care. One example of a cross-sectoral programme is in Swaziland where in 2005 the Ministry of Education began bringing essential services into schools in pilot areas under the 'Schools as Centres of Care and Support' initiative. That model has evolved and expanded into the present 'Learning Plus' initiative, and has been scaled up by the government to reach schools throughout the country. When needed, parents bring clean water to school by donkey and provide needed labour to build kitchens so children can have a meal at school. Donor agencies have complemented the governments' actions to construct additional classrooms throughout the country, expanding access and reducing crowding⁴².

Countries that have differentiated the role of implementing social protection programmes from providing oversight to programmes have improved the effectiveness of overall social protection programmes. In South Africa, a Social Security Agency has been created to administer the national cash transfer programme, which will help free up the social welfare ministries to address their core mandate of child protection, alternative care and social welfare service coordination. This reduced fragmentation and duplication while improving links between cash transfers and social assistance services.⁴³

While the momentum on social protection is not directly related to HIV and AIDS, the pandemic provides urgency, political profile, and resources to the movement to strengthen social welfare ministries and social protection systems, and to increase coverage for vulnerable children and families.

Communities and community and faith based organizations have played a crucial role in supporting vulnerable children and families. A six country survey of faith based organisations in sub-Saharan Africa found that 220 out of 464 initiatives supporting children affected by AIDS were established in the last four years. In Lesotho an estimated 5,000 support groups exist, many of them without any form of external support⁴⁴. Community initiatives are increasingly recognized as essential to ensuring funding reaches the needs of vulnerable children and some funding streams have emerged to strengthen this community response. But while many donors and governments have acknowledged the need to strengthen community responses, a gulf still exists between the availability of funding at macro level and the resource needs of community groups at grassroots level.⁴⁵ Non Government Organisations (NGO) have often been used as intermediaries to bridge the gap between macro and grassroots levels but evidence from eastern and southern Africa shows that NGO

⁴² Joint working group on education and the IATT on children affected by AIDS (2007)

⁴³ Temin, M (2008) Expanding Social Protection for Vulnerable Children and Families: Learning from an Institutional Perspective', working paper. A paper for the Inter-Agency Task Team on Children and HIV and AIDS: Working Group on Social Protection

⁴⁴ UNICEF (2008) Getting in Line: Coordinated Response of Donors, Civil Society and Government for Children Affected by HIV/AIDS

⁴⁵ Taylor, N (2008) The role of international donors in supporting communities responses to vulnerable children in countries severely affected by HIV and AIDS. An issues paper for the Inter-agency Task Team on Children Affected by HIV and AIDS Working Group on Strengthening the Community Response, (DRAFT), August 16

responses have often been aligned with international organisations through funding and reporting rather than aligning with government⁴⁶.

Many donors are emphasizing the principles of the Paris Declaration on Aid Effectiveness, resulting in a more predictable funding, greater proportion of resources for budget support, pooled systems and national systems strengthening. As such, the funding environment for children affected by HIV and AIDS now includes not only project orientated funds, but also social transfers to vulnerable households, sector support, and investment in national system strengthening (health, education, and social protection).

Where civil society, community and faith based organizations have worked together with governments and donors, scale up has been more successful. One example is Zimbabwe's Programme of Support (POS), where the government works closely with donors and civil society organizations. As of March 2008, six donors had committed over USD 80 million to a pooled fund. Twenty-six NGOs had successfully applied for funding for a period of three years, covering a range of activities in line with Zimbabwe's National Plan of Action (NAP) for Orphans and Vulnerable Children.

These NGOs in turn managed and funded over 150 community groups reaching an estimated 180,000 vulnerable children in 68 districts with potential to reach 400,000 children nationwide. All information is reported through a unified monitoring system. The POS's comprehensive monitoring and evaluation system has made it possible to measure coverage. The model is resulting in positive impacts for children and families as well as building local capacity to enable scale-up⁴⁷. The kind of partnership exemplified by the POS demonstrates the value of civil society engagement in a national response.

Civil society organisations are active in service delivery working in partnership with governments. Examples include piloting approaches to cash transfers in Zambia and Swaziland and developing and implementing the national plan of action for orphans and vulnerable children in a number of countries within eastern and southern Africa⁴⁸.

Legal Protection

Legal protection and enforcement of justice is an essential component of social protection. Effective legal and child protection services are needed to combat disinheritance by making the process of executing and registering wills easier, and improving civil registration – both birth and death registration - including eliminating fees and linking birth registration with other commonly accessed services. Improved legal protection services can also help to strengthen child-sensitive protective services within police, justice, and social welfare systems; design and enforce legislation on child labour, trafficking, sexual abuse and exploitation; and support community-based monitoring mechanisms to identify children at risk and make referrals⁴⁹.

However, legal protection and enforcement is currently weak, as are civil registration services. The OPPEI found that legislative review scored low within efforts in national response to orphans and vulnerable children. Data from nine countries suggest that less than half of mothers or caregivers have identified a standby guardian to take care of a

⁴⁶ UNICEF (2008) Getting in Line: Coordinated Response of Donors, Civil Society and Government for Children Affected by HIV/AIDS

⁴⁷ UNICEF Zimbabwe; Ministry of Public Services Labour and Social Welfare, Zimbabwe; National AIDS Council (2008) A partnership making a difference. Zimbabwe's Programme of Support to the National Action Plan for Orphans and other Vulnerable Children.,

⁴⁸ Country examples from DFID and UNICEF

⁴⁹ The Enhanced Protection Framework for Children Affected by HIV and AIDS, 2007

dependent child or children in the case of disability or death and currently birth registration rates in sub-Saharan Africa lag behind those in the CEE/CIS and Latin America⁵⁰.

A PROGRAMMING CONTINUUM: LINKING EDUCATION, PREVENTION, TREATMENT AND PROTECTION

Protection, care and support are needed at every stage of a child's life. Ensuring that programmes on prevention, treatment, education and protection are linked can assist in ensuring a continuum of care for children.

Without intervention, about a third of children born with HIV will die from an HIV-related cause by their first birthday and half will die before their second birthday.⁵¹ Only approximately one-quarter of the estimated 491,000 children in need of antiretroviral therapy (ARV) in low and middle income countries in 2006 received it, still a 77 per cent increase in coverage during 2006. Of the 20 countries with the largest numbers of children in need of ARVs, only four have reached at least 50 per cent of them: Brazil, Botswana, Namibia and Thailand⁵².

Based on country reporting, WHO estimated that in 2007, less than 58,000 (4 per cent) of 1.5 million children born to pregnant women with HIV initiated cotrimoxazole by two months of age⁵³. Reasons for the low coverage include the lack of national-level guidance to health providers on cotrimoxazole prophylaxis, the lack of opportunities to document its provision in registers or child health cards and erratic supply and frequent stock-outs of drugs⁵⁴. The lack of supply of this essential medicine highlights the need for strengthening medicines supply systems in low-income countries. Another problem is that diagnosis of HIV infection in children remains constrained and must be expanded.

In 2007, approximately 45 per cent of all new HIV infections worldwide were among young people aged 15 – 24 years.⁵⁵

The Inter-Agency Task Team on HIV and Young People explains how education plays an important role in protecting children from HIV infection:

- A good basic education itself is a strong protective factor for preventing HIV risk behaviour among young people
- Girls' education contributes to a number of factors that are thought to decrease vulnerability to HIV infection, such as female economic independence, delayed marriage, use of family planning and work outside the home
- Girls who have completed secondary education (rather than only primary education) have lower risk of HIV infection and are more likely to practise safe sex
- Pregnancy is a major cause of school drop out for girls in many countries. Sex and relationships education can reduce girls' chances of an unwanted pregnancy or sexually transmitted infection.

Schools can also play an important role in delivering treatment, care and support to young people living with and affected by HIV through facilitating access to treatment education,

⁵⁰ UNICEF (2008) Progress Report for Children Affected by HIV and AIDS

⁵¹ Newell, Marie-Louise, et al (2004), "Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: A pooled analysis", *The Lancet*, vol. 364, October 2004,

⁵² WHO, UNICEF (2006) PMTCT report card

⁵³ WHO, UNAIDS, UNICEF (2008) Towards Universal Access, Scaling up Priority HIV/AIDS interventions in the health sector, Progress Report 2008

⁵⁴ Ibid

⁵⁵ UNAIDS (2008) Report on the global AIDS epidemic update 2008. UNAIDS: Geneva

including education about antiretroviral therapy, how to access and take medication and the need to follow treatment regimes; access to psychosocial support and counselling; facilitating access to HIV prevention health services; respond to basic needs such as nutrition; and facilitate home based care education so that older students and teachers can support ill community members.

The Global Campaign for Education estimates that universal primary education would prevent 700,000 new cases of HIV each year⁵⁶.

Evidence highlights how caring for, supporting and protecting children affected by AIDS is an HIV prevention strategy. Many young people may be especially vulnerable to HIV because of such factors as displacement⁵⁷; disability; ethnicity and social exclusion; having parents, siblings or peers who inject drugs; migration (internal and external);⁵⁸ family breakdown and abuse; harmful cultural practice; and poverty. Ways to strengthen protection of these children include education and access to services designed for young people, stronger enforcement of protection legislation: working with the justice sector and the police against sexual abuse.

To be more successful, HIV prevention among adolescent girls should be integrated with their physical and social protection. Research by the Population Council found that adolescent girls, particularly those 10-14 years old and those who are married, need initiatives that help them overcome their isolation, create 'safe' spaces (e.g. for girls only), and give them opportunities to learn life-skills⁵⁹.

Interventions to support children affected by HIV and AIDS are most effective when they form part of strong health, education and social welfare systems that work together to link prevention, education, treatment and protection.

Child Participation

Children are most vulnerable to exploitation and abuse in situations where they are isolated, with limited social networks, and do not have opportunities to voice their views. The participation process can teach children where and how to access information and services in their community while enabling children to break the silence surrounding exclusion and discrimination that they may experience.

Children and youth participation in programming have different types of effects and their participation can be categorised as 'performed' or 'lived'⁶⁰. Many reviews analyze the mechanisms and results of participation, but few rigorously evaluate the impacts against the different types of impact. Findings from a JLICA literature review indicate that more systematic research on the effects of participation need to be designed in order to build an evidence-base from which "best practices" for child and youth participation in programming for children affected by HIV and AIDS may be developed.⁶¹

⁵⁶ Global Campaign for Education (2004) Learning to survive: How education for all would save millions of young people from HIV/AIDS

⁵⁷ See Inter-Agency Task Team (IATT) on HIV and Young People (2008) *Global Guidance Brief on HIV Interventions for Young People in Humanitarian Emergencies* for more information on vulnerability to HIV among young people

⁵⁸ Ibid

⁵⁹ Bruce, J (2007) *Girls Left Behind: Redirecting HIV Interventions Towards the Most Vulnerable*. Population Council

⁶⁰ Kirrily Pells, (Forthcoming), "No One Ever Listens to Us": challenging obstacles to the participation of children and young people in Rwanda', in N. Thomas and B. Percy-Smith (eds) *A handbook of children's participation: perspectives from theory and practice*, Routledge, London and New York

⁶¹ Vatsia, Usha (2007) *Child and youth participation in programming for children affected by HIV/AIDS: A literature review of the evidence of effect*. Joint Learning Initiative on Children and HIV/AIDS, 2007