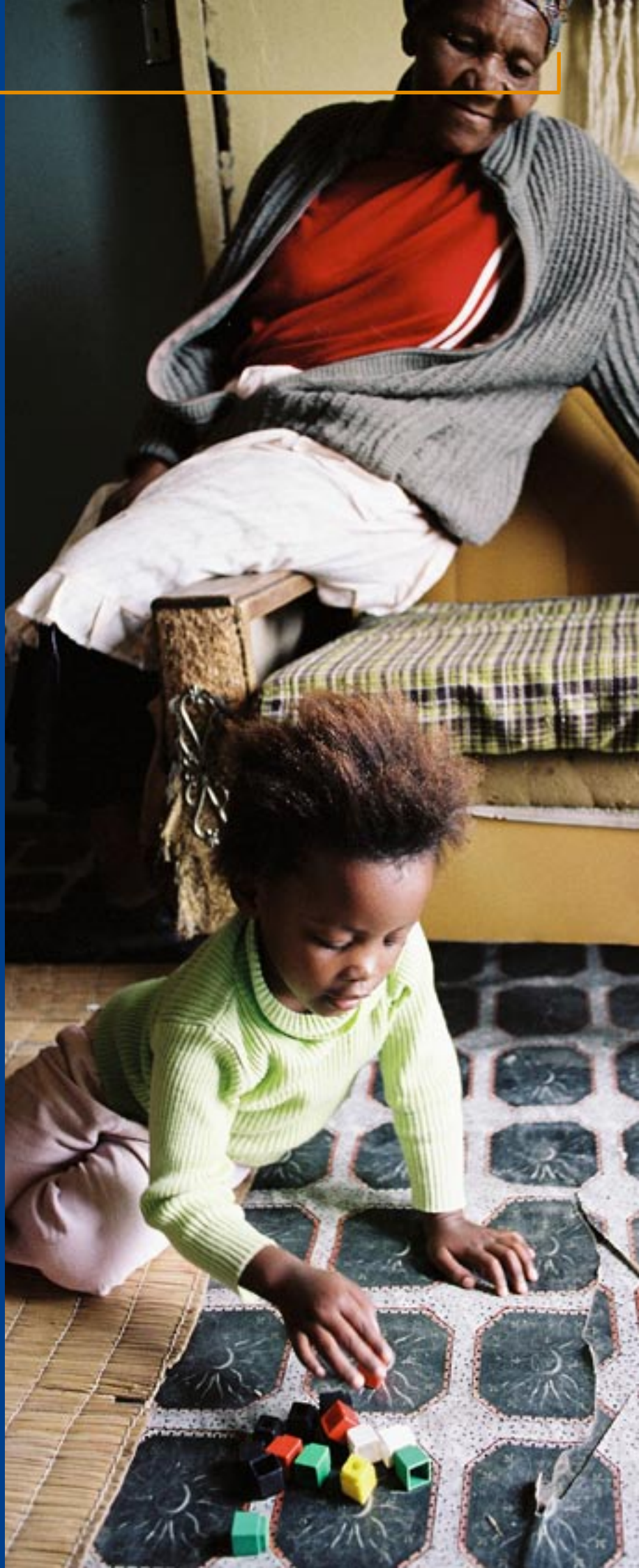


No small issue: Children and families Universal Action Now

Plenary Presentation at the XVII
International AIDS Conference,
"Universal Action Now", Mexico City,
6 August 2008

Linda Richter



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– **Linda Richter**

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Early learning in a family setting, Mtata Region, Eastern Cape, South Africa. Photo: Paul Weinberg

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Executive summary

This plenary presentation argues that children and families have been severely neglected in our responses to HIV and AIDS. It makes the case that responses should be large-scale, integrated and national, characterized by social justice enabled by basic income security and by universal access to essential services such as health, education and social welfare.

Children and HIV/AIDS

In 2007, an estimated total of 2 million children were living with HIV – eight times more than in 1990 – while both new infections and deaths among children have grown three-fold globally since 1990. Around 90% of these children live in sub-Saharan Africa, where 12.1 million children are estimated to have lost one or both parents to AIDS (UNAIDS et al. 2008).

Beyond these basic facts and figures, however, we lack good data on children and HIV/AIDS – and what data we have is not well used. For example, population-based surveys in many African countries identify very small numbers of households headed by children or with only grandparents, but many policies, programmes and advocacy efforts focus very large amounts of money and effort on these relatively rare situations.

What has gone wrong?

- **HIV prevention is failing children.** The overwhelming majority of children who are HIV-positive are infected through mother-to-child transmission. Though their effectiveness is proven, interventions to prevent mother-to-child transmission (PMTCT) are not reaching enough of those who need them.
- **Children living with HIV have far less access to treatment than do adults in the same settings.** Globally, only about 10% of children living with HIV received antiretroviral treatment (ART) last year. Only about 8% of infants in low- and middle-income countries were tested within two months of their birth (WHO et al. 2008). Fewer than 4% of two-month-olds exposed through maternal HIV received preventive or prophylactic co-trimoxazole (WHO et al. 2008).
- **It is not only orphaned children who are affected by HIV/AIDS.** Orphans are only the tip of the iceberg of vulnerable children. In HIV-affected communities, where there is also extreme poverty and deprivation, orphans are seldom worse off than other vulnerable children. Singling out specific groups of children, such as orphans, may lead to other equally or more destitute and needy children and families being passed over.
- **Families, extended kin and communities – many living in extreme poverty – are largely left to support affected children with little or no funding or assistance from governments.** It is estimated that fewer than 15% of households supporting children orphaned or made vulnerable by HIV and AIDS are reached by either community-based or public sector support programmes (UN Secretary General 2006).

Why change is needed

Currently, efforts to protect children affected by HIV and AIDS consist largely of localized projects run by civil society organizations. These can only take us so far. For our efforts to be effective, they must instead be founded on a bedrock of state support for families, and on 'public health' or systemic approaches that have authority, reach and continuity (Richter and Foster 2006; Richter and Rama 2006; Richter et al. 2007).

We need to improve and expand approaches to prevention, treatment and care for both adults and children. Leadership and a commitment to a rights-based approach are critical. The AIDS struggle is a history of

bringing human rights issues under the spotlight; the right of the poorest families in the poorest countries to social protection and universal access to services now needs to be recognized as an imperative for action.

Four recommendations

1. Policies, programmes and funding must be redirected to provide support for children to and through their families. Families care best for children, yet many efforts to assist children have ignored the clear benefits of supporting families. We should not support institutional, orphanage and other forms of non-family care on a large scale. These have well-documented problems and cost up to ten times more than family care. If families had the same amount of money per child that donors give to orphanages, they would do equally well or better.

For these reasons, and because in generalized epidemics HIV and AIDS cluster in families, strengthening the capacity of families through systematic, public sector initiatives has been identified globally as one of the most important strategies of building an effective response for preventing and mitigating the impacts of the epidemic on children (Foster et al. 2005; UNICEF 2004).

2. A dramatic rethink in policies is needed to develop comprehensive and integrated family-centred services. By targeting only individuals, many HIV interventions and services – such as PMTCT, the home care of a very ill person or the initiation of a family member on antiretroviral treatment – are missing critical opportunities to reach out to family and community members as well.

Action for children's wellbeing must address not only their health, but also their basic material needs, psychosocial wellbeing and cognitive development. Comprehensive approaches provide crucial opportunities to reinforce key components of primary health care delivery for all, integrate health sector action with child-focused work in other sectors, and leverage broader advances in social development.

3. As the backdrop to much of the impact of the AIDS epidemic is extreme poverty, much greater attention must be given to social protection for poor families. AIDS-affected households, in both low and high prevalence settings, typically experience a worsening of their socioeconomic status. One study estimated that the implicit annual 'tax' on affected households from reduced income was equal to a quarter of the average household's income for the entire year (Basaza et al. 2007).

AIDS activism has increased access to ARV treatment. Now, in the same way, we must improve the ability of people to claim social protection entitlements. Social protection packages are affordable. The International Labour Organization has estimated the cost of a small universal old-age pension, universal primary education, free primary health and child benefit payments as between 1.5 to 4.5% of GDP for low-income African countries (Pal et al. 2005).

4. We should expand the use of income transfers. It is critical that additional resources go directly to the poorest families affected by HIV and AIDS, not via the many intermediaries that currently stand between various forms of aid and the children who need it. Income transfers have demonstrated impressive results in supporting poor and vulnerable families, including those affected by HIV and AIDS.

Children: At long last, their time has come

I would like to thank the Conference Coordinating Committee, the President of the International AIDS Society, Pedro Cahn, and the AIDS 2008 local conference chair, Luis Soto Ramirez, for giving a plenary slot to children and HIV. In the 23 years since the first International AIDS Conference, this is the first plenary statement that has been devoted to the wellbeing of all children affected by HIV and AIDS.

A focus on children is long overdue. Children have been visible in the photo opportunities and headlines, but almost invisible in the response to HIV.

In recent years, advocates have increasingly mobilized to give more impetus to children's issues. Following the XVth International AIDS Conference in Bangkok, a Coalition for Children Affected by AIDS (CCABA) was formed, which has now hosted two very successful pre-conference symposia on children's issues. The Bernard van Leer Foundation brought together researchers, practitioners and policymakers in a year-long process to consider how we might best respond to children affected by the epidemic and, in 2006, the Joint Learning Initiative on Children and HIV/AIDS (JLICA) was created to provide an independent analysis of what is working, and what needs to change, in the global response to HIV and children. Some of its findings are being released at this conference, and are also incorporated into this presentation.

Thank you to all these organizations and to many others which, through their combined advocacy and leadership, have ensured that children and families would be highlighted here today.

Too minor to matter and too small to count?

Laying out and updating the basic facts and figures helps to get a handle on a problem. But, in the main, children have been simply too small to count.

There is a lack of good data on children and HIV and AIDS, especially between the period of pregnancy and infancy (when mother-to-child transmission occurs) and young adulthood (the time of adolescent risk of infection). The information that is available is kept in several agencies and stored in programmatic silos. This makes it difficult to establish links between HIV data, prevention programmes, child survival and wellbeing, and other key development goals (Stringer et al. 2008).

Likewise, data on children and HIV do not conform to the definition of a child established under the Convention on the Rights of the Child (Office of the High Commission for Human Rights 1990) (0–18 years), but cover the age range of 0–14 years. For this age group, however, data from UNAIDS and other sources indicate the following.

An estimated total of 2 million children were living with HIV in 2007, 90% of them in sub-Saharan Africa. The number of these children, estimated per year, has grown eight-fold since 1990 (see Figure 1).

Both new infections (see Figure 2) and deaths among children (see Figure 3) per year have grown three-fold globally since 1990; again, the greatest majority (89% in both cases) occurring in sub-Saharan Africa. New infections started leveling off around 2000 with the expansion of prevention of mother-to-child transmission services, and have been declining since. Nevertheless, some 370,000 new infections occurred in children in

2007, comprising 17% of all new HIV infections globally (UN Secretary General 2007). In 2007, about 270,000 children are estimated to have died from AIDS.

Parental deaths – that is, the death of a mother, a father or both – have increased significantly, especially in sub-Saharan Africa (Figure 4). In 2007, 12.1 million children in the region were estimated to have lost one or both parents to AIDS (UNAIDS et al. 2008), comprising approximately 37% of parental loss from all causes. Importantly, however, the majority of children classified as orphans (about 80%) do have a surviving parent (UNAIDS et al. 2004). This makes treatment for adults an imperative for the wellbeing of children.

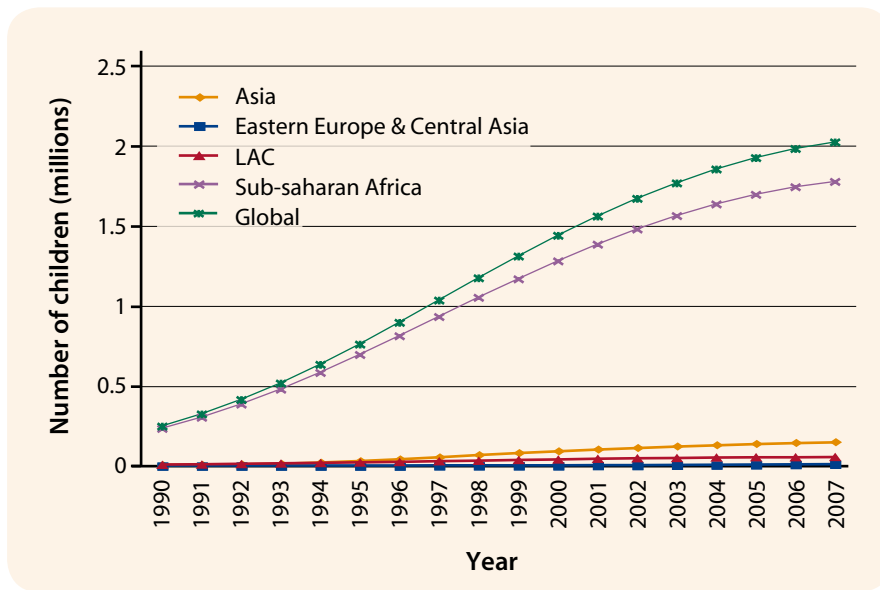


Figure 1. Children living with HIV by region, 1990–2007 (Source: UNAIDS, 2008 estimates)

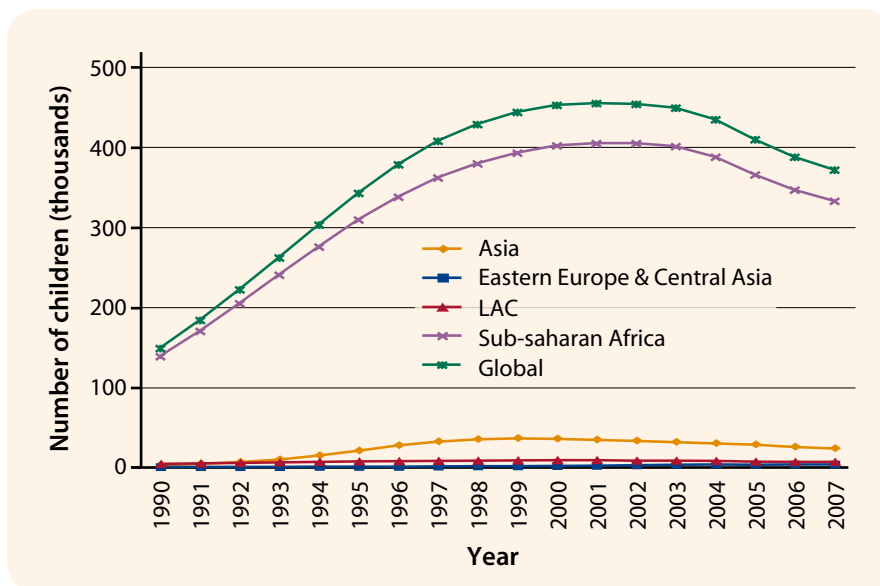


Figure 2. New infections among children by region, 1990–2007 (Source: UNAIDS, 2008 estimates)

Very little is known about infections among children between infancy and 15 years of age. However, a household survey undertaken in South Africa in 2005 found the HIV prevalence in children aged 5 to 9 years to be 4.8%. These data suggest that either HIV-positive children are living longer than has previously been assumed or that there are other, mostly undocumented, later sources of infection – for example, sexual abuse, unprotected care for infected people in the home, or transmission in public health facilities (Shisana et al. 2008). That we know so little about these infections, and that there is as yet no plan for action, is another stark reminder of how much we have neglected children affected by HIV and AIDS.

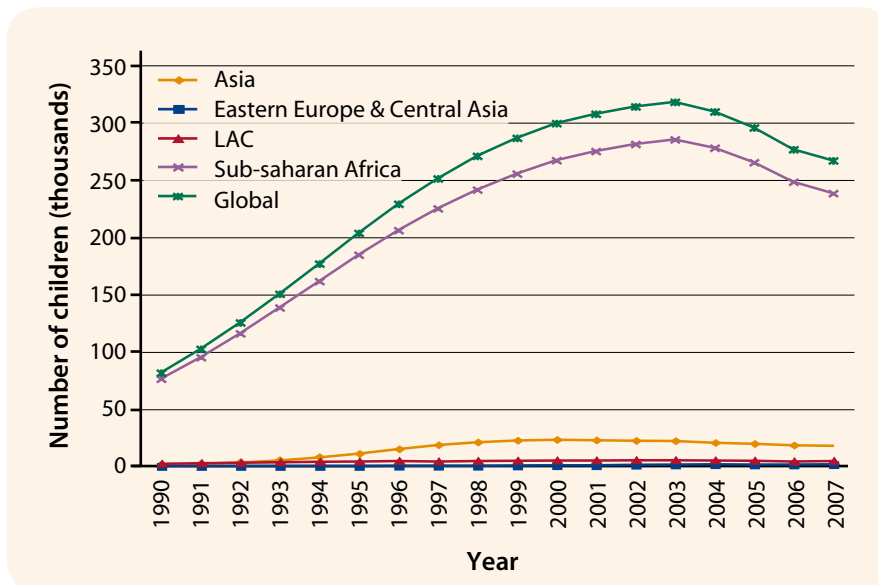


Figure 3. Child deaths attributed to AIDS by region, 1990–2007 (Source: UNAIDS, 2008 estimates)

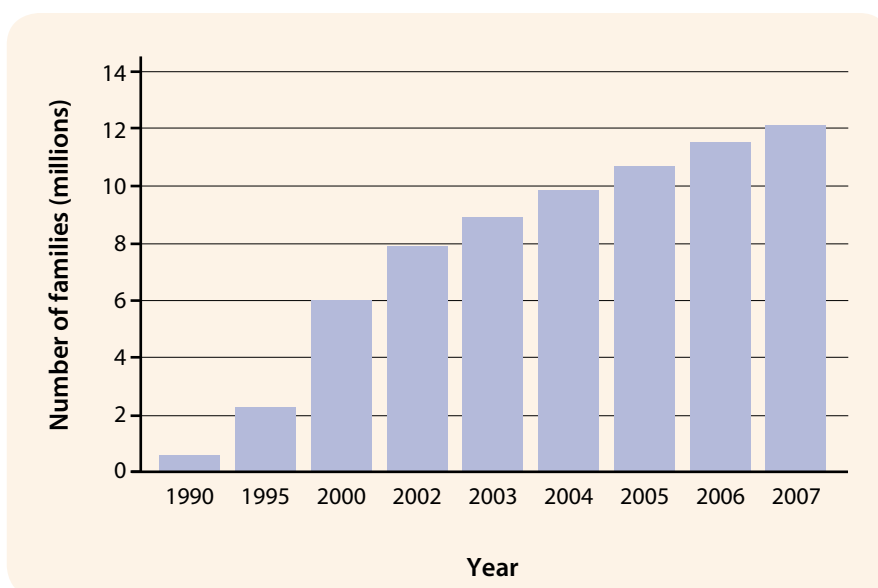


Figure 4. Estimated number of children under 18 who have lost one or both parents to AIDS in sub-Saharan Africa, 1990–2007 (Source: UNAIDS/WHO, estimates 2007)

Not only do we lack data on children and HIV and AIDS, but what we have is not well used. For example, population-based surveys in many African countries identify very small numbers of child-headed households (typically less than 1%) (Hosegood 2008; Richter and Desmond 2008) or skip-generation families with only elderly people and children. But many policies, programmes, and advocacy efforts continue to focus very large amounts of money and effort on these relatively rare situations. These extremely vulnerable households are tragic expressions of social breakdown, and neglect by state and civil society services. However, to focus narrowly on these is to blinker ourselves to the much larger numbers of children and families that urgently require protection and support.

Where have we gone wrong?

Children affected by HIV and AIDS, and the families that care for them, are enduring terrible suffering and deprivation. This suffering is largely needless. It is needless because it results, in the main, from our failure to prevent infection among, and treat, both adults and children. It also results from our failure to assist the poorest families to deal with the social and economic disruptions brought by the epidemic.

1. HIV prevention is failing children

The overwhelming majority of children who are HIV-positive are infected through mother-to-child transmission. However, interventions to prevent mother-to-child transmission (PMTCT) – the effectiveness of which has been established for over 10 years – are not reaching enough of those who need them. In contrast, good quality programmes in Europe and the United States have brought vertical transmission down to below 2% (European Collaborative Study 2005). While coverage of PMTCT services in low- to middle-income countries has increased from 10% to 34% over the last three years (DeCock and De Lay 2008), this is still very significantly lower than that of adult ARV treatment in nearly all southern African countries. Large numbers of pregnant women do not know their HIV status and, of those who are able to access services, most continue to receive monotherapy (single-dose nevirapine), which is much less efficacious than a prophylactic combination regimen (Le Coeur et al. 2003).

2. Children living with HIV have far less access to treatment than do adults in the same settings

Early infant diagnosis among HIV-exposed children is essential for timely initiation of prophylaxis and treatment. But last year, only about 8% of infants in low- and middle-income countries were tested within two months of their birth (WHO et al. 2008). Preventive or prophylactic co-trimoxazole has been demonstrated to reduce significantly illness and death amongst HIV-exposed and HIV-infected children. However, in 2007, fewer than 4% of the estimated 1.5 million children exposed through maternal HIV started receiving the antibiotic by two months of age (WHO et al. 2008).

The number of children under the age of 15 receiving antiretroviral treatment between 2005 and 2007 has practically doubled across all regions over each succeeding year. At the end of 2007, about 198,000 children globally were receiving ART. But this is only about 10% of the estimated 2 million children living with HIV. In sub-Saharan Africa, children are significantly less likely to receive ARVs than adults.

3. It is not only orphaned children who are affected by HIV/AIDS

Children are *infected* by HIV and they are also *affected* – affected, that is, by the devastating impact of the epidemic on their families and the communities in which they live. Children affected by HIV and AIDS are often

grouped together with children who are orphaned because of AIDS – and then categorized as ‘orphans and vulnerable children’. But, in reality, orphans are only the tip of the iceberg of affected children.

The much-used term, ‘AIDS orphan’, in itself causes enormous confusion (Sherr et al. 2008). The UNAIDS definition of an orphan – a child under 18 who has lost *one or both parents* (UNAIDS et al. 2004) does not accord with common-sense meanings in different cultures. In Western countries, the usual meaning of an orphan is a child who has lost both parents; in much of Africa, it is someone without family or close kin.

However defined, children who lose their parents are of concern. But it is the needs of all children, especially vulnerable children – not whether they meet a definition of ‘orphan’ – that must be our primary focus when designing and implementing policies.

To illustrate this, in HIV-affected communities, where there is also extreme poverty and deprivation, orphans are seldom worse off than other vulnerable children. Recent household data in 15 high-burden countries indicate a small and decreasing gap between orphans and non-orphans, for example, in their likelihood of attending school (UN Secretary General 2006). Indeed, experience shows that singling out specific groups of children, such as orphans, leads to undesirable effects such as increased stigmatization. Children may be ‘labeled’ by families in an effort to be able to access desperately needed assistance, while other equally or more destitute and needy children and families are passed over in highly-targeted programmes.

More importantly, though, the focus on orphans has individualized the challenge of care and support. It has framed the epidemic’s impact on children as an individual rather than a national social problem, and has separated assistance to children from efforts to support families and communities. Close to 60% of families are affected in the hardest-hit countries (Figure 5), impacting on very large numbers of children. As a result of focusing too specifically on orphans, our efforts to improve the life chances of much larger numbers of children have been considerably less effective than they should have been.

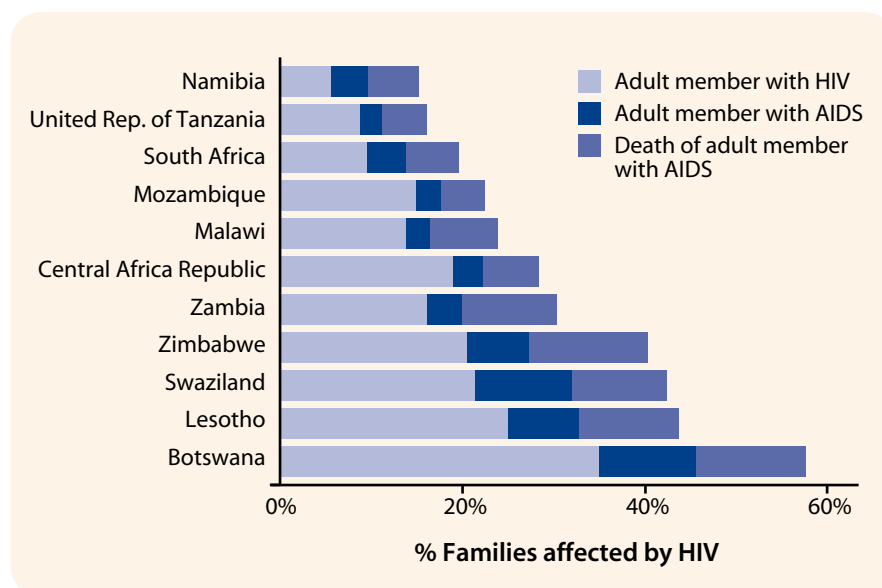


Figure 5. Percentage of families affected by HIV illness and death, 2003 (Source: Belsey (2005))

4. Families, extended kin and communities – many living in extreme poverty – are largely left to support affected children with little or no funding or assistance from governments

The numbers of children affected by HIV and AIDS are increasing against a background of deepening poverty. In most of southern Africa, over 60% of children live below the poverty line in already poor countries. In such situations, support to individual children by local community-based organizations, while necessary, is not enough. ALL children in communities hard hit by HIV are made vulnerable by the epidemic. ALL require support.

But, to date, few interventions for children have been formulated, resourced or implemented on a scale commensurate with the impact of the epidemic. Based on the few reports from countries available in 2007, it is estimated that fewer than 15% of households supporting children orphaned or made vulnerable by HIV and AIDS are reached by either community-based or public sector support programmes (UN Secretary General 2006). This figure is only barely up from the 5% estimated eight years ago, in 1999 (Deininger et al. 2003). In the most severely affected regions, families and communities carry the overwhelming burden of HIV, including an estimated 90% of the financial cost.

The major sources of support for children and families still come from civil society organizations, many of them faith groups, operating in circumscribed areas often by happenstance. Even if magnified many fold, these approaches cannot hope to address the required needs.

For our efforts to protect children affected by HIV and AIDS to be effective, they must be founded on a bedrock of state support for families, and on 'public health' or systemic approaches that have authority, reach and continuity (Richter and Foster 2006; Richter and Rama 2006; Richter et al. 2007). Such a bedrock would also enable civil society organizations to better render much-needed individual services, such as psychosocial and moral support.

In summary, children have been short-changed in the response to HIV and AIDS.

In addition to achieving painfully little, we have missed many opportunities to expand our response, and we have often compounded the problems we try to address. PMTCT is far from becoming PMTCT Plus (<http://www.columbia-icap.org/whatwedo/mtctplus/index.html>); that is, to routinely include the treatment of mothers. Mixed and uncertain messages have caused confusion about infant feeding (Chopra et al. 2002; Gray and Salojee 2008). Child testing and treatment, family support, and the promotion of children's development – including of those children who are HIV-negative (Stein et al. 2005) – remain to be linked. Our efforts to help orphans to the exclusion of other poor and vulnerable children have often caused needless deprivation and unwittingly contributed to their increased isolation and discrimination.

While the global response to AIDS has accelerated, children lag behind in all aspects of HIV control – prevention, testing, diagnosis, treatment and care – especially in sub-Saharan Africa, the worst affected region in the world (Coovadia and Schaller 2008). Combined with poverty, worsening social and economic conditions, political instability, corruption and conflict, the AIDS epidemic constitutes both a humanitarian crisis and one of the greatest threats to the development of the region (UN Secretary General 2006).

What now needs to be done?

The world is beginning to heed the call for 'more' to be done for children. We now have to be specific about what 'more' involves.

We need to improve, expand, intensify, amplify and escalate effective approaches to prevention, treatment and care – for both adults and children.

Leadership and a commitment to a rights-based approach to children and families are critical. The AIDS struggle is a history of bringing human rights issues under the spotlight. Examples include efforts to overcome stigma and discrimination, exclusion from school and work, gender power imbalances, and access to treatment. In each case, AIDS has served as the impetus to challenge abuse and disregard of our dignity, and to advance the fulfillment of human rights.

Similarly, in addressing the needs of children affected by HIV and AIDS, the right of the poorest families in the poorest countries to social protection and universal access to services now needs to be recognized as an imperative for action.

It is with this issue in mind that I would like to offer four main recommendations to re-focus our responses to HIV and AIDS so that they can achieve what they should for children.

Recommendations

1. My first recommendation is that policies, programmes and funding must be redirected to provide support for children to and through their families.

The overwhelming majority of infected and affected children globally are cared for in families. This is right because families care best for children – and here, I am defining ‘families’ in the broadest way, taking into account the varying structures that exist in different contexts. Yet many efforts to assist children affected by HIV and AIDS have ignored the clear benefits of supporting families.

In generalized epidemics, HIV and AIDS cluster in families, affecting many people at once. Families are also a critical entry point and platform for effective and lasting behaviour change in the context of the epidemic (Pequegnat and Szapocnik 2000). For example, adolescents who are emotionally close to and supported by their families are less likely to engage in sexual behaviours at a younger age and to be exposed to other forms of risk for infection (Youngblade et al. 2007).

It is the socioeconomic conditions of families, the resources they have at their disposal, and the services, safety nets and support they can access, which largely determine the nature and extent of the epidemic’s impact on children. The poorest families have faced the worst effects of the epidemic by diversifying their livelihoods to compensate for lost income and labour, financing the health care of those who are sick, providing home palliative care, and assisting and absorbing kith and kin. They have done this, by and large, by reducing consumption – eating less, and spending less on education and health care for other members of the family. All of this critically affects the wellbeing of children (Donahue 2005; Heyman et al. 2007; Phiri and Tolfree 2005).

This response by families has also come with other costs. Household dissolution, abandonment, neglect of informally fostered children of relatives, property grabbing and abuse have all been recorded. These anomalies do not detract from the importance of family support; rather, they emphasize the need for stronger mechanisms of social justice and welfare in highly-affected communities.

What is clearly inappropriate as an alternative response is to attempt to provide institutional, orphanage and other forms of residential, or non-family, care for the great majority of affected children – who still have families, however poor (Phiri and Webb 2007). The fact that institutions can provide better food, shelter, education and health care than most very poor families is deceptive. If families had the same amount of money per child that donors give to orphanages, they would do equally well or better. Orphanages produce problems of their own, with documented ill-effects on young children's growth, cognition and socio-emotional development (Nelson 2007). They also cost up to ten times more than family care and divert valuable resources from efforts to strengthen, rather than replace, families (Desmond et al. 2002).

Families are the most influential force in the lives of children and adolescents (Bronfenbrenner 1986). Strengthening the capacity of families through systematic, public sector initiatives has been identified globally as one of the most important strategies of building an effective response for preventing and mitigating the impacts of the epidemic on children (Foster et al. 2005; UNICEF 2004).

2. My second recommendation is that a dramatic rethink in policies is needed to develop comprehensive and integrated family-centred services.

In generalized epidemics, all activities in prevention, treatment and care, lend themselves to a family focus. By targeting only individuals, many HIV interventions and services are missing critical opportunities to reach out to family and community members as well.

For example, HIV testing among couples and even whole households is proving to be a promising approach (Bateganya et al. 2007; Chomba et al. 2008; Zhou 2007). Opportunities to reach out to family networks exist naturally through services such as PMTCT, when a pregnant woman presents at a service point. Other entry points include the home care of a very ill person or the initiation of a family member on antiretroviral treatment.

Family-focused studies indicate that treatment for adults also provides very significant benefits for children in a household. A longitudinal micro-economic study in Kenya demonstrated that adults on treatment were able to resume working, and that their return to employment was associated with important child benefits – children's nutrition and growth improved, child labour was reduced and children returned to school (Kimou et al. 2008; Thirumurthy et al. 2006).

Action for children's wellbeing must address not only children's health, but also their basic material needs (food, clothing, clean water, shelter), their psychosocial wellbeing, cognitive development and the changing needs of boys and girls at different stages of their development.

Comprehensive approaches to children's wellbeing provide crucial opportunities to reinforce key components of primary health care delivery for all, integrate health sector action with child-focused work in other sectors, and leverage broader advances in social development.

3. The backdrop to much of the impact of the AIDS epidemic is extreme poverty. My third recommendation is, therefore, that much greater attention must be given to social protection for poor families.

Social protection is a crucial missing ingredient in responses to children affected by HIV and AIDS. AIDS deepens poverty at the household, community – and, over time, the country level (Collins and Leibbrandt

2007). Poor families have fewer resources and reduced capacity to deal with illness and death. While I have mostly referred to sub-Saharan Africa, a review of 363 papers on children in low-prevalence and concentrated epidemic communities has shown that children affected by HIV/AIDS everywhere face similar challenges – exposure to stigma and discrimination, emotional distress, possible separation from siblings, relocation to unfamiliar surroundings, material deprivation and loss of opportunities and entitlements, heightened risks of further HIV infection in the family, illness and possible death (Quality Assurance Project et al. 2008).

Everywhere, HIV-affected households typically experience a worsening of their socioeconomic status, they frequently become indebted, sell assets and reduce their consumption, especially of food. They spend more on the health care of sick members and suffer a loss of income as a result of declining productivity. In a 2002 study conducted in Uganda, USAID estimated that the implicit annual 'tax' on affected households from reduced income was equal to a quarter of the average household's income for the entire year (Basaza et al. 2007). Similarly, in Botswana during the same period, households were found to spend an additional 25% of their income on each person living with HIV (Cornia and Zagonari 2007).

Social protection for developing countries is now firmly on the development agenda (Guhan 1994). Evidence from around the world is demonstrating the benefits of social security in poor countries and communities – regular, relatively small payments, in cash or kind, to individuals and families who, for one reason or another, are dependent on others, including the state, for their needs. These include the aged who may receive pensions, children grants, and poor families who may be given income or in-kind transfers (Barrientos and Hulme 2008).

Every developing country, no matter how poor, can afford to support a social protection package for children affected by HIV, AIDS and extreme poverty. The International Labour Organization has estimated that the cost of a social protection package for low-income African countries – consisting of a small universal old-age pension, universal primary education, free primary health and a child benefit of \$0.25 per day – ranges between 1.5 to 4.5% of Gross Domestic Product (GDP), depending on the context (Pal et al. 2005).

A recent effective Zambian pilot programme provided US\$15 per month to each of the poorest 10% of households. If this approach was implemented in all low-income countries in sub-Saharan Africa, it would cost only 3% of the aid to Africa agreed at Gleneagles (DFID 2005).

AIDS activism has increased access to ARV treatment. Now, in the same way, we must improve the ability of people to claim social protection entitlements. If citizens are not empowered to reach out, demand and receive social protection and other rights, improvements in services, including HIV prevention and treatment, will even further divide those that already have from those with little or nothing.

But it is also critical that the 'more resources' we are requesting go directly to the poorest families affected by HIV and AIDS, not via the many intermediaries that currently stand between various forms of aid and the children who need it.

4. This leads me to my fourth, and final, recommendation. We should expand the use of income transfers; these have demonstrated impressive results in supporting poor and vulnerable families, including those affected by HIV and AIDS.

A continuum of social protection strategies exists, ranging from micro-lending such as implemented by BRAC in Bangladesh (Bangladesh Rural Advancement Committee (BRAC), <http://www.brac.net/>), to skill training

programmes, and work initiatives like Botswana's Labour-Based Relief Programme. However, the degree of incapacity of the worst hit and poorest families affected by HIV and AIDS mean that they are often unable to take advantage of these approaches. In these cases, income transfers have been found to be particularly effective in providing immediate relief and averting disastrous borrowing and sale of assets. The use of health services, education, child nutrition and children's development, have been enhanced by income transfers to the poorest families in over 20 low- and middle income countries. Direct transfers are also less labour intensive and require less administration than in-kind contributions, such as food. They also maximize the choices of poor families, giving them the flexibility needed to make decisions under precarious circumstances.

Income transfer programmes can take many forms. Some may take the form of universal social security entitlements, such as old-age pensions and child support grants. Others may be implemented as programmatic interventions of varying duration, targeted geographically to vulnerable communities and households. Still others may comprise treatment allowances, or small amounts of money to cover the transport and opportunity costs of accessing HIV and AIDS prevention and care services. Some may be given as part of relief operations in response to crises.

Approaches will vary across countries and even communities. But some form of income assistance for the most needy households is urgently needed. In many high-prevalence countries in Africa, poverty is arguably the single biggest barrier to the scale-up of HIV treatment and prevention. In fact, further expansion of these services may not be possible without addressing individual and household incapacity to access them. Because of potential stigmatization and perverse incentives, targeting should be to the poorest families in high prevalence areas, rather than specifically to HIV-affected families or children. In countries such as Malawi, South Africa and Zambia, this approach has been shown to reach the majority of families extremely affected by HIV and AIDS (Schubert et al. 2007).

Income transfers are cost-effective. They should be prioritized in both aid disbursements and national budgets. They are not the solution – rather, they are an entry point to large-scale integrated national responses characterized by access to essential services, such as health and education, social welfare and social justice, enabled by basic income security.

Conclusions

In conclusion, let me express the hope that this plenary presentation both reflects and inspires a greater awareness of children in our response to HIV and AIDS.

Children and families have been very severely neglected in our responses to date. Prevention, treatment and care for children continue to lag behind adults. Support for affected children has been left largely to families, extended kin and communities. Although they are the most appropriate groups to help children, they cannot protect and care for children without assistance.

As a result of projects such as the Joint Learning Initiative on Children and HIV/AIDS and vigorous advocacy by a number of child-oriented agencies, the spotlight is now moving to children.

The current response is largely composed of temporary or *ad hoc* projects with limited outreach that are often poorly designed and underfunded. These efforts undoubtedly alleviate some of the distress experienced by

children and families. But small, localized projects can only take us so far. To have a bigger impact requires larger and more systemic responses – responses which support families and address the pervasive poverty in which so many of them live. Putting needed resources into the hands of affected families should be urgently considered in order to expand the impact of small scale programmes currently reaching only very small numbers of children. Families are the crucial link in providing sustainable assistance for children over the long-term and, in turn, building stronger communities that can be more resilient to HIV.

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About the Bernard van Leer Foundation

The Bernard van Leer Foundation funds and shares knowledge about work in early childhood development. The foundation was established in 1949 and is based in the Netherlands. Our income is derived from the bequest of Bernard van Leer, a Dutch industrialist and philanthropist, who lived from 1883 to 1958.

Our mission is to improve opportunities for children up to age 8 who are growing up in socially and economically difficult circumstances. We see this both as a valuable end in itself and as a long-term means to promoting more cohesive, considerate and creative societies with equality of opportunity and rights for all.

We work primarily by supporting programmes implemented by partners in the field. These include public, private and community-based organisations. Our strategy of working through partnerships is intended to build local capacity, promote innovation and flexibility, and help to ensure that the work we fund is culturally and contextually appropriate.

We currently support about 140 major projects. We focus our grantmaking on 21 countries in which we have built up experience over the years. These include both developing and industrialised countries and represent a geographical range that encompasses Africa, Asia, Europe and the Americas.

We work in three issue areas:

- Through “Strengthening the Care Environment” we aim to build the capacity of vulnerable parents, families and communities to care for their children.
- Through “Successful Transitions” we aim to help young children make the transition from their home environment to daycare, preschool and school.
- Through “Social Inclusion and Respect for Diversity” we aim to promote equal opportunities and skills that will help children to live in diverse societies.

Also central to our work is the ongoing effort to document and analyse the projects we support, with the twin aims of learning lessons for our future grantmaking activities and generating knowledge we can share. Through our evidence-based advocacy and publications, we aim to inform and influence policy and practice both in the countries where we operate and beyond.



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