WORKING PAPERS IN

Early Childhood Development

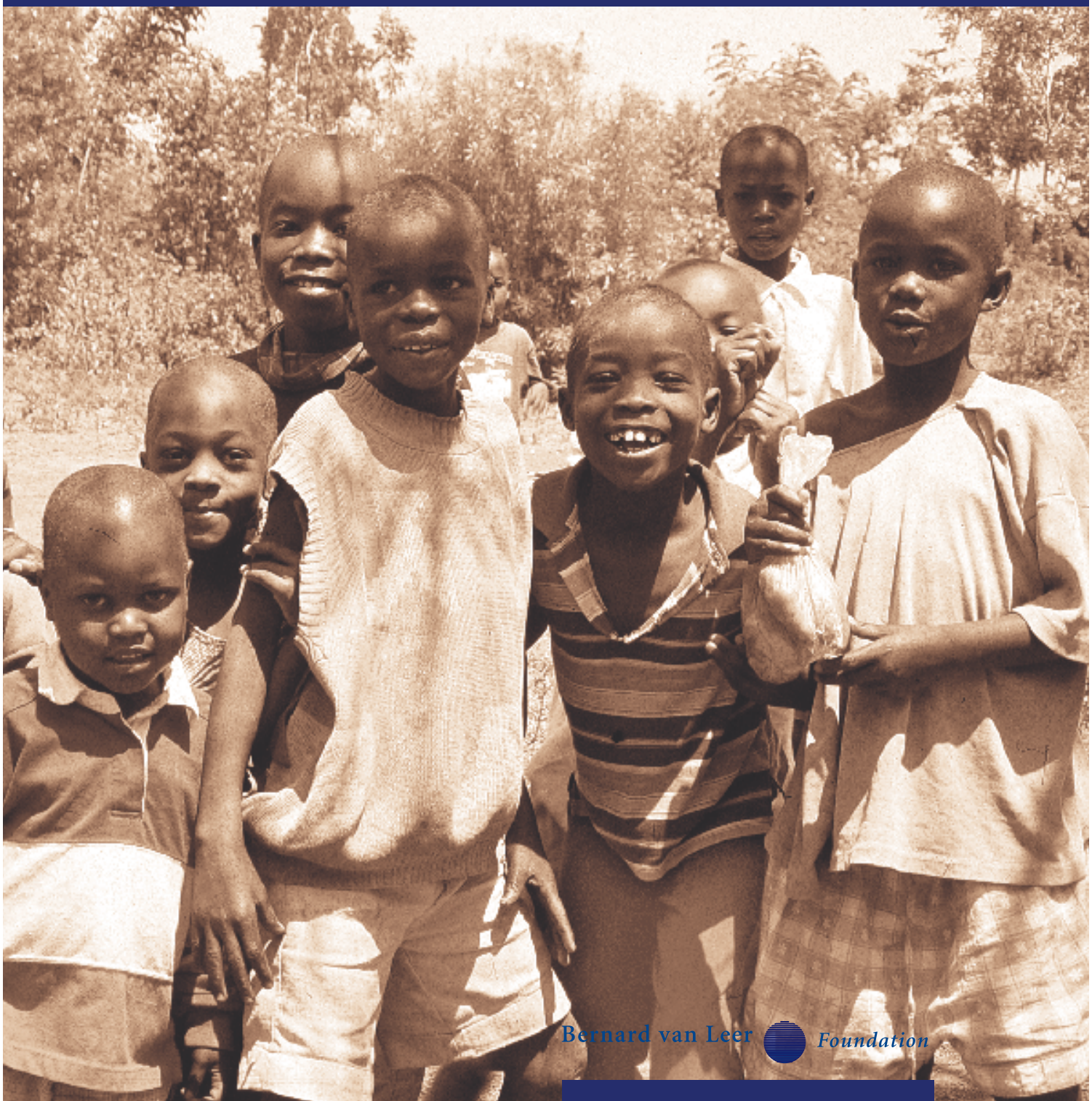
Young children and HIV/AIDS sub-series

37

The way the money goes

An investigation of flows of funding and resources for young children affected by HIV/AIDS

by Alison Dunn



Bernard van Leer Foundation

About the paper

This paper is one of a dedicated 'Early Childhood and HIV/AIDS' sub-series of our long-standing 'Working Papers in ECD' series. The purpose of the sub-series is to generate work that responds to emerging needs, or that present information, experiences, ideas, and so on, to inform all those concerned with young children impacted by HIV/AIDS – including ourselves.

Papers will often be 'think pieces' deliberately produced quickly to reflect the fact that ideas, understandings and approaches are developing rapidly, and to share emerging lessons fast and efficiently.

Each is tightly focused and has a specific purpose. *The way the money goes: An investigation of flows of funding and resources for young children affected by HIV/AIDS* surveys the ways in which funding for HIV/AIDS care is disbursed. It is evident that only a small and insignificant amount is being targeted on interventions focusing on early childhood development in HIV/AIDS-affected communities. Certain categories of intervention under headings like 'prevention' and 'orphans and vulnerable children' can extend suitable support to very young children, but the question remains: Is this the most effective way to spend the available funds, bearing in mind the special needs of such children?

In order to redirect funding towards this area it is important to understand how and why money is spent on HIV and AIDS. Decisions on the distribution of funds are frequently based on political factors rather than on sound evidence from front-line responses in the field which have been informed by those people most directly affected by HIV and AIDS.

It makes urgent sense to carry out research and undertake evaluations of current work in ECD and HIV/AIDS so that evidence can be effectively communicated within and across networks of practitioners, researchers and policy makers. Influencing strategic and policy-level decisions is vital to ensure that funding is directed in an influential manner and communicating research and learning to decision makers and donors is of great value in this process. Better knowledge sharing needs to be supplemented by social mobilization and action at grassroots level to reach and directly consult young children in neighbourhoods affected by HIV/AIDS.

In the current climate, it may be preferable to advocate the reallocation of more funds towards the categories of orphans and vulnerable children and the prevention of mother-to-child transmission. However, this needs to be done within a context of questioning the success of current HIV/AIDS approaches. If very young children are receiving an insignificant portion of the available global funds for HIV and AIDS, a possible option would be to support long-term and community-directed responses that could include very young children as part of a whole.

Cover: Preschool children in the Ambira project, western Kenya. Implemented by the African Network for the Prevention and Protection against Child Abuse and Neglect (ANPPCAN), the project focuses on mitigating the effects of HIV/AIDS on children. Photo: TANJA VAN DE LINDE/Bernard van Leer Foundation.

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May 2005

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About the author

Alison Dunn is a researcher and development practitioner who works for Exchange, a UK-based networking and learning programme for health communication in development. She has a social development background with considerable experience of participatory action research and communication in West Africa. Current work focuses on grassroots communication around health issues and the communication of research into policy and practice.

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Executive summary

This paper, produced by Exchange for the Bernard van Leer Foundation, surveys the routes by which HIV/AIDS care funding is disbursed, based on the most recent (2003) analysis. Although we cannot hope to chart these routes precisely or comprehensively, it is evident that only a small and insignificant amount is being targeted on interventions focusing on early childhood development in the shadow of HIV/AIDS (ECD-HIV/AIDS for short).

Scrutiny of the channels by which global HIV/AIDS funding reaches resource-poor countries reveals that certain categories of intervention under headings like 'prevention' and 'orphans and vulnerable children' have a potential to extend suitable support to very young children (up to 8 years old). Yet the question needs to be raised and tackled: Is this the most effective way to spend the available funds, bearing in mind the special needs of such children?

Much advocacy and campaigning effort goes into boosting the amount of HIV/AIDS money made available. Yet little effort goes into deeper questioning and analysis of how funding is currently being spent and whether it is effective. Last year five million people became newly infected with HIV, more than in any previous year.[1] The 2004 UNAIDS report on global trends in HIV/AIDS suggests that double the current level of funding is needed if interventions are to have a decisive impact on the situation. Notwithstanding this call, serious questions surround the effectiveness of current interventions.

We need to analyse the shortcomings of the past 20 years, during which a lot of money has made little impact. By urging donors to integrate their responses to HIV/AIDS, the 'Three Ones' principles recently sponsored by UNAIDS come as a welcome development in this respect. This more co-ordinated approach may clarify the big picture of HIV/AIDS spending, but will take time.

Recent examples suggest that the most effective responses to the HIV/AIDS crisis come from within communities themselves and are complex and long-term. Donors find it difficult to support these types of responses and continue to distribute funding in a manner characterised by rigid structures and measurable outputs. The Panos Institute report *Missing the Message* argues that "despite many positive and courageous steps by initiatives such as the Global Fund to fight AIDS, TB and Malaria (GFATM), funding structures and policies are poorly positioned to support the kind of long-term, cross-sectoral, difficult to evaluate and locally driven initiatives that constitute the most appropriate responses to HIV/AIDS."[2] For very young children in communities affected by HIV/AIDS, it could make a vital difference in the light of this argument to assess, identify and support the long-term, cross-sectoral and locally-driven initiatives most likely to get them through the crisis in their midst.

Two prominent categories of early childhood intervention currently attract significant funding – the prevention of mother-to-child transmission and the care of orphans and vulnerable children. Programmes for prevention of mother-to-child transmission are generally well-established and usually involve a one-off medical intervention and subsequent promotion of changes in breast feeding behaviour. Under the category of orphans and vulnerable children there is potential to reach the youngest (0–8) age group, but it is largely unrealised and care for this age group is significantly under-resourced.

Before more resources can be routed in the direction of ECD-HIV/AIDS interventions, research is needed to examine specific interactions between ECD and HIV/AIDS, informed by responses on the ground and the realities of what currently works well or less well. To make sense, this 'reality check' must involve participation by adults and children who are living with and affected by HIV/AIDS, so the problems faced by those most affected can be addressed.

Networking, communication and knowledge exchange between communities and sectors about the most appropriate responses to ECD and HIV/AIDS will also be a critical factor. Recent studies indicate that research is often not communicated effectively and that dynamic networks can be important in bridging the gap between research and policy. Effective monitoring of interventions and swift communication of research findings, lessons learned and project evaluations can speed progress towards real changes in the way that HIV/AIDS funding is spent. Good advocacy and communication will be critical to ensure that policies which draw lines between ECD and HIV/AIDS are made on the basis of evidence rather than political factors or guesswork.

Acknowledgements

Thanks to Andrew Chetley and Dr Robin Vincent of the Exchange Programme for insights into issues raised in this paper and for valuable critical comments.

Introduction

This paper discusses routes by which HIV/AIDS money is dispersed and received. It notes that capturing accurate data on actual spending patterns of large donors can be difficult, as there is no uniform tracking or reporting system and much HIV/AIDS money is spent under the broader category of sexual and reproductive health. Most of the information contained in the first two sections is based on main reports that assess the general manner in which HIV/AIDS money as a whole is being distributed. Moving on from who is providing funds for HIV/AIDS initiatives at global level, it tracks sources and flows from governments, through bilateral and multilateral channels. It does not include estimates of household spending on care and treatment, which cannot be realistically quantified. Information follows on top US and European donors, the international business community and pharmaceutical companies.

Later sections look into ways HIV/AIDS funding is being spent, with the proviso, as before, that detailed breakdowns of actual spending are rare. The broadest categories are prevention, care and treatment, orphan support and research. Within the field of ECD vis-à-vis HIV/AIDS, funds are being directed through two main areas of concern – prevention of mother-to-child transmission and the care of orphans and vulnerable children. These pages describe major players in these arenas, showing that efforts are being made by a few agencies though the amount of funding directed along these channels is minimal in contrast to other target areas. Fundamental questions are raised about current donor priorities and there follows some discussion touching areas where new or reallocated HIV/AIDS funding could be directed.

Obvious gaps in the provision of money for ECD and HIV/AIDS support are then identified along with opportunities to carry out work to fill such gaps. The final section examines what it would take to direct more money to support young children living in the shadow of HIV/AIDS. Including very young children in HIV/AIDS response strategies will ultimately depend on individual communities devising their own solutions. Ideas and experiences from within communities can and should be shared to help boost care for very young children affected by AIDS/HIV and to convince funders of the worth of backing more interventions delegated at local level. Potential areas of research and advocacy need to be identified by the people most affected by the pandemic. Some areas are listed that have so far emerged from this grassroots process.

A further section highlights the critical importance of sharing knowledge through networks that communicate and disseminate evidence-based research findings and project evaluations. In conclusion, this paper calls for advocacy to urge that more funding should go to ECD-HIV/AIDS needs and that current funding approaches to dealing with the crisis need, in addition, to be tracked and evaluated, with a view to promoting more and better ways of meeting the unfulfilled needs of very young children affected by HIV/AIDS.

Chapter 1: Where the money comes from and where it goes

Gathering information on HIV/AIDS funding

It is difficult to gather and analyse data on global funding for HIV/AIDS as there is no uniform reporting system. Most donors do not publish progress reports till after a one-year delay. When they do report, they often merge HIV/AIDS funding into broader categories such as sexual and reproductive health, and there is little detailed breakdown of the money spent, or its impact.

Governments

Governments of countries much affected by HIV/AIDS rarely have mechanisms to collect and report current, accurate and comparable data. They do not have the infrastructure required to keep detailed information on a disease like HIV/AIDS. Health budgets do not separate HIV/AIDS from other health service categories. This problem is not unique to developing countries. Recently the UK Department for International Development (DfID) came under criticism by the National Audit Office who claimed that DfID did not know how much it was spending on its HIV/AIDS strategy and that it lacked a separate system for monitoring the impact of its spending.[3]

Multilateral and bilateral funding

When funds flow through many different channels there is a notable difference between budgeted funds and actual spending, again making it difficult to understand spending patterns. UNAIDS has estimated that actual disbursements from US bilateral programs in 2003 will be less by about 30% than budget allocations.[4] There is also a time-lapse. For example, when funds are donated to the Global Fund they can take months to reach front line providers and people affected by HIV/AIDS.

Foundations, corporations and NGOs

Again, there is little current and adequate information. Most data in this category come from Funders Concerned About AIDS (FCAA) and UNAIDS. Foundations often distribute HIV/AIDS money under different programs such as sexual and reproductive health or community-based healthcare. Similarly NGOs rarely have a tracking system for their HIV/AIDS spending.

Who spends what on HIV/AIDS support?

Key sources that offer some information on global funding patterns include:

- analysis done by OECD and UNAIDS in a report called *Analysis of aid in support of HIV/AIDS control, 2000-2003* [5], which shows a clear trend towards increasing aid donations to fight HIV/AIDS;
- a report by the Henry J. Kaiser Family Foundation (*Global Funding for HIV/AIDS in Resource Poor Settings*, 2003), which presents estimates of current and actual spending of all major global funders;[6]

- estimates of current and future funding needs in *Macroeconomics and Health: Investing in Health for Economic Development* 2001[7], published by WHO's Commission on Macroeconomics and Health (CMH);
- the European HIV/AIDS Funders group's report *European Philanthropy and HIV/AIDS* 2004, which also sets out an analysis of information on spending by European trusts, foundations and charities.[8]

The study in hand draws on these reports as it examines routes by which HIV/AIDS money is channelled to support very young children. As expected, a relatively new area such as HIV/AIDS in ECD does not feature in any standard analysis. Funding that flows through these main routes does, however, reach very young children in various ways, even if very little of it is directly targeted on this age-group. Estimates suggest that funds budgeted for overall HIV/AIDS actions in resource-poor areas in 2003 totalled US $4.2 billion.[9]

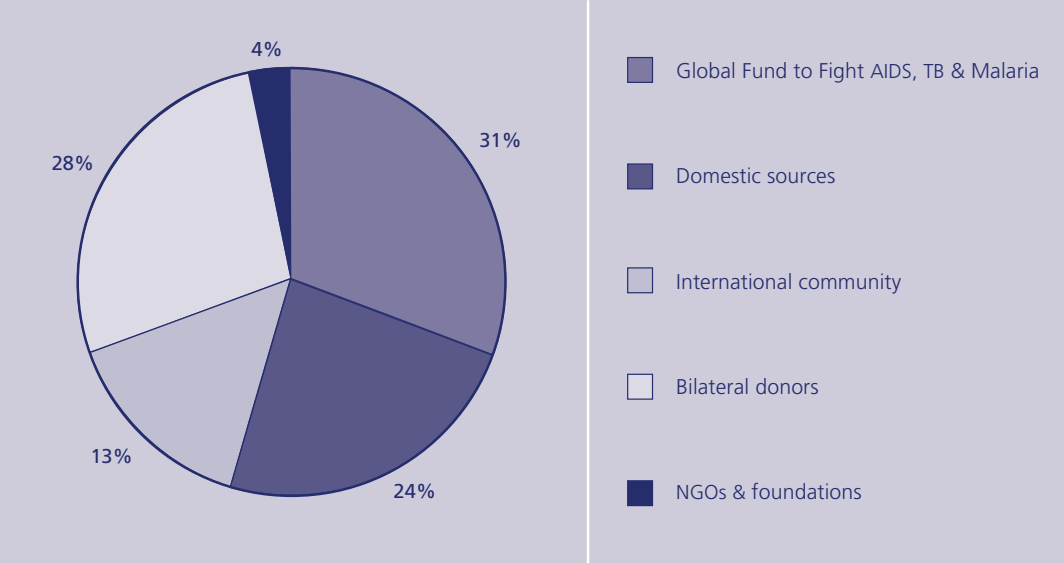
Actual spending was about $3.6 billion – a 30% increase over the previous year. The difference between budgeted and actual spending ($625 million) is attributed to the variance between government-budgeted and actual spending and also to the time–lag before contributions are made to the Global Fund.[10]

Household spending

The estimates charted above (figure 1) do not include money spent by individuals and households on care and treatment, including purchases of condoms and of medication to treat HIV-related illness. It could also include time given by carers in home settings, reducing time spent on income-generating activities. It is important to get a sense of household expenditure, using appropriate participatory and ethnographic research methods, and with it a clearer picture of the burden on households and recognition of the resources, financial and in kind, that communities themselves already commit to tackling the epidemic.

Sources of funding	Budgeted amount
Donor governments	$2 billion
Government contributions to Global Fund (AIDS only)	$350 million
UN agencies	$547 million
World Bank grants/loans	$120 million
Foundations and major NGOs	$200 million
National governments of affected countries	$1 billion
Household spending	Unmeasurable

Figure 1: Estimates of how allocated spending on HIV/AIDS will be divided in 2005 [11]



Multilateral and bilateral agencies

Between 2000 and 2002, the largest multilateral donor was the International Development Association of the World Bank, which spent $237 million on HIV/AIDS programmes. Next came UNAIDS, spending $88 million, the EC spending $53 million and UNICEF spending $44 million.[11] The current top multilateral donors are the Global Fund, UNAIDS and the World Bank.

In the same period, donor governments worked with 140 recipient countries. In total 75% of all aid relating to HIV/AIDS was allocated to Africa.[12] In 2003 donor governments provided 61% of budgeted funding to HIV/AIDS in resource-poor settings, by bilateral and multilateral channels. Altogether, donor governments budgeted to give $2.6 billion to HIV/AIDS work through bilateral aid and $547 million through contributions to the Global Fund. This does not include contributions to multilateral institutions such as the World Bank or UN not earmarked for HIV/AIDS but still used for this purpose.[13]

The Global Fund to Fight AIDS, Tuberculosis and Malaria. The Global Fund was launched in June 2001 at United Nations General Assembly Special Session (UNGASS) on HIV/AIDS and is an independent public-private partnership. It aims to raise new resources to fight AIDS, tuberculosis and malaria and to give grants to support prevention, care and treatment programs to countries with the greatest need. By November 2003 the Global Fund had received pledges of $4.8 billion payable through 2008 and had received payments on theses pledges of $1.7 billion. Some 98% of pledges to the Global Fund have come from governments. The Bill and Melinda Gates Foundation has pledged nearly $100 million (accounting for

nearly all of the foundation and corporate giving). There are wide-ranging prevention and treatment programmes. More than half (58%) of first, second and third round grants were given in Africa.

UNAIDS – The Joint United Nations Programme on HIV/AIDS. UNAIDS coordinates the HIV/AIDS related activities of nine co-sponsors:

- UNICEF: United Nations Children's Fund
- UNDP: United Nations Development Programme
- UNFPA: United Nations Population Fund
- UNESCO: United Nations Educational, Scientific and Cultural Organization
- UNDCP: United Nations Drug Control Program
- WHO: World Health Organization
- The World Bank
- ILO: International Labour Organization
- WFP: World Food Programme

UNAIDS encourages global action and provides technical support, though most country-level programs are implemented not by UNAIDS but by its co-sponsors. Each co-sponsor collaborates with the UNAIDS Secretariat to develop unified two-year budgets and workplans. Budgets include both designated and non-designated funds. The UN's 2004–2005 total budget for HIV/AIDS stands at $1.34 billion.

The UNAIDS secretariat is funded by designated contributions from donor countries. In 2002 the USA provided 20% of the UNAIDS budget ($18million).[14]

UNAIDS recently presided over a donor agreement called 'The Three Ones', for marshalling national AIDS responses round three unifying principles:

- one agreed HIV/AIDS action framework that provides the basis for coordinating the work of all partners;
- one National AIDS Coordinating Authority, with a broad-based multi-sectoral mandate;
- one agreed country-level monitoring and evaluation system.

As a way of strengthening the latter provision, UNAIDS has developed a Country Response Information System (CRIS) software package, which will enable information to be shared that has been gathered across a range of initiatives and projects, using a variety of different indicators. The information can also be harmonised and synthesised at a range of different levels of analysis, whilst 'building on what is there already'. Gathering of data on funding trends is a component of this system that would enable more effective tracking of HIV/AIDS-related spending. CRIS is an ambitious venture, and it remains to be seen whether the capacity will exist to make it an effective tool for organisations engaged in advancing the global response to HIV/AIDS.

The World Bank. The World Bank is a co-sponsor of UNAIDS and trustee of the Global Fund. It awards grants, interest-free 'concessionary' loans and cut-rate loans to governments of highly affected countries, working with governments, NGOs, bilateral organisations and multilateral agencies. Since

1986 it has committed at least $2.2 billion to at least 110 HIV/AIDS related projects. Most loans are made through its Multi-Country AIDS Programs (MAPs) in sub-Saharan Africa. The Bank supports HIV/AIDS prevention, care, support and treatment, and the MAP initiative expects to donate $1 billion in grants and interest-free loans towards HIV/AIDS work.

UNAIDS has made some calculations based upon the grant value equivalent of WB loan distribution between what was loaned and the real dollar value of what would be repaid. It reported that the Bank has distributed the grant equivalent of $95 million in 2002 and $120 million in 2003. The Bank also has a Leadership Program on AIDS through which it supports efforts in AIDS research, and contributes to leadership and capacity building. It focuses on training journalists, assessing economic impacts of HIV/AIDS and dovetailing HIV/AIDS into its broader health initiatives.[15]

Top US and European donors

USAID. USAID administers most US government funding for international HIV/AIDS support. US contributions to the Global Fund are channelled through USAID. The USA budgeted funding on international HIV/AIDS for the fiscal year 2003 totalled $1.2 billion, excluding research. Priorities of the current administration are made clear by the $2.7 billion allocated in 2005 for international HIV/AIDS compared to $17.1 billion on domestic HIV/AIDS funding. International HIV/AIDS funding has, however, grown by 20% over the 2004 budget figure.

The Presidential Emergency Plan for AIDS Relief. The 2005 request to Congress for global HIV/AIDS funding is part of PEPFAR, the Presidential Emergency Plan for AID Relief[16]. Launched in January 2003 with an offer of $5 billion to continue to finance current programmes and nearly $10 billion in new funding, PEPFAR targets 14 priority countries by way of the Global Fund. PEPFAR is pledged to provide $15 billion over five years for care, treatment, prevention and research efforts related to HIV/AIDS, TB and Malaria. Its goals are to prevent seven million new infections, treat two million HIV-infected people and care for 10 million HIV-infected people and AIDS orphans.[17]

The strategy of PEPFAR has recently attracted fierce criticism arising from debates driven by conflict between political and fundamentalist religious ideologies and (on the other hand) evidence-based responses. Evidence overwhelmingly contradicts assumptions on which the PEPFAR strategy is based, raising serious questions for those who are trying to tackle the crisis.[18]

Funders Concerned About Aids (FCAA). FCAA comprises 51 top US philanthropic funders whose commitments for HIV/AIDS programmes in 2002 totalled $292.6 million.[19] Top donors were:

- Bill and Melinda Gates Foundation
- Bristol-Myers Squibb Foundation
- Kaiser Family Foundation
- Ford Foundation
- Rockefeller Foundation
- United Nations Foundation
- Elizabether Glaser Pediatric AIDS Foundation

- Merck Co. Foundation
- Robert Wood Johnson Foundation
- Abbott Laboratories Fund

Most US donors specialise in health or HIV/AIDS concerns, whereas among European organisations only four declare a specific interest in HIV/AIDS.[20]

Top European donors

EuropeAID is the EC's principal development agency and is estimated to have spent over €80 million in 2003 on HIV/AIDS funding. The total estimated spending by European philanthropic donors on HIV/AIDS in developing countries was €28.4 million. Ten foundations accounted for €24.1 of this total. Self-financed activities by four NGOs accounted for an additional €59.2 million in 2002–2003. The European HIV/AIDS Funders Group has suggested that there is significant capacity among European foundations for increased spending on HIV/AIDS in developing countries.[21]

Leading European HIV/AIDS donors operating in developing countries are:

- Wellcome Trust
- Open Society Institute
- Panos London
- Fondation François-Xavier Bagnoud
- Bernard van Leer Foundation
- King Baudouin Foundation
- Hope HIV
- Health Foundation
- Fondazione Monte dei Paschi di Siena
- AVERT

No recent increase has been reported in funds pledged to HIV/AIDS activities among European donors. Four European NGOs that have made outstanding contributions to HIV/AIDS healthcare are:

- Médicins sans Frontières
- International Federation of the Red Cross and Red Crescent
- International HIV/AIDS Alliance
- Marie Stopes International

The international business community[22]

The international business community is a promising potential source of funding for ECD and HIV/AIDS initiatives, bearing in mind the impact of the pandemic on the economic productivity and spending power of populations. Whilst this notion may challenge current thinking among ECD healthworkers, which tends to hinge on the importance of improving children's lives in the present, it is felt by some that ECD interventions represent an investment for the future and that it might therefore make good business sense for the private sector to back health promotion initiatives for very young children.

Some companies that operate in highly affected areas support workplace prevention and education programs. Others also offer VCT (Voluntary Counselling and Testing) and treatment support. Pharmaceutical companies should play a key role as they produce drugs that can reduce the risk of mother-to-child transmission of HIV and prevent and treat opportunistic infections. Within the private sector grant making is often reported under

broad and non-standard categories so money dedicated to HIV/AIDS is difficult to track. More HIV/AIDS donations may be transacted than reports currently show.[23]

Major foundations

Bill and Melinda Gates Foundation. Established in 2000, the Foundation has an endowment of about $24 billion. Prevention of HIV/AIDS is its top global health priority. So far the Foundation has committed approx $500 million in multi-year HIV/AIDS grants, which includes $100 million to the Global Fund. In 2002 the Bill and Melinda Gates Foundation jointly convened the Global HIV Prevention Working Group with the Henry J. Kaiser Family Foundation.

The Ford Foundation. The FCAA has reported that in 2000 the Ford Foundation made grants of $89 million relating to human development and reproductive health, including grants with HIV/AIDS components. Around $7 million was specifically for global HIV/AIDS grant aid, mostly in Africa. By 2002, the amount had risen to $14 million. HIV/AIDS funding is typically channeled through the Foundation's Peace and Social Justice work and supports a wide variety of community mobilisation, advocacy, education and care programmes.

The Henry J. Kaiser Family Foundation. Major health issues including HIV/AIDS are a top priority of this California-based independent philanthropic foundation. It develops and runs its own policy and communications programs, providing facts, analyses and public education on HIV/AIDS to policy makers, media, community organisations and the general public. In 2000 it committed $27 million to HIV/AIDS policy and public education initiatives. An additional $16 million was added each year in 2001 and 2002.

The Rockefeller Foundation. The Rockefeller Foundation has been supporting HIV/AIDS research and prevention initiatives for more than a decade. It helped launch the International AIDS Vaccine Initiative in 1996, a new Partnership for Microbicides in 2002 and a Columbia University Programme to reduce mother-to-child transmission of HIV in 2003. The FCAA reports that in 2001 the foundation gave $5 million in HIV/AIDS related grants and an additional $13 million in 2002.

United Nations Foundation. Most of this foundation's grants are made to UN agencies but it does give support externally, too. The FCAA reports that in 2001, UNF committed $6.8 million in grants and pledged $16 million in funding for a new HIV/AIDS program on youth. In 2002, the foundation awarded $12 million in grants for HIV/AIDS activities.

Open Society Institute, Soros Foundation. Based in New York, this operation is the hub around which Soros Foundations and organisations in more than 50 countries revolve. FCAA reports that it provided $5.5 million in HIV/AIDS related grants in 2001 and $7.8 million in 2002 – a 42% increase.

Clinton Foundation. It does not provide significant funding but it has played a visible

role in efforts to expand access to prevention and treatment of HIV/AIDS. It supported South Africa's expanded prevention and treatment plan in November 2003. It also negotiated with drug producers that resulted in substantial price discounts to South Africa. It established and convenes an HIV/AIDS treatment consortium of organisations that work in prevention, care and treatment. This is done through volunteer doctors, business leaders and educators.[24]

Major business networks and councils

The following list of major business networks, forums and councils from the Kaiser Family Foundation report (2003)[25] may be key areas where the profile of ECD and HIV/AIDS can be raised in an attempt to mobilise resources towards this area.

United Nations Global Compact <www.unglobalcompact.org>. A network orientated organisation that promotes corporate leadership around sustainable growth by bringing companies together with UN organisations, international labour organisations and other civil society groups.

International Business Leaders Forum (IBLF) <www.iblf.org>. Works at international level to promote responsible business practice and sustainable development.

Corporate Council on Africa (CCA) <www.africacncl.org>. A membership organisation of corporations dedicated to strengthening and facilitating economic and commercial relationships between African and American corporations, organisations and individuals.

Business Exchange on AIDS and Development (BEAD) An NGO which brings together representatives from multinational companies, universities, WHO, DfID and the NGO sector.

Pharmaceutical companies

The Kaiser Family Foundation Report on Global Funding in Resource Poor Settings[26] provides a list of pharmaceutical companies indicating the types of philanthropic efforts being made by each. It is worth noting, however, that the effort being made to mitigate the impact of HIV/AIDS is minimal compared to the promotion of drug use at high financial cost and gain to the pharmaceutical companies themselves.

Oxfam, Save the Children and Voluntary Service Overseas challenged the pharmaceutical companies in a report called *Beyond Philanthropy: The pharmaceutical industry, corporate social responsibility and the developing world*.[27] The report suggests that once drugs are developed, most companies are not willing to ensure World Health Organisation standards of conduct.

Companies are not (says the report) willing to make efforts in the self-regulation of marketing and drug safety monitoring in countries where there are weak regulatory systems. The report also suggests that companies should have policies on access to treatment in developing countries,

which includes policies on pricing, patents, joint public private initiatives, research and development and the appropriate use of drugs.

As demonstrated below, activities of pharmaceutical companies tend towards philanthropic giving rather than corporate social responsibility programmes.

Abbott Laboratories. In 2000 Abbott established 'Step Forward' – a program to address the needs of AIDS OVCs, focusing on VCT, basic assistance and education. Abbott also offers rapid HIV testing kits and some cheap ARV (anti-retroviral) drugs.

Boehringer Ingelheim. In 2000, Boehringer Ingelheim started a program to distribute Nevirapine™ free of charge in five years in over 100 countries. Included in this are 63 programs to reduce mother-to-child transmission in 36 countries.

Bristol Myers Squibb. Bristol Myers Squibb's HIV/AIDS program is 'Secure the Future', which is a $115-million five-year initiative in Southern and West African countries. It supports capacity building of government and NGO providers, community education and outreach and medical research. It also funds HIV/AIDS medicine to some NGOs to support care and treatment.

GlaxoSmithKline. GlaxoSmithKline created 'Positive Action' in 1992 – a program of education, care and treatment and community support in 49 countries in Central and South America, Asia and Africa. It has since spent $55 million. 'Community Lessons, Global Learning' is a partnership between the International HIV/AIDS Alliance and Glaxo Wellcome's Positive Action programme and it aims to share lessons about responding to HIV/AIDS between communities, countries and continents. GlaxoSmithKline also offers preferential prices for ARV drugs to governments of poor countries.

Merck & Company. In 1998 Merck created the 'Enhancing Care Initiative'. In July 2000 it joined forces with the Republic of Botswana and the Gates Foundation to establish the 'African Comprehensive HIV/AIDS Partnership', a five-year commitment to improve HIV/AIDS prevention, care and treatment in the country. $100 million was contributed, 50% from each partner. Merck also offers two of its HIV/AIDS drugs at no profit in resource-poor countries. The FCAA reports that it has $11.4 million in both 2001 and 2002 for HIV/AIDS related grants.

Pfizer. Pfizer offers Diflucan™ to treat AIDS-related fungal infections at no charge to 50 countries identified by the UN as being the least developed and having the highest HIV prevalence. The FCAA reports that Pfizer provided $1.6 million in support in 2001 and an additional $2.5 million in 2002.

Viacom. Viacom is one of the world's largest media companies, and has teamed up with the Kaiser Family Foundation to develop KNNOW HIV/AIDS, a global public education initiative. The advertisement placement value for the first year of the campaign exceeds $120 million.

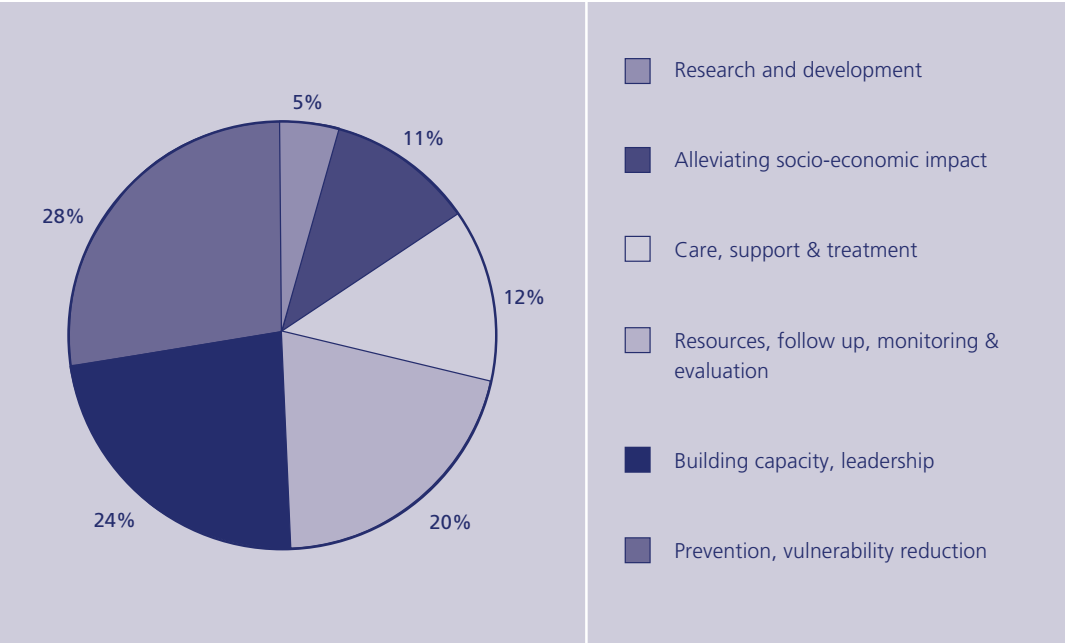
What the money is spent on

Very little information is available on the allocation of global HIV/AIDS funding. It is usually broken down under headings like prevention, care, orphan support and research. The estimates in the Kaiser Family Foundation report (see figure 2) are mostly based on more readily available information from the USA.[28]

Schwärtlander et al (2001) identified a core set of prevention and care services. Overall for 2003 they estimated that 53% is needed for prevention, 40% for care, support and treatment and 7% for orphans support. Africa may need more support for care, support and treatment and Asia may need more money for prevention. The proportions may change over time as more and more people gain access to anti-retroviral drugs (ARV) treatment.[30]

WHO's Commission on Macroeconomics and Health has estimated that $13.6 and $15.4 billion should be spent on prevention and care (including strengthening infrastructure) in 83 selected countries by 2007. This should rise to between $21 and $25 billion by 2015. The next priority should be ARV and other care and support services. By 2015 there should be an equal amount of resources going to prevention and ARV, the rest going to care and support.[31]

Figure 2: Budget for HIV/AIDS activities of UNAIDS co-sponsors by activity area, 2004-2005[29]



Prevention

Activities classified under prevention include:

- voluntary counselling and testing
- prevention of mother-to-child transmission
- improving blood safety
- prevention and care of STDs
- avoiding occupational exposure among health workers
- youth interventions
- public-private partnerships
- behaviour change awareness for young and other vulnerable groups
- preventing transmission through injection drug use.

In 2001 prevention activities represented over a third (39%) of funding distribution. UNAIDS suggest that this will remain steady through the next few years until 2007.[32] Even so, another UNAIDS-sponsored report has estimated that the actual amount spent on prevention in resource-poor countries in 2001 was around $800 million[33] – far short of current UNAIDS assessments of the amount distributed. Another report published by the Gates and Kaiser Family Foundations estimated spending on prevention in 2002 at $1.9 billion, a figure still well below the level suggested by UNAIDS. Applying the UNAIDS yardstick, total funding for prevention should increase to $6.6 billion in 2007.[34]

Care and treatment

Care and treatment activities include:

- palliative care
- HIV testing
- treatment and prophylaxis for opportunistic infections
- ARV therapy.

UNAIDS estimates suggest that the treatment of opportunistic infections accounted for 25% of annual funding requirements for HIV/AIDS care in resource-poor countries in 2001. They predict this share is likely to decrease to 8% of total resource needs by 2007.[35] Funding requirements for ARV therapy stood at 14% of needs in 2001 but the figure is expected to raise to 25% of total needs by 2007, as the number of people with access to ARV increases and the cost of delivering the drugs decreases. It remains noteworthy that the number of people still in need of drugs remains low. Improved access to ARV and the resulting improvements in health will also lead to decreased spending on opportunistic infections.

The increased support for access to HIV care and treatment, especially ARV, is an outcome of increased spending by public and private donors, governments of affected countries and concessionary pricing and donations from pharmaceuticals. This upward trend is likely to persist over the next few years. USAID has 25 care and treatment projects in 14 countries and in 2001 and 2002 devoted around 12% of its global funding money to care and treatment. It reports that: "For 2004 and beyond, care and treatment are expected to play an increasingly important role in US strategy on global HIV/AIDS." The WHO 3x5 initiative aims to get 3 million people on treatment by 2005.

Orphan support

Funders have recently begun to look into ways to meet the needs of orphans and other children made vulnerable by HIV and AIDS. DfID for example, has designated £150 million over the next three years to this area (from a total HIV/AIDS budget of 1.5 billion) and intends to support national efforts to achieve the ambitious target of setting National Plans in place by 2005 to meet the needs of orphans and vulnerable children (OVC).[36] The latest *Children on the Brink* 2004 report shows that currently there are only 17 countries with generalised epidemics which currently have a national OVC policy to guide strategic decision making and resource allocation. UNAIDS estimates that addressing the needs of these groups is expected to require an additional $900 million by 2007.[38]

Research

Research costs are not usually included in analyses of global spending on HIV/AIDS. Many governments do not distinguish between HIV/AIDS research and other biomedical and behavioural research spending. An exception is the US National Institute of Health, which is the world's largest funder of research. NIH reports a budget of $2.6 billion for HIV/AIDS related research in 2003. $252 million of this supports international research. Funding for international HIV/AIDS research increased from $160 million in 2001 to $275 in 2004. Excluded from this is the share of the US contribution to the Global Fund which passed through NIH in 2003 and was $99.3 million.

Where should new or reallocated money be spent?

Early analyses of the amount of funding needed to address HIV/AIDS came to around $7 to $10 billion per year. Later analyses increased that amount and it is now an estimated $14.9 billion per year by 2007. WHO's CMH study set out a 2007 target for extra spending of $12.6 billion to $15.4 billion.[39]

The 2004 UNAIDS report on global trends in HIV/AIDS goes even further. It estimates the financing needed to combat the epidemic at up to $20 billion by 2007 for prevention and care in low-income and middle-income countries. This would provide ARV therapy to over 6 million people (4 million of them in sub-Saharan Africa), support for 22 million orphans, VCT (Voluntary Counselling and Testing) for 100 million adults, school-based AIDS education for 900 million students and peer counselling services for 60 million young people not in school.[40]

Demands for more spending on HIV/AIDS are often made, and there is much activity and advocacy taking place around the need to put more global resources into HIV/AIDS. However, this debate takes place within an arena where already there is little indication of the effectiveness of current spending. The negative impact of increasing HIV/AIDS funding also needs to be considered. In Europe, recent economic conditions mean that there have

been serious constraints on available funding, meaning there is a risk that money is directed towards HIV/AIDS at the expense of other priorities.[41]

The Panos Institute report *Missing the Message* takes a critical look at the successes and failures of the last 20 years of the global response to HIV/AIDS. "Past successes have been characterised not only by strong national leadership but also by open public debate. Ownership and participation are vital. What works is when the energy, anger and mobilisation of civil society have been at the forefront of our responses."[42] *Missing the Message* also suggests that funding allocations need to be more strategic and consultative. When donors have to prove the impact they are having, it leads to the demonstration of quick results rather than addressing the long-term and complex problems that AIDS presents. Impact is not so simple to measure. It begs the question as to why people are so vocal in demanding more funds without demands for a deeper analysis around why and for what purpose?

Donor priorities

Responses which have shown most success in combating HIV/AIDS are those that have come from within communities and which are complex and long-term responses. Panos argues that it is these types of responses that donors find it difficult to support and to evaluate.[43] There are obvious questions to be asked around current funding allocations. Are current prevention approaches working and does prevention need more funding in the current vein? Would a more holistic approach to prevention be more appropriate and effective? Is more funding needed for care and support? How can affected people be better cared for and supported? What funding is aimed at reducing stigma and discrimination? Do particular groups need different approaches and ways of support? What can be done to identify the needs of different groups and how can they be addressed?

Is there a need for more ARV drugs and access to drugs to treat opportunistic infections? The cost of treatment for people with AIDS is slowing coming down in price although it easily surpasses the health budgets of most developing countries.[44] Is it possible to extend treatment in a responsible manner within existing healthcare systems in developing country contexts?

There are also emerging concerns over integrating prevention and treatment approaches. With the scaling-up of treatment through WHO's 3x5 initiative and the promotion of ARV therapy by pharmaceutical companies, it is important that improving access to treatment does not detract from prevention efforts. A forthcoming report on HIV/AIDS communication and the scaling up of treatment argues that it is necessary to link prevention, testing and treatment. in ways that allow the voices of those most affected by the epidemic to be heard.[45] This issue was also raised in various forums at the Fourth International Conference on HIV/AIDS convened in Bangkok in June 2004. With ARV treatment being raised high on the agenda, there

is a danger that the integration of prevention, treatment and care could be overlooked.[46] Another key issue is whether we need to argue for a more integrated and holistic approach to HIV/AIDS spending. Would the same amount of funding going into improved nutrition, health services, education and income generation have an impact on the epidemic? If this holistic approach is more appropriate, would such a redirection of HIV/AIDS spending have a greater impact on the lives of very young children in HIV/AIDS-affected communities?

Chapter 2: Early childhood development concerns funded today

Main areas of HIV/AIDS spending

Major categories currently used to classify initiatives that receive funding are:

- prevention
- care and treatment
- social and legal assistance
- mainstreaming testing, counselling and treatment activities into broader fields of education, rural development, agriculture and transport
- research.

There is some potential for the needs of very young children to be addressed under all or any of these categories, yet the meagre attention those needs actually attract suggests a lack of awareness of the immediate situation of very young children in HIV/AIDS-affected communities. It is also worth noting that working with very young children in HIV/AIDS-affected communities can be difficult. Such children 'invisible' as they are not in institutions but in families at home and hence difficult to identify and reach. These children also take more effort to communicate with, so it is easy to overlook their needs, focusing instead on older children who are easier to interact with.[47]

The two main areas within the category of early childhood development which HIV/AIDS money is currently reaching are prevention of mother-to-child transmission (PMTCT) and care for orphans and vulnerable children (OVC).

Prevention of mother-to-child transmission

PMTCT normally comes under the general funding category of prevention and has been much promoted in an attempt to reduce the rate of HIV infection, not least because it has mostly been achievable through existing maternal health care systems. Yet there are no clear statistics showing how much money is spent annually on PMTCT and the established approach has been inadequate in many ways, tending to focus on a one-off medical intervention to prevent new-born babies from acquiring HIV infection. Fresh interventions and behaviour-change information come later, to prevent transmission of HIV to babies through breastfeeding.

A more focused and holistic approach could be devised to caring for young babies affected by HIV/AIDS. It would mean paying greater attention to the health and welfare of the mother in relation to her own HIV status, by providing her with adequate treatment, care and support, and to the interaction between an HIV-positive mother and her baby by means of mother-and-child community support networks. It would also mean providing sustainable care for the child and support to

families and communities. Opportunities exist to extend the provision of family care in the direction of this more interactive and sustained approach but have so far been largely missed.

Orphans and vulnerable children

Care and support provision in the funding category of orphans and vulnerable children could similarly provide timely opportunities to address the needs of very young children in HIV/AIDS-affected communities, providing that the situation of these young children is given sufficient exposure. A stock response has been to place orphans and vulnerable children in institutional care. Though such care may be the only option in many cases, it is now understood that is not the most effective way of meeting the needs of very young children.

Initiatives that take more holistic approaches are rare in front-line responses to HIV/AIDS, but there are some valuable examples of work in progress. The Bernard van Leer Foundation has pioneered many new ways of working at community level to address the needs of very young children affected by HIV/AIDS.[48] Different ways of meeting the needs of very young children have also been addressed by REPSSI (Regional Psychosocial Support Initiative), which provides technical support to one of its partners called the Salvation Army Masiye Camp. The project runs 'Lifeskills' camps for orphans and vulnerable children under the age of 5 years affected by HIV/AIDS. This is a new initiative that started in mid-2003. While at the camp, children are engaged through counselling processes that mainly employ game-playing and role-play skills. There is a deliberate effort to bring carers to a better understanding of children in their care, and particularly to provide care and support to children infected with HIV/AIDS.

An opportunity to increase funding intended to benefit very young orphans affected by HIV/AIDS has arisen in the form of the new UNICEF (2004) *Children on the Brink*[49] report, which specifically mentions the special vulnerabilities of the younger age-group. Moreover, UNICEF's Framework for the Protection, Care and Support of Orphans and Vulnerable Children living in a World with HIV and AIDS (2004)[40] highlights the fact that few resources are reaching families and children who are at the front line of responses to HIV/AIDS. The framework identifies concerns requiring urgent action, including priority support for orphans and vulnerable children and their families in national policies and plans of countries affected by HIV and AIDS. This priority applies as much to very young children as to older children, and the UNICEF findings could be cited to justify any new intervention in this area.

Top players in the HIV/AIDS-ECD arena

Several early childhood development initiatives feature efforts to work with the 0–8 age group in HIV/AIDS affected areas, and form significant exceptions to the general inadequacy of responses to this group's needs. Such efforts

could provide channels by way of which funding could be redirected, evaluations shared and lessons learned.

UNESCO. UNESCO's activities in relation to young children and HIV/AIDS hinge on building partnerships for documenting issues and initiatives affecting young children in the context of HIV/AIDS, by prompting information-sharing and debate by way of e-mail forums and website features.[51] Multimedia materials and modules are being developed and support offered through networking and workshops set up to air issues surrounding young children and HIV/AIDS.

UNICEF.[52] UNICEF has a constitutional interest in early childhood development, reporting on the condition of very young children in developing countries in *The State of the World's Children* annual report and the biannual *Children on the Brink*. UNICEF has also played an intermediary role by publishing reports on HIV/AIDS-ECD and setting up working groups and conferences.

Working Group on Early Childhood Development.[53] The Working Group on Early Childhood Development was created in 1997 with UNICEF as lead agency. Closely associated with the group is the Association for the Development of Education in Africa.[54] It is guided by a consultative group of representatives of African countries that have demonstrated interest in ECD and of international agencies and sub-regional organisations with a firm commitment to ECD. Its goal is to support national governments in Africa that commit to and invest in ECD and it encourages countries to develop strategies to help young children affected by HIV/AIDS.

Consultative Group on Early Childhood Care and Development.[55] The Early Child Development Group or the Consultative Group on Early Childhood Care and Development (CGECCD) is an international inter-agency group dedicated to improving the condition of young children at risk. It includes a broad-based network of agencies and regional delegates that represent (or are involved in developing) broader regional networks of early childhood planners, practitioners, researchers and policy makers.

Early Childhood Development Network for Africa. The Early Childhood Development Network for Africa (ECDNA), created in 1994, is a group of professionals attached to young child development programmes in Africa who are interested in furthering holistic approaches to child development, survival, protection and education. It works on information and communication strategies, documentation, case studies, training and action research programmes. It also contributes to policy dialogue and to the development of integrated early childhood development policies and programmes. It recently set up an initiative called 'Young Child and HIV-AIDS' to try to meet the needs of orphans and vulnerable children in Africa.

The Bernard van Leer Foundation. Over many years, the Bernard van Leer Foundation has focused its efforts on ECD, with a view to improve the chances of young children living in disadvantaged situations. In 2002 it completed several years' work on a 'Young Children and HIV/AIDS' initiative and is now supporting HIV/AIDS initiatives in this area. The initiative will be a bridge between communities of knowledge and action on ECD and HIV/AIDS, assessing how ECD programmes are responding to the HIV/AIDS challenge and bringing ECD concerns to the attention of HIV/AIDS organisations and programmes.[58]

World Bank Early Childhood Development Team.[57] The World Bank ECD Programme and Website is a collaborative effort of the Bank itself, the Consultative Group (CGECCD) and the Organisation of American States (OAS). The website <www.worldbank.org/children> offers a useful HIV/AIDS section, along with documents, reports and links to other sites with a regional focus on Africa, the Caribbean and Latin America.

Chapter 3: Gaps in funding provision for HIV/AIDS-ECD

Global overview of ECD and HIV/AIDS funding

Most ECD and HIV/AIDS work that is carried out today comes under the auspices of smaller local NGOs and larger international organisations such as the Bernard van Leer Foundation or the Consultative Group on Early Childhood Development. UNICEF and UNESCO are starting to engage with this area of concern as it becomes more evident that there is a gap in programming and that the needs of very young children are being overlooked.

A rough estimate from UNESCO suggests that despite its prominent ECD and HIV/AIDS programme, less than 5% of HIV/AIDS money is being targeted towards very young children.[58] The World Bank, too, is seeking to engage with very young children in the belief that the quality of their lives will affect the future productivity of communities and nations. They are seen as an investment in the future. In practice, however, it seems that World Bank funds are not being directed to any significant extent towards ECD-HIV/AIDS.

Two examples stand out among the many instances where the situation of very young children in HIV/AIDS-affected communities is passed over by major funding agencies. Under PEPFAR, the first recipients of grants in the category of supporting programs for orphans and vulnerable children are Habitat for Humanity, Opportunity International and Catholic Relief Services. It is unlikely that any or much of this money will be targeted at very young children, as to date none of these organisations appears to be working specifically with this age group. The *World Bank Directory of HIV/AIDS Interventions in Africa,* part of the Bank's Early Childhood Development Program 'Helping the Children' summarises data from 1986–2001 for freestanding HIV/AIDS projects and projects with HIV/AIDS components. It highlights examples of initiatives to improve the lives of young children made vulnerable by HIV/AIDS. Yet only one out of 42 active projects cited (namely Eritrea's Integrated Early Childhood Development Program), is explicitly aimed at improving the situation of children under 6.

Gaps and opportunities

The following section describes where the gaps in provision are most evident. In these areas lie promising opportunities to pursue research and advocacy aimed at improving the situation of very young children affected by HIV/AIDS.

- Few efforts are made to probe impacts of HIV and AIDS on very young children in the context of mass poverty and high levels of infection. Only minor attention is given to how the pandemic may affect the personal and social lives of very young children in the present or future.
- There is little 'hard' evidence to show if ECD

interventions in the South reach children experiencing poverty in childhood and/or whether they are effective in mitigating poverty in the long term.[59] If this same uncertainty applies to young children in HIV/AIDS-affected communities, the relevance and necessity of ECD interventions in the context of HIV/AIDS needs to be probed and based on sounder evidence.

- Little funding or support goes to families where there are one or more care-givers for very young children living with HIV/AIDS. Although orphans and vulnerable children are now a significant focus of international concern, benefits of this concern rarely reach the youngest family members who live with ill and exhausted care-givers.
- More investigation is needed into the lack of primary care-giving to very young children. Strengthening families and communities is one way of improving child health, nutrition, development and the like. But if it is undermined by the impact of HIV/AIDS, what can be tried instead?
- Little funding or support goes to help older care-givers such as grandparents. A recent HelpAge International Report highlighted the struggles that older people face when their sons and daughters die and they have to bring up very young children.[60] This situation is likely to worsen as the number of adult deaths from AIDS and the subsequent number of orphans reaches a peak over the next few years.[61]
- There is little exploration and work done in the area of nutrition and nutritional support. This is a critical need considering the role of good nutrition in protecting the immune system. Support provisions need to go beyond nutritional supplements to ensuring baseline food security.
- Support is patchy for mother and child health initiatives in HIV/AIDS-affected areas. Many women of reproductive age are infected and otherwise impacted by HIV and AIDS. One of the impacts is the increase in acute childhood illnesses owing to a reduction of care-giving activities. Little is being done to devise strategies to protect, support and sustain child development in this context. The role of the father also needs exploring as it is unusual for men to take young children to mother and child health clinics.
- PMTCT initiatives that focus on one-off medical interventions are important but are limited in the sense that they do not take into account the support needs of the mother and child once the baby has been delivered and has received ARV therapy. These interventions could be broadened with a view to adopting a more holistic approach that supports both mother and child, whatever their HIV status, in the longer term.

Chapter 4: What would it take to attract more money to ECD-HIV/AIDS efforts?

An initial step towards redirecting a fairer share of HIV/AIDS funding towards ECD and HIV/AIDS initiatives is to trace the channels through which funding presently flows and to ask how current HIV/AIDS money is being spent and whether it is being spent effectively. Is there a more effective way of spending global HIV/AIDS funding and – if so – how should this funding relate to very young children? Another key element is ensuring that spending is (as far as possible) based on objective evidence, rather than political bias. Redirecting funds towards ECD and HIV/AIDS will take concerted effort on the part of many different people, from the grassroots up to the corridors of power.

Advocacy is needed on behalf of very young children to get them included in the formulation of national and international policies. Advocacy should extend beyond influencing policy to include social mobilisation and action to change the ways that very young children are cared for in HIV/AIDS-affected societies. Good communications will be vital to advancing new agendas and practices.[62]

There should be rigorous new research and more effective evaluation of current ECD and HIV/AIDS initiatives. Original research needs to be carried out on which a solid case can be built for giving very young children special attention in the context of HIV/AIDS. It is vital that the research agenda is informed by real responses to the pandemic and that research priorities are set by adults and children most affected by HIV and AIDS. Current responses to meeting the needs of very young children in affected communities need to be carefully evaluated and the results communicated and shared.

A range of recent work has highlighted the importance of networking to optimise the impact of research on practice and policy. An ODI investigation into bridging the gap between research and development policy has shown that a key factor is attention to the dynamics of interplay between researchers and policy makers.[63] This work has also highlighted the fact that political factors have been an important influence on policy makers, and that assumptions that policy is based on current research and is 'evidence based' are questionable.

The 'Pelican Initiative', a joint initiative of the European Centre for Development Policy Management, International Development Research Council and Exchange is aiming to strengthen evidence-based learning and communication. An initial workshop with a range of European donors explored what constitutes evidence and how learning from evaluation and research can be maximised for social change and improvement of development practice.[64]

A recent review of research strategy published by DfID in the UK also highlighted the need to make sure that research is networked from the outset. If the research agenda is informed by policy challenges and findings, results are more likely to have a direct impact on the agendas of policy makers.[65]

Research into specific topics of concern

Some areas of research which are currently unexplored are:

- What is the impact of HIV and AIDS on very young children living in affected communities and in households where care-givers are infected by HIV and AIDS?
- How effective are ECD interventions in HIV/AIDS-affected communities?
- What is the impact of HIV and AIDS on interaction between mother and child?
- What is the impact (on grandparents and on young children) of a grandparent as the primary caregiver?
- What are the best ways of providing support to young children and their caregivers in HIV/AIDS affected communities?
- How and to what extent can nutritional support play a role in improving the lives of young children and families affected by HIV/AIDS?
- Which current health systems can best be utilised to support very young children and how can they be strengthened to do so?

Sharing experiences and ideas

International, national and local NGOs are starting to engage with the troubles that face very young children in HIV/AIDS affected communities. Whilst they will never be major donors in the field of HIV/AIDS, their scope to influence the direction of the flow of funds is critical. Sharing experiences and ideas is a key to identifying more effective ways to spend HIV/AIDS money and should also prove a potent way of demonstrating what works and does not work, if more such funding is directed towards ECD initiatives as a result.

A Panos/WHO report *HIV/AIDS Communication and Treatment Scale-Up* argues that a global coordination mechanism is needed to ensure systematic dissemination of best practice in dealing with HIV/AIDS communication. The report warns that lack of such a mechanism has wasted opportunities for sharing lessons. It notes the importance of agenda setting and open society values and the central relevance of the views of people most affected.[66] The report then goes on to identify social mapping activities currently underway and ways of mobilising resources and building evidence.[67]

Exchange, a networking and learning programme on health communication for development funded by DfID, has been engaged in mapping and facilitating the sharing of good practice in several areas of health communication. Joint staffing with PANOS and the Communication Initiative has been proposed as a way to fuse together what works best in HIV/AIDS communication and related advocacy and in the sharing of lessons learned.[68]

The Bernard van Leer Foundation, in association with local NGOs, has already carried out a series of projects that involve work with very young children affected by HIV/AIDS. The work is in its early stages with several organisations in sub-Saharan Africa taking the lead. The resulting experiences, framed as case studies, could be drawn upon by others aiming to work in the field, including organisations and communities in other developing countries of the world seeking a South-South engagement.

Advocacy

Advocacy is about building a convincing case and getting it across to people who are in a position to influence, formulate or implement policy and the decision-making process.'

(WHO, Promoting Rational Drug Use in Communities)

The case for supporting very young children in communities affected by HIV/AIDS needs to be based on sound research carried out in areas like those noted above and on evaluations of existing interventions. Experience from developing-country projects and programmes can be drawn upon as evidence. A first step would be to identify local people and organisations in developing countries who can promote support for very young children in HIV/AIDS-affected communities, including access to local resources.

Working with these individuals and organisations to advocate more and better attention to the needs of very young children is a direct way of engaging in dialogue between community members, NGOs, donors and decision makers.

Supporting capacity development for advocacy is a key principle. There is a need to create spaces where people can express their views and voice their concerns. Advocacy needs to emerge at and from the grassroots level with community groups skilled in articulating their concerns.[69] Areas for advocacy should be identified by local people and organisations but could well include:[70]

- promoting a holistic view, including nutrition, food security, economic security, empowerment agendas and improvement of health systems;
- providing support to families affected by AIDS who have HIV-positive members caring for very young children;
- offering support to grandparents who care for very young children;
- offering legal and economic support to child-headed households so that children can stay with siblings and assert their land rights;
- offering legal support to children who are victims of violence;
- combating stigma and discrimination;
- advocating affordable, accessible ARV drugs for mothers to curb MTCT;
- urging priority treatment of opportunistic infections and ARV provision, as well as counselling and support group centres, for those who provide care to young children;

- pressing for redirection of HIV/AIDS spending so that community front-line responses are better supported.

Query and analysis of current HIV/AIDS global spending

Important benefits could arise from careful questioning and analysis of the ways in which all HIV/AIDS funding is distributed and spent. This process could be followed up by advocacy and communication around more targeted and effective ways of spending HIV/AIDS money. Critical questions include:

- What is the most appropriate and effective way of using HIV/AID funding?
- Might a more effective way of supporting people who are infected and affected by HIV/AIDS lie in a more holistic approach that considers nutrition, food security, access to health systems, economic security, psychosocial support, community support and the like?
- Would spending HIV/AIDS money on broader poverty reduction and empowerment agendas be more effective in combating the impact of HIV/AIDS? Would such an approach more consistent with supporting the youngest community members?
- Is it appropriate to reorient HIV/AIDS programming so that the needs of very young children, their caregivers and siblings are better met?

Conclusion

Despite a lack of clear data, it is evident that only a small and insignificant amount of funding for AIDS/HIV interventions reaches those working to support very young children in HIV/AIDS-affected communities. In order to redirect funding towards this area it is important to examine routes by which funding is presently distributed and to understand how and why money is spent on HIV and AIDS. Decisions on the distribution of funds are frequently based on political factors rather than on sound evidence from front-line responses in the field which have been informed by those people most directly affected by HIV and AIDS.

This lack of informed direction and the fact that attempts to address HIV and AIDS are falling far short of an urgent and effective response to the crisis, support arguments for a deeper exploration and challenging of current ways of spending HIV/AIDS funds. The UNAIDS CRIS framework promises to help improve tracking of funding for HIV/AIDS response measures, but it remains to be seen how effectively this scrutiny will work as an agent of constructive change and how soon it will provide a comprehensive picture.

In addition, it makes urgent sense to carry out research and undertake evaluations of current work in ECD and HIV/AIDS so that evidence can be effectively communicated within and across networks of practitioners, researchers and policy makers. Influencing strategic and policy-level decisions is vital to ensure that funding is directed in an influential manner and communicating research and learning to decision makers and donors is of great value in this process. Better knowledge sharing needs to be supplemented by social mobilization and action at grassroots level to reach and directly consult young children in neighbourhoods affected by HIV/AIDS.

In the current climate, it may be preferable to advocate the reallocation of more funds towards the categories of orphans and vulnerable children and prevention of mother-to-child transmission. However, this needs to be done within a context of questioning the success of current HIV/AIDS approaches. If very young children are receiving an insignificant portion of the available global funds for HIV and AIDS, a possible option would be to support long-term and community-directed responses that could include very young children as part of a whole.

As it is these kinds of responses that are most difficult for donors to support and evaluate, donors and decision makers must be encouraged to take a long-term view which is based on the realities of members of communities radically affected by AIDS/HIV and not constrained by rigid bureaucratic structures. Communities need to own the strategies they use in their response to HIV and AIDS and if very young children are to be better supported, communities should be enabled to shape their own ways of facing the future.

Abbreviations and acronyms

AIDS	*Acquired Immunodeficiency Syndrome*
ARV	*anti-retroviral drugs*
CGECCD	*Consultative Group on Early Childhood Care and Development*
CMH	*Commission on Macro-Economics and Health (WHO)*
DfID	*UK Department for International Development*
ECD	*early childhood development*
FCAA	*Funders Concerned About AIDS*
HIV	*Human Immunodeficiency Virus*
ILO	*International Labour Organization*
PMTCT	*prevention of mother-to-child transmission*
NGO	*non-governmental organisation*
NIH	*National Institute of Health (USA)*
PEPFAR	*Presidential Emergency Plan for AID Relief*
UNAIDS	*Joint United Nations Programme on HIV/AIDS*
UNDCP	*United Nations Drug Control Program*
UNDP	*United Nations Development Program*
UNESCO	*United Nations Educational, Scientific and Cultural Organization*
UNFPA	*United Nations Population Fund*
UNGASS	*United Nations General Assembly Special Session*
UNICEF	*United Nations Children's Fund*
VCT	*voluntary counselling and testing*
WHO	*World Health Organization*
WFP	*World Food Programme*

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About the Bernard van Leer Foundation
The Bernard van Leer Foundation, established in 1949, is based in the Netherlands. We actively engage in supporting early childhood development activities in around 40 countries. 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 vulnerable children younger than eight years old, growing up in socially and economically difficult circumstances. The objective is to enable young children to develop their innate potential to the full. Early childhood development is crucial to creating opportunities for children and to shaping the prospects of society as a whole.

We fulfil our mission through two interdependent strategies:

- Making grants and supporting programmes for culturally and contextually appropriate approaches to early childhood development;
- Sharing knowledge and expertise in early childhood development, with the aim of informing and influencing policy and practice.

The Foundation currently supports about 150 major projects for young children in both developing and industrialised countries. Projects are implemented by local actors which may be public, private or community-based organisations. Documenting, learning and communicating are integral to all that we do. We are committed to systematically sharing the rich variety of knowledge, know-how and lessons learned that emerge from the projects and networks we support. We facilitate and create a variety of products for different audiences about work in the field of early childhood development.

Information on the series and sub-series
Working Papers in Early Childhood Development is a 'work in progress' series that presents relevant findings and reflection on issues relating to early childhood care and development. The series acts primarily as a forum for the exchange of ideas, often arising out of field work, evaluations and training experiences.

The purpose of the *Young children and HIV/AIDS sub-series* is to share information, ideas and emerging lessons with readers who are concerned with young children affected by HIV/AIDS. As 'think pieces' we hope these papers will evoke responses and lead to further information sharing from among the readership.