From words to action
Support for young children challenged by poverty and AIDS
Promoting dialogue, debate and change
Acknowledgements

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For more information, contact:
Panos London
9 White Lion Street
London N1 9PD
United Kingdom

tel +44 (0)20 7278 1111
fax +44 (0)20 7278 0345

info@panos.org.uk
www.panos.org.uk

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Children are neglected when it comes to the response to AIDS and many miss out on support and access to public services.

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Introduction

This paper draws on the voices and experiences of people living in communities affected by poverty and HIV and AIDS as they attempt to provide care and support for children. In recent years, a consensus has developed among international NGOs and UN agencies working to support children affected by HIV and AIDS, with general agreement around key principles and priorities. There is also increasing recognition that investment in children’s early years of life gives the greatest returns. Yet far too little has been done to put principles into practice and there is an urgent need for concerted government action. Although there has recently been more focus on how HIV and AIDS affect young people, the issue of children affected by AIDS is still relatively neglected, and where very young children are concerned, their invisibility is striking.

This report, the first in a series, highlights some of the policy challenges facing the people and organisations responsible for putting plans and strategies to address the impact of HIV and AIDS on children in their early years into practice. There must be more effective action on young children and HIV and AIDS and continued public and policy debate to address barriers to progress.

Key points

- More effective ways of channelling resources to poor communities and families without undermining their existing support strategies need to be identified and scaled up.
- Universal access to essential services and livelihoods needs to be realised as a necessary foundation for family and community initiatives to support children.
- National plans and strategies for early childhood development need to be integrated with national AIDS strategies and broader national development plans, and fully resourced and implemented by governments and international donors.
- The specific needs of young children must be addressed as an essential part of broader action on HIV and AIDS.
- Civil society organisations need to promote public debate on effective action for children affected by HIV and AIDS, and monitor implementation of plans to hold governments to account.
- Efforts to promote children’s rights need to engage communities in addressing local cultural norms and practices but also need to address broader social and economic rights.
- Stigma and discrimination need to be addressed effectively to allow open discussion and collaborative action on HIV and AIDS.

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1 Many of the examples are drawn from research and interviews conducted for a book by Anthony Swift and Stan Maher in South Africa. The book is part of a wider Panos communications initiative to generate greater public and policy debate and effective action to support children affected by HIV and AIDS worldwide, supported by the Bernard van Leer Foundation. Throughout the second half of 2008 the Joint Learning Initiative on Children and HIV/AIDS (JLICA) and the Inter-Agency Task Team on Children and HIV and AIDS are producing a range of reports that review the most recent research and evidence. Here we aim to highlight practical challenges emerging from the specific experience in South Africa, to encourage broader public and policy debate


Children are absent from the world response to the AIDS pandemic. Less than 10% of the world’s children who have been orphaned or made vulnerable by AIDS receive public support or services. Ann Veneman, UNICEF Executive Director
An effective response to the needs of young children affected by HIV and AIDS should be a cornerstone of the wider response that is urgently needed.

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In many ways the response to HIV and AIDS in young children is a microcosm of the challenges for an effective response overall – there is a need to address the broader determinants of health, such as nutrition, water and sanitation, as well as the social barriers of stigma and discrimination, gender inequity and economic inequity. An effective response to children with HIV or AIDS is vital, but it could also be the cornerstone of the effective response that is urgently needed overall.

With consensus on key actions, why has progress been so slow?

The consensus among international organisations working to support children affected by HIV and AIDS was consolidated in 2004 with the publication of The framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS, which was reinforced through a range of other declarations and forums. Families and communities are acknowledged as the foundation of an effective response, while institutional care – aside from being relatively expensive – is judged as failing to meet the developmental and long-term needs of young children. Access by children affected by HIV and AIDS to a range of essential services is also considered vital. But action has been lacking.

What is actually happening to young children in the face of HIV and poverty?

‘In the middle of nowhere we came across this little boy carrying a two-year-old girl on his back. Both were dirty, dressed in little more than rags and malnourished – the girl severely so and near death. She was dressed in only a grubby vest. We asked the boy: “Who is looking after you?” He replied: “I am.” There were traces of earth around his sister’s mouth. In some areas people do feed earth to infants to provide some vitamins but it seemed he had been feeding her soil in an attempt to keep her alive. While we were talking, a well-dressed young woman with an infant on her back picked her way down the hillside. We asked whose children these were. A sister had gone to Durban to look for work and had left them with her. Her own child was well cared for. We asked her to accompany us to the hospital as the little girl’s life was in danger. When she said she had other things to do, we insisted. We were too late to save the girl but the boy survived and we are following up on him.’

Vicky S, project coordinator with a community-based early childhood development support organisation, tells of a roadside encounter with children in KwaZulu-Natal.

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4 Such as the Call to Action by the Coalition on Children Affected by AIDS and the Global Partners Forum on Children Affected by HIV and AIDS: www.jlica.org/ and www.unicef.org/aids/index_39782.html
Governments made commitments to implement national policies and strategies to realise a supportive environment for orphans and other vulnerable children as far back as the UN General Assembly Special Session on HIV and AIDS in 2001. Yet, while children and HIV and AIDS are now more integrated into national policy frameworks in 20 sub-Saharan countries, only 35 per cent of these had matched this commitment with budgetary resources in May 2006 (in 14 countries for which data were available). The lack of progress is even more apparent when we consider the situation of orphans and vulnerable children in terms of prevention and treatment – despite considerable progress over the last year:

- Fewer than one in five pregnant women gets antiretrovirals (ARVs) to prevent mother-to-child transmission.
- At most, only one in five children who need ARVs gets them.
- Children who have lost both parents are less likely to attend school.
- Fewer than one in three young people in many countries knows enough to protect themselves against HIV.

So why has there been so little progress in putting the various commitments and strategies into practice?

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7 UNICEF estimated a proportion of 1 in 10 in their 2007 stock-taking report based on 2005 figures, and in their 2008 report logged a 70% increase in numbers of children receiving treatment in 2006, in the absence of estimates of those needing treatment to calculate the precise ratio.
Families and communities under strain

‘Ubuntu is dead, AIDS has killed ubuntu. Everybody is busy with their own loneliness.’

Participant of therapy group
Katlehong, South Africa

With parents dying or moving away to find work, grandparents have stepped in to care for children. Sometimes, grandparents are frail and it is children who assume family responsibilities.

Communities have long been at the forefront of responding to HIV and AIDS, providing support and care for orphans and vulnerable children, even where government and external support has been minimal. More than 90 per cent of all children are cared for in communities and extended families, the latter increasingly headed by grandparents; spending by households is the largest single component of overall HIV and AIDS expenditure – and greater than official HIV funding.

Traditional help and reciprocity in poor communities in Africa, as in many parts of the ‘majority world’, have provided an essential source of support, ranging from food, money and childcare to advice and employment. Such everyday help blends both material and psychosocial support and is seen as an integral part of family and community life, rather than being a matter of charity.

The notion of ‘your child is my child’, for instance, reflects the collective nature of childrearing among many African extended families. Such help may be low-cost and flexible when compared to the external interventions of NGOs, and arguably just as effective, as the community is often best placed to target support to where it is most needed.

9 Urassa et al (1997) cited in Where the heart is, see note 2
10 S Wilkinson-Maposa, A Fowler, C Oliver-Evans and C F N Mulenga (2006) The poor philanthropist: how and why the poor help each other, University of Cape Town Graduate School of Business
But these informal coping mechanisms and the social relations they depend on are increasingly at breaking point, and it is often a case of ‘the very poor helping the destitute’. In many impoverished communities, the capacity of people to respond in socially caring ways has been severely eroded.

This has led to calls for support and resources to be channelled directly to families and communities to strengthen their existing coping mechanisms. There is a need for a continuous, locally appropriate, steady supply of resources so that communities can sustain their response and improve the wellbeing of their children. However, very few effective mechanisms for channelling resources to community-level organisations have been found, and there is an urgent need to identify and implement such mechanisms. At the same time, there is a very real concern that some external interventions can undermine local responses and actually make things worse. External organisations need to take on complementary roles, to really support community action and build the capacity of local organisations. Yet, communities often end up with a fraction of the money available, as it is absorbed by a host of intermediary organisations.

‘When [they] come, we sing, we dance, they take our picture, and they go back and show everyone how they are helping the poor black children. But then all they do is hijack our projects and count our children.’

Manager of a small community-based care and support programme commenting on the difficulties of working with large external organisations with their own targets and agendas

Community self-help or exploitation?

Both government and non-governmental initiatives to address HIV and early childhood development at the community level have tended to rely heavily on unpaid volunteers, but this can be double-edged. In one sense, mutual support is a tradition in many poor and rural communities. At the same time, the way of life that supported such traditions of reciprocity is fast being eroded by economic and political change that has made rich people richer and poor people poorer. Communities and neighbourhoods that are already stretched are being asked to find the time, resources and energy to address problems that are determined way beyond their immediate locality.

‘We used to do things because we wanted to out of love, but now we have changed and we make a business out of helping someone. These days, money changes the way you help each other.’

Respondent in a research study by Susan Wilkinson-Maposa

In such a context, when formal initiatives draw on local traditions of voluntarism and mutual support in the absence of either viable livelihoods or statutory assistance, there is a fine line between helping local people to do what they do better, and exploiting them.
People in communities affected by HIV and AIDS continue to put employment at the top of the list of things they need to help them deal with the impact of the epidemic. Jobs are an important foundation for livelihoods and providing employment opportunities may be the most effective way of ensuring that more resources reach those struggling with poverty. In South Africa, the government’s ‘expanded works programme’ aimed to employ people in labour-intensive work, such as 122,000 new jobs in home and community-based care and 19,800 in early childhood development (ECD) from 2003–2008. This initiative has to be placed in the context of the decimation of jobs under the neo-liberal growth, employment and redistribution (GEAR) economic policy implemented throughout the 1990s, when most new jobs created were predominantly in the informal sector.18

‘You sometimes get big organisations that have money and so could pay these people but they tend to exploit them… I think it is unfair.’

Therapy group facilitator
Johannesburg

But creating social sector jobs may be just as important in channelling resources to communities as the ameliorative action of development projects and programmes. Another effective way of channelling resources to households and communities most in need has been the provision of social protection grants or cash transfers as part of government social protection measures, and these are discussed in more detail below.
Although a range of grants and allowances is in place to support families, they require detailed documentation, which many families do not have.

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How can laws and policies create an enabling environment for support to children?

International organisations working to support children affected by HIV and AIDS are increasingly highlighting the need for all people to have access to essential services and for effective social support to be in place. In addition to medical priorities, such as the vital development of new paediatric formulations, there needs to be long-term support for poverty alleviation, community development and social security and a strengthening of the general health and education systems – in short, a comprehensive public health approach rather than a short-term ‘crisis’ response that only targets individual children living with HIV or AIDS. This welcome recognition of the need to tackle underlying vulnerability points to the need for a shift from an AIDS-targeted to an AIDS-sensitive approach that does not lose sight of the interaction between AIDS and other adversities.

The need for integrated essential services for all vulnerable children

The Third Global Partners Forum on Children Affected by HIV and AIDS in 2006 argued that countries need to develop social welfare systems with specific budget allocations for supporting children affected by HIV and AIDS. It recommended a package of essential services for orphans and vulnerable children, including civil registration of births and protective judicial systems, basic health and nutrition, water and sanitation, access to social services and social protection, and abolition of school fees and indirect education costs. It also argued that national plans should be integrated across all sectors and at all levels of operation, and that support for children affected by HIV and AIDS should be integrated into services that benefit all vulnerable children. Needs assessments should, however, be specific to each locality, to identify the ways such services can best address local vulnerabilities, working with and building upon existing community responses. Equally, there needs to be more effective decentralisation of decision-making and financial authority so that people affected by HIV have input into how resources are used.

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"The only way to guarantee a future for the poorest children and children affected by HIV and AIDS is to ensure equity in health, education and other services." 
Secretary of State for International Development
UK Department for International Development (DFID)

23 L Richter, G Foster and L Sherr (2006) Where the heart is, p33
24 Alex de Waal, personal communication
25 See note 22
Social protection grants

Cash transfers – in the form of grants and benefits – are an important component of providing sustained social protection and welfare. The 2006 Livingstone Intergovernmental Regional Conference called for costed, national social transfer plans to be integrated into national development plans within 2–3 years; and the Commission for Africa called for regular cash transfers of US$2 billion a year rising to US$5 or 6 billion annually by 2015.26 A 2004 study of child-centred transfer programmes in 15 countries found that they led to a reduction in child poverty. Evidence suggests that such grants do not need to be targeted at children affected by HIV and AIDS and their families and carers to have a positive impact on their wellbeing.27 Botswana, South Africa and Namibia had introduced child support grants and other benefits on a national scale by 2007, and in South Africa 7.1 million children under 14 living in poverty – 79 per cent of those eligible – were getting the child support grant by April 2006. This was a twentyfold increase since the year 2000 – a significant achievement.28 Such examples are more the exception than the rule, however, and many governments have made slow progress in developing comprehensive social support systems. Even where national policies and plans are in place, implementation is often lacking.

The challenges of policy integration and implementation – the case of South Africa

In a very frank interview in 2006, Marie-Louise Samuels, the Department of Education’s ECD national director, noted that in spite of a range of ‘beautiful policies’ on paper, ‘in many cases [this] hasn’t yet changed people’s experience at the grass roots’. She blamed the legacy of apartheid inequalities and the tendency to make policy public before resources were allocated: ‘There has been a tendency in the past for us to make public new policies before there was money on the table or even programmes drawn up for their implementation.’ Samuels also commented on people’s lack of awareness at community level of their entitlements and the need to build community awareness and demand for services.29

South Africa identified early childhood development as a national priority, and its impressive Integrated Plan for Early Childhood Development 2005–1030 aimed to co-ordinate the roles of the education, health and social development departments, weaving together the range of detailed policies that have a bearing on young children’s development in the context of HIV and AIDS. In practice, however, such integration has proved elusive, and despite considerable support at the policy level, practical action on the ground is lacking.31

South Africa also introduced child support grants, foster grants and pensions for the elderly – all of which have the potential to improve the welfare of young children in poor communities. However, a study conducted in 2007 found that many of these provisions were not being fully implemented. Child support grants have suffered from bureaucratic delays, and while school fees should be waived for those who cannot afford them, many people are not sufficiently aware of this to claim their entitlement. At the same time, only a small fraction of children who could benefit from attendance at ECD facilities can be accommodated at present; since ECD programmes are dependent on fees, children from poor families often cannot access them.32

27 See note 26
29 A Swift and S Maher (2008), forthcoming, see note 8
31 J Kvalsvig, M Chhagan and M Taylor (2007) Getting down to basics: principles and strategies for inclusion of children on antiretroviral treatment in the education system and support for other children affected by HIV and AIDS, UNICEF and University of KwaZulu-Natal
32 See note 31
Barriers to accessing government grants in South Africa

Many people in the poorest communities in South Africa continue to be frustrated by the cost and difficulty of acquiring the requisite identity documentation to access government services, including a range of grants and benefits on which millions of people depend for their survival. This includes the child support grant (a means-tested monthly grant per child up to the age of 14), the much more substantial foster care grant, and the state pension. Documentation is also needed to access key national health provisions such as antiretroviral treatment, or to apply for the waiving of school fees for poor families. Many families have either never had such documents or if they did, they have been lost. The deaths of primary carers and multiple placements of orphans have greatly contributed to the problem.

Pius Makhanya, a community activist, was still waiting for his pension two years after he applied for it. He had been made to report to the department several times only to be fobbed off with various excuses. For people living in poverty, and in all likelihood in debt, such delays are crippling. Each visit to a government department costs money they don’t have. Many eventually give up.

Endemic corruption by government officials is also an issue, something that led to the setting up of a special investigations unit in 2005. By 2007, 6,000 public servants were paying back an estimated 5 million rand, the proceeds of fraud, while still others were being investigated.33 The same study suggested that community workers, particularly ECD staff, needed to be given sufficient remuneration, including incentives such as benefits and opportunities. It was hopeful that the national ‘expanded works programme’ would go some way towards meeting this need. Ultimately, all services need to be extended through community-based care and support, with non-profit and community-based organisations supported to develop parent groups and other community initiatives to bring care and stimulation to vulnerable children – supported and monitored by professional staff and with referral systems in place.34

Strengthening health systems

It remains the case that few countries have adequate and functioning state social support and health systems. Many countries in sub-Saharan Africa face a human resource crisis, with health workers and other key personnel dying from AIDS, as well as absenteeism and the ‘brain drain’ of staff to Northern countries. At the same time, the health infrastructure in many countries is still failing to deliver key services such as prevention of mother-to-child transmission and access to ARVs, threatening two of the four priority actions to address HIV among young children. Equally, without the foundation of effective healthcare, poor people become even more vulnerable to contracting HIV, as well as other illnesses.

33 Extracts from A Swift and S Maher (2008), forthcoming, including citation of Social Cluster 2 Media briefing Parliament Cape Town, 15 February 2007
34 J Kvalsvig, M Chhagan and M Taylor (2007), see note 31
The specific needs of young children should not be neglected

A particular challenge relating to the impact of HIV infection on young children is the higher risk of neurological damage, developmental delays and lower cognitive performance compared with uninfected children. Many of these effects may be arrested or reversed following antiretroviral therapy (ART), and early treatment within the first few months of life can dramatically improve survival rates of children with HIV, but there may be residual difficulties, some of which will require special education facilities. The physiological effects of HIV include malnutrition, anaemia, and recurrent and chronic illness. Care-givers and service providers need to understand that ART can help to contain the damage wrought by infection, poverty, poor nutrition, stigma and the orphaning process, and for this to happen early identification and access to ART is vital.

As more children with HIV survive through infancy they will need support to come to terms with chronic illness, as well as possibilities for treatment and general psychosocial support related to living with HIV; a key part of this will be to build their confidence after lost early development opportunities. Yet, many of today’s generation of young children will not enjoy the crucial support of grandparents. Inevitably, ECD programmes will assume an increasingly important role in early childcare.

Why is there not more public and policy debate on action for children affected by AIDS?

The slow progress on action for children affected by AIDS in many countries points to a need for ongoing scrutiny by civil society, to hold governments to account. Human Rights Watch, commenting on the case of South Africa, criticised researchers and the media for turning a blind eye to service shortcomings: ‘The failure of government to address the problem of children affected by AIDS adequately is, however, little discussed in the media as it is in academic literature.’ In fact, there is remarkably little media and public discussion of AIDS in general throughout the African countries most affected by the pandemic, despite its enormous social impact. Breaking the silence and promoting public debate around AIDS remains a significant challenge, and will require greater efforts to support independent media and journalism, which are still weak in many countries.

Policy challenges

- There is a need to implement the essential services and social protection measures promised in national action plans on children and HIV and AIDS, and in many cases the actions of the different ministries involved need to be better integrated.
- There is a need for public and policy debate around action to support children affected by HIV and AIDS and ongoing monitoring of implementation to hold governments to account.
- ECD programmes seem set to play an increasingly important role and as such, need dedicated and sustained support.
The consensus on action to support children affected by HIV and AIDS outlined in the previous section has taken shape within a broad human rights framework that takes both the UN Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child as reference points. Core principles include considering the best interests of the child in any initiative, promoting children’s survival, protection and development, non-discrimination, and respect for children’s views. The latter includes recognition that children’s opinions should be given due weight and that they should be able to ‘participate in decisions that affect them’; General Comment 7 on implementing rights in early childhood makes a more detailed case for the effective involvement of young children being part of the consolidation of their relationships and agency in the social world.40

A report by the African Child Policy Forum argues that the notion that children have rights is no longer a contentious issue in Africa, even though progress on harmonising national legislation with child rights conventions is slow in many of the 19 Eastern and Southern African countries it surveyed. In practice, however, birth registration systems are underdeveloped and many laws to protect children from discrimination or violence remain unimplemented. Institutionalised mechanisms for child participation or hearing children’s voices and opinions are also underdeveloped.41

Involving children in the response and respecting children’s rights

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The main challenge for rights-based approaches is how they can be deployed in contexts where people’s understanding and beliefs do not neatly fit the rights language of international agencies or governments, and where there may be little institutional or legal infrastructure to ensure accountability. Situations in which adults’ rights are routinely compromised also make addressing children’s rights more difficult. Anthony Swift, commenting on the challenges of caring for children in the context of poverty and AIDS in Southern and Eastern Africa, has wryly noted that ‘if socially excluded people had their own aid organisation it might well be called “Save the adults so that we might have the chance to look after our own children”.’

This is not to deny the importance and non-negotiable character of children’s rights. In South Africa, for example, where there are high levels of violence and rape, many vulnerable children are in family and community care settings that leave them open to further sexual predation by both relatives and non-relatives. It is vital that the issue of violence against children is not avoided as a taboo subject, and more public debate and greater public scrutiny need to be encouraged to promote action to address it. At the same time, it is important to start where people are, with their existing beliefs and practices, and to work in a participatory way to engage them in determining solutions to the challenges facing children’s rights in any context. After all, any customs that may violate children’s rights will only change with the support and co-operation of the community and traditional leaders, who will need to be involved in building consensus for change and appropriate actions at the local level as well as mobilising for any legal changes.42

Love and discipline to protect children

To the west of Lesotho in the Free State, Joseph and Mavis, who are in their 70s, once had six children whom they assumed would care for them in their old age. Sadly, all but one have died of AIDS-related illnesses. Now they have just one daughter, who has a learning disability, and they are caring for 16 grandchildren and two great-grandchildren aged between 2 and 18. They have little to show for their lifetime of hard work. Until recently, they were all living on Joseph’s pension (700 rand – about US$89 a month) and what fruit and vegetables the couple manage to grow on their small plot. They show real affection for the children – particularly the two toddlers. ‘We like living with them,’ they say. They like the company and appreciate the children’s help with cooking, fetching water and other chores. Any tensions seem to be managed with good humour.

Their big worry was controlling the children for their safety’s sake in the context of a small township. How could an elderly couple keep tabs on so many youngsters? Joseph reached behind himself and produced a long horsewhip. ‘I use this,’ he said. ‘The trouble is that they come back from school now and threaten me with children’s rights. If I punish them with this they will send me to prison, they say.’43


43 Based on an extract from A Swift and S Maher (2008), forthcoming, see note 8
You can’t say children’s participation happens in some cultures but not in African culture… You have to say, these are people and they have been living like this and then ask yourself how do we begin to support them.

Tobello Masita
Diketso Eseng Dipuo Community Development Trust

In the case of Joseph and Mavis, we can see that their use of what some might see as excessive ‘discipline’ was linked to genuine fears for their grandchildren’s safety in the neighbourhood, in the absence of other means and resources for keeping the children safely occupied. This reliance on authority and discipline in insecure social settings is something that has been observed in poor communities elsewhere.44 Focusing on childrearing alone, without attempts to change the wider social and structural context, is unlikely to lead to sustainable change.

Turning to the question of involving children in the response, Tobello Masita, of Diketso Eseng Dipuo Community Development Trust (DEDI) in Bloemfontein, points to different cultural traditions of participation and says it is a mistake to think that African children do not already participate: ‘You can’t say children’s participation happens in some cultures but not in African culture. We had children’s participation but it had a different form. It was participation in the sense of taking part in what was going on – it was not about what came out of the child’s mouth but about what the child would do. If you want to bring in children’s participation in the children’s rights sense you have to respect the context in which this intervention has to be made. You have to say, these are people and they have been living like this and then ask yourself how do we begin to support them.’

A range of effective participatory approaches such as the International HIV/AIDS Alliance’s ‘Building blocks’ and other child-centred initiatives45 remind us that communities, including children, are usually already adapting to challenging situations and are more creative and ready to work for change than is often assumed46 (even though most participatory activities still do not involve young children).47 Beyond the immediate interactions of carers and children, however, it is important to look at the way notions of authority and discipline are sustained by wider patterns of social and economic power, as well as within particular institutions, such as schools and workplaces, and at the policy–legal level. Recognising the need to work at a number of different levels, practitioners at UNICEF developed a human-rights based approach that begins with local community beliefs and practices and builds from this starting point to engage successive groups of stakeholders, from the local community to national policy.48

**Policy challenges**

- Practical approaches to children’s rights that engage communities in addressing their cultural norms and practices need to be further developed and supported.

- National laws based on international child rights instruments need to be implemented to provide the enabling environment for such rights to be realised.

- Participatory approaches that support children’s right to expression and participation in decision-making need to be further developed and supported. More attention needs to be given to appropriate ways to involve young children.

- Violence and other forms of abuse against children need to be addressed as an urgent priority.

45 See Source Key list on child-centred approaches, available at: www.asksource.info/res_library/ecd.htm
47 G Lansdown (2005) *Can you hear me? The right of young children to participate in decisions affecting them*, Working Paper 36, the Hague, the Netherlands: the Bernard van Leer Foundation
48 Although this is no longer the UNICEF approach, it is a useful model for building on community initiatives. See N Ford, D Odallo and R Chorlton (2003) ‘Communication from a human rights perspective: responding to the HIV/AIDS pandemic in Eastern and Southern Africa’, *Journal of Health Communication*, vol 8, no 6, pp919–612
Stigma makes many people living with HIV reluctant to go for treatment.

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Stigma is a complex social process and may combine people’s fears of contagion, moral judgements about people’s behaviour, and the denial associated with difficult survival decisions. It can be found everywhere from everyday beliefs and actions, to institutional settings, to legal and economic frameworks, and societal attitudes around gender, illness and sexuality. Stigma and discrimination are major obstacles preventing effective HIV and AIDS responses; they make people less likely to participate in prevention activities, less likely to get tested for HIV, fearful of disclosing their status, postpone seeking care, and less likely to enrol for treatment, where it is available. Stigma may directly affect children in some of these ways, but for young children it also affects them indirectly, as it hampers adults and carers’ ability to address HIV and AIDS and live longer, thus being able to care for the children for longer.

Where stigma is strong, people will not talk freely about AIDS and open up the space to find ways to address it together. Such open discussion has been key to tackling HIV in successful responses. Evidence suggests that initiatives to tackle stigma and discrimination need to combine interventions in community and interpersonal settings with those in institutions such as schools and workplaces, together with changes in legal and policy frameworks. Caring for others with HIV can de-mystify the virus and promote greater understanding. In Zambia, a youth care-giver project was able to promote awareness about transmission risks, and promote family reconciliation and community discussions. In educational settings, it is important to tackle stigma through age-appropriate education, since children as young as 3–5 are already discriminating between HIV-positive children and others at pre-school. It is also important to approach the question of disclosure among young children as a process of gradual and progressive discussion rather than a single revelation, and to train and support care-givers to approach it in this way.

In communities where the combined impacts of poverty and HIV and AIDS have already stretched extended families to the point of collapse, people’s inability to help others and the ‘excessive’ demands of those needing care made upon others who are already stretched are both a source of deep shame and tension in contexts where reciprocity has been a way of life. This impossible situation of not being able to live up to local ethics of mutual help may play a bigger role in fuelling HIV stigma than has previously been realised – as people are confronted with terrible choices and react with denial. Without improvements in people’s broader social and economic situation, this will be difficult to address; thus, stigma provides us with yet another example of how support for children needs to be holistic and include action that stretches from local families and communities to policies and legal frameworks.
Keeping the promises: action on children and HIV and AIDS

It is encouraging that there is growing international recognition of the need to tackle the challenges facing children affected by HIV and AIDS, and the general principles and strategies that have been developed are welcome. Several governments have earmarked at least 10 per cent of their HIV and AIDS funding to services for children, including PEPFAR (the US President’s Emergency Plan for AIDS Relief) and the UK’s Department for International Development. The development of a range of core indicators by Unite for Children Unite against AIDS in 2005 to measure national-level progress also promises to make HIV responses more concretely accountable in future. Yet, few countries systematically collect information on early infant diagnosis or cotrimoxazole prophylaxis.

As we have seen, the stubborn realities of poverty and AIDS frequently prevent practical progress on the ground. At the same time, the specific needs of very young children may get even less attention in the face of the broader social challenges facing the Southern African region and other developing countries. Practical and policy challenges remain and it is vital that there is wide-ranging public and policy debate to address these challenges, hold authorities to account on implementation of their commitments, and ultimately enhance effective action to support young children affected by HIV and AIDS.
About Panos London

Inclusive
We believe that embracing the views of poor and marginalised people is essential for sustainable and effective development.

Taking part in dialogue and debate contributes to a healthy and vibrant society.

Empowering
We believe that poor and marginalised people should drive and shape the changes needed to improve their lives.

We enable people to share information and ideas, speak out and be heard.

Balanced
We believe people need accessible information reflecting a wide range of views.

This allows them to make informed choices about crucial issues that have an impact on their lives.

Diverse
We respect different views, value local knowledge and encourage a range of approaches in our work worldwide.

We believe that freedom of information and media diversity are essential for development.

Illuminating
We shed light on ignored, misrepresented or misunderstood development issues.

We believe that the views of poor and marginalised people give greater insight into their lives and offer unique perspectives on the challenges they face.

www.panos.org.uk
The voices in this paper speak of the forces that are eroding people’s capacity to care for young children affected by poverty, HIV and AIDS. Despite the efforts of many and a consensus among policymakers that strengthening families and communities is best, the difficulties people face are undermining attempts to provide effective support.

*From words to action* challenges policymakers and practitioners to look beyond agreements in principle and recognise that on the ground, policies are not always working. It urges them to remove barriers to progress and redouble their efforts to put support structures in place. Finally, it encourages them to listen to the experiences of children and communities affected by HIV and AIDS so that future debates and practical responses are informed by real needs.