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Supporting the educational needs of HIV-positive learners:

lessons from Namibia and Tanzania

with RAISON Namibia and TAMASHA Tanzania

EduSector
AIDS Response Trust

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This report was written by Peter Badcock-Walters, Director of the EduSector AIDS Response Trust (ESART), in collaboration with Jane Kvalsvig, Wendy Heard and Vicky Anning. It consolidates and analyses the findings of two country research studies, as well as a literature review and desk study, which can be accessed in full on the UNESCO website at http:// unesco.org/aids

Viv Ward and John Mendelsohn of Research and Information Services of Namibia (RAISON) were responsible for the country research study in Namibia, while Richard Mabala of Youth Participatory Development Centre (TAMASHA) was responsible for the equivalent study in Tanzania. Jane Kvalsvig and Peter Badcock-Walters wrote the literature review and desk study. The research instruments were designed by ESART and adapted in the field by both RAISON and TAMASHA.

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBO	Community-Based Organization
COS	Circles of Support
CSO	Civil Society Organization
ESART	EduSector AIDS Response Trust
ETSIP	Education & Training Sector Improvement Programme
FBO	Faith-Based Organization
HAMU	HIV and AIDS Management Unit
HIV	Human Immunodeficiency Virus
MoE	Ministry of Education
MoEVT	Ministry of Education and Vocational Training
MoHSS	Ministry of Health and Social Services
NGO	Non-Governmental Organization
OVC	Orphans and Vulnerable Children
PEP	Post-Exposure Prophylaxis
PLHIV	People Living with HIV
RACE	Regional AIDS Committee on Education
RAISON	Research and Information Services of Namibia
SCCS	School-Centred Care and Support
SRH	Sexual and Reproductive Health
TACAIDS	Tanzanian Commission on AIDS
TAMASHA	Youth Participatory Development Centre
TANOPHA	Tanzania Network of Organizations of People Living with HIV and AIDS
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
VCT	Voluntary Counselling and Testing

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Executive summary

There are an estimated 2 million children below the age of fifteen living with HIV worldwide. Nearly 90% of these are in sub-Saharan Africa. The increase in the number of children and young people living with HIV poses new challenges to the education sector. Given the increase in access to treatment across sub-Saharan Africa, the need to support HIV-positive learners at school will only gain in urgency and scale. However, in spite of this identified need, there has been little understanding of how the education sector should support this vulnerable group of learners in the region. To address this gap, UNESCO commissioned a review of best practice, as well as an exploratory study in two countries – Namibia and Tanzania. The aim was to identify the specific challenges faced by the education system in responding to the needs of HIV-positive learners and to develop a set of recommendations and guidelines about how best to support them.

The research process, including the review of best practice, was designed to establish answers to the following questions:

a) what barriers face HIV-positive learners in accessing education and staying at school?

b) what challenges are faced by teachers and schools in supporting HIV-positive learners?

c) how can HIV education programmes be adapted to suit the sexual and reproductive health (SRH) needs of HIV-positive learners?

d) how does the education sector need to adapt to meet the needs of HIV-positive learners?

Main findings

The review of best practices revealed that the families of HIV-positive children are likely to have been adversely affected by HIV and AIDS themselves, and so will be unable to offer strong support for the development of their children. With disproportionate numbers of HIV-positive children living in residential care, the school becomes an important adjunct to institutional care. The inclusion and care of HIV-positive children in schools is a key education sector priority. Education ministries have a role to play in making appropriate subsidies available to ensure the integration of HIV-positive learners in the school environment. School-based health education that is teacher-led and part of the curriculum has been shown to reduce the incidence of new infections.

Taken together, the country reports confirm that the educational needs of HIV-positive learners are not being met and that this failure may signal wider systemic problems in the education sector. The studies indicate that HIV and AIDS are exacerbating existing problems in education, and that the sector has considerable difficulty in effectively discharging its obligations to learners in general – and HIV-positive learners in particular.

Research confirmed that the home environment often is a profoundly complicating factor. In fact, one of the worst cases of abuse encountered by researchers was at the hands of a child's parents in Tanzania. Worryingly, foster parents and guardians of HIV-positive orphans often lack understanding and sympathy, and offer little emotional support. Indeed, very many children referred to their guardians rather than their parents, confirming the overlap between being HIV-positive and being orphaned.

The most striking research finding was the pervasive theme of stigma and discrimination. Every HIV-positive child interviewed in both Namibia and Tanzania cited personal and continuing experience of the negative consequences of disclosure, and emphasised greater safety in silence. These fears were the consequence of intolerant attitudes in the school and even the home, severe peer pressure and the absence of responsive measures or support from school staff and the education sector as a whole. Stigma was described as "more killing" than the disease itself, and levels of denial evident in the system "could be said to promote the spread of HIV". In short, stigma in both countries was said to be seriously affecting the national response to HIV and AIDS in every way.

In addition, poverty is cited as a limiting condition at almost every level of the learners' experience and is a key influence in the attitudes and actions of many parents. Poverty is linked to school drop-out and hunger, the latter posing a real problem for children on antiretroviral therapy (ART). A recurrent sub-theme throughout the study was the increased level of hardship and difficulty for HIV-positive and other vulnerable children in rural settings. Closely associated with the issue of poverty, respondents suggested government and non-governmental organization (NGO) services were in comparatively limited supply in rural areas. This includes access to ART as well as primary health care and nutritional supplementation, including feeding schemes.

The two-country study found the education sector in Namibia and Tanzania wanting in many respects in its response to the epidemic. The study revealed a pervading sense of denial at the school level. The response was seen to remain "depersonalized and remote from the needs of the individuals infected and affected by the disease". Associated with the pervasive silence surrounding HIV-positive learners is the lack of communication about sex or reproductive health. In schools, this subject is treated "flippantly".

In Namibia, the Education Sector HIV and AIDS policy was generally considered to be strong, although many respondents flagged the "lack of leadership and capacity in HIV and AIDS Management Unit (HAMU)" as well as the lack of coordination between sectors and service providers. Namibian key informants noted failures to make learners (including HIV-positive children) aware of their rights; failures to facilitate access to ART or support adherence; non-consensual disclosure of learner's HIV status by teachers; lack of training and capacity-building for teachers and school counsellors; and failures to develop appropriate curricula to provide requisite knowledge and understanding of HIV and AIDS.

In Tanzania, the Ministry of Education and Vocational Training (MoEVT) claims that it has "given prominence to the issues of HIV and AIDS in its structures" but concedes that "there are no specific policies or guidelines relating to children living with HIV and AIDS". The gulf between the views of the MoEVT and its clients is remarkable. Ministry officials claim that curricula are "state of the art in prevention and impact mitigation" and that "early warning and diagnosis of children living with HIV and AIDS" is included in this. However, many respondents inside and outside the MoEVT contested this view, citing lack of teacher training and failure to integrate any sexual or reproductive health education into the curriculum.

Recommendations and lessons learnt

The failure to support HIV-positive learners and issues of HIV and AIDS more generally are masked by lack of data and investigation. Evidence of reduced school fees and expanding feeding schemes for orphans and vulnerable children (OVC) and HIV-positive learners suggest that "things are getting better". The next step is recognition of the ground-level realities and the urgent and comprehensive initiation of remedial action. In this regard, the report makes thirty recommendations in eight focus areas. Taken together, these recommendations focus as much on improving the equitable delivery of accessible, quality education for all as they do on specific interventions for HIV-positive learners. In order for the education response to succeed, there is a need for formal partnerships with other social sector ministries and NGOs, including networks of people living with HIV (PLHIV).

Chapter 1:

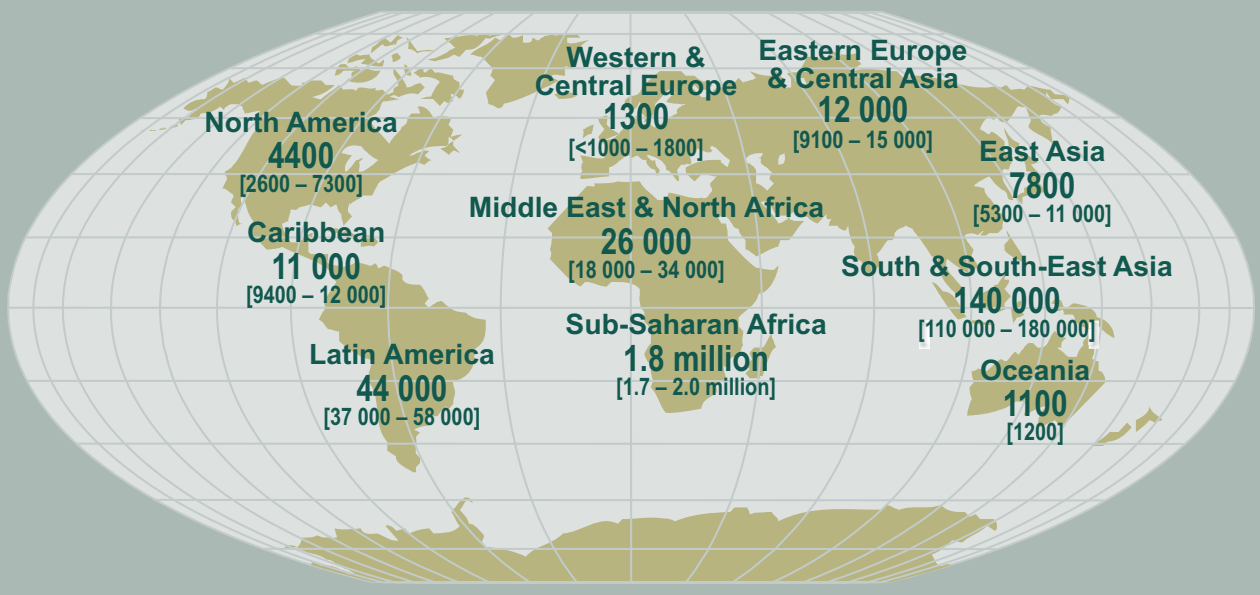
Introduction

Background

In this era of expanded access to ART, the population of children and adults living with HIV is growing as their life expectancy increases. There are an estimated 2 million children below the age of fifteen living with HIV worldwide.[1] The number of new infections among the same age group in 2007 alone was estimated to be close to 370,000.[2] The number of 15–20 year olds living with HIV is increasing as access to treatment improves.

The scale of the problem worldwide is obvious in the UNAIDS maps of the regional distribution of the epidemic (see Figure 1). The absolute numbers of people infected in sub-Saharan Africa are so much higher than any other region that treating and supporting the estimated 22 million infected people will require interventions of unprecedented scale for the governments concerned.

Figure 1: Children (<15 years) estimated to be living with HIV, 2007



Total: 2.0 million (1.9 – 2.3 million)

Source: WHO/UNAIDS. 2008 Report on the Global AIDS Epidemic. Geneva, UNAIDS

The 2007 UNAIDS update[3] notes that countries fall into two basic categories with respect to the epidemic: (1) those typical of sub-Saharan countries, and especially the southern part of Africa, where the epidemic is sustained in the general population, and (2) those typical of the rest of the world, where the epidemic exists mainly among high-risk populations. These high-risk populations are men who have sex with men, injecting drug users, and sex workers and their sexual partners.

This review is concerned mainly with the first category, where any child can be affected by family deaths, or infected through vertical transmission from an infected mother, or are at risk of infection when they become sexually active. The financial, educational and social support normally given to a child living in a family environment is likely to be weak for infected children. Their own families are likely to have been adversely affected by HIV infections and deaths; the children may have been moved to another family, or to an institution. For these children, their schools are particularly important in preparing them for adulthood, and consequently the education system is a promising avenue for intervention and support.

For the purposes of this research, two countries were chosen: Namibia in Southern Africa and Tanzania in East Africa. Namibia is a lower middle-income country with a population of 2 million, and a gross national income per capita of US$3,230.[4] Namibia has a high antenatal HIV prevalence rate of 15.3%.[5]

By contrast, the United Republic of Tanzania (including Zanzibar) is a low-income country with a population of 39.5 million, and a gross national income per capita of US$350,[6] making it one of the poorest countries in the world. It will be no surprise, therefore, that extreme poverty and lack of programme funding are more widely reported in Tanzania than Namibia – although Namibia shows evidence of more unequal distribution of income and wealth. Mainland Tanzania[7] has a medium antenatal HIV prevalence rate of 6.2%.[8]

Achieving Education for All

While the problem across sub-Saharan Africa is patently desperate for those concerned, there is as yet no way of quantifying the number of children affected, or even the proportion of learners involved. Indeed, as evidenced by the explosion in the number of orphans in affected countries, the real scale of the problem may add significant weight to the tragedy. Thus, some better estimation of numbers is required, not least because, as the Tanzanian country report suggests, around 50% of HIV-positive adolescents are infected as a result of sexual abuse or early sexual debut.

The reality for these HIV-positive young people is that increasing access to drug treatment is allowing more and more of them to develop into healthy young adults. Before the availability of ART, children born with HIV had very little chance of survival. Two-thirds of HIV-positive children died before the age of three and nearly 90% died by the age of ten. This is no longer the case. In Namibia, for example, 52% of children under fifteen who are in need of ART are receiving treatment. In Tanzania, this percentage is 6%.

The increase in the number of children and young people living with HIV poses new challenges to the education sector, particularly in terms of ensuring equal educational opportunities and access to HIV-positive learners as part of efforts towards the Education for All (EFA) goals.

While many may argue that an education institution's response to HIV and AIDS should be limited to education about HIV prevention, schools and other institutions can – and do – play a significant role in supporting all the dimensions of a comprehensive response to HIV and AIDS: including prevention, treatment, care and support. Indeed, the rights of

HIV-positive learners are enshrined in the United Nations Convention on the Rights of the Child.[9]

Schools in sub-Saharan Africa urgently need to respond to the HIV-related needs of their students. And, given the increase in access to treatment across Africa, the need to support HIV-positive learners at school will only gain in urgency and scale. Past evidence has shown that an early and whole-hearted response at the level of national government can avert the main force of the epidemic simply by taking into account the basic human rights of those involved.

However, in spite of the identified need, there has been little understanding of how the education sector should support this vulnerable group of learners in the region. To address this gap, UNESCO commissioned a review of best practice, as well as an exploratory study in Namibia and Tanzania. The aim was to identify the specific challenges faced by the education system in responding to the needs of HIV-positive learners and to develop a set of recommendations and guidelines about how best to support them.

The objective of this summary report is to describe the various educational and HIV-related needs of HIV-positive learners and young people; to provide examples of successful strategies and case studies; to give emphasis to the voices of HIV-positive learners and young people; and to draw together conclusions and recommendations for the education sector, UNESCO, researchers and the region more generally.

Efforts must be made to ensure educational opportunities for learners, including those living with HIV, to attain the EFA goals.

Chapter 2:

Methodology

Background

Commissioned in November 2007, the first part of the research consisted of a stock-taking exercise to draw together international best practice on support for HIV-positive learners, children and young people. This desk study of available literature and service provision to HIV-positive children and young people was designed as a precursor to a two-country research study in Namibia and Tanzania, and the drafting of this summary report.

Three organizations carried out the research. The EduSector AIDS Response Trust (ESART) in South Africa was tasked with developing the desk study, ethical and research guidelines and questions, a sampling strategy, technical support to the country teams and the drafting of this summary report.

Two national research organizations, Research and Information Services of Namibia (RAISON) in Namibia and the Youth Participatory Development Centre (TAMASHA) in Tanzania, were tasked with carrying out semi-structured interviews and focus group discussions in their respective countries to form the basis of the two-country research study. Separate reports are available on each country study, which can be accessed from UNESCO's website at http://unesco.org/aids

The research process was designed to establish answers to the following questions:

a) what barriers face HIV-positive learners in accessing education and staying at school?

b) what challenges are faced by teachers and schools in supporting HIV-positive learners?

c) how can HIV education programmes be adapted to suit the SRH needs of HIV-positive learners?

d) how does the education sector need to adapt to meet the needs of HIV-positive learners?

Desk-based research

The first stage in the research process was a desk-based review of literature designed to provide background information prior to data and information collection and research activities in Namibia and Tanzania.

The purpose of this desk-based research was to review policy with respect to the education of HIV-positive children and to examine how their education can be encouraged and supported in primary and secondary school settings. This was done through an appraisal of the scientific literature that had a bearing on the special needs of the children, and the public statements of national and international organizations dealing with the epidemic.

The desk study focused particularly on the educational needs of children in highly endemic, but resource-poor, settings. This was done on the assumption that the education systems of developed countries have a greater capacity to support children with chronic illnesses, including those who are HIV-positive, through their special education facilities and counselling services.

The information sources are biased towards those emanating from southern Africa, but this bias is not necessarily a disadvantage. This is where the HIV epidemic is at its worst, and most of the countries in this region are hampered in their response by weak infrastructures in both the health and education sectors. If guidelines can be developed for these very stringent conditions, they may well apply effectively in most other regions.

The study gave priority to educational issues but did not ignore the fact that HIV-positive learners and children need adequate medical support, nutrition and suitable home care in order to take advantage of educational opportunities. Nor did it ignore the implicit need for multisectoral partnerships across the social sector, to provide services and support. It confirmed that state support for HIV-positive children necessarily involves several government departments, noting that health, social welfare and education are the three ministries that have most responsibility for the care and protection of children.

While there are large numbers of relevant policy documents on children affected by the AIDS epidemic, the actual experiences of educators and learners in developing countries provided crucial information and detail for practical interventions. Their understanding of what can or should be achieved educationally to support HIV-infected children remains largely unexplored. Accordingly, the desk-based review first discussed the framework for action in terms of policies and guidelines, then the epidemiological

environment, and finally the special needs of HIV-positive children. The aim was to build a picture that will assist educators at different levels of the formal and non-formal education systems.

The emphasis on basic and secondary education was intentional but meant that related experience at the post-secondary and tertiary level was neither reviewed nor documented. It is hoped, however, that a further study on the needs of HIV-positive learners at this level of education will be considered and will build on this evidence.

Following the desk-based research, the results of field research in Namibia and Tanzania were analysed and incorporated into this final report, which is designed to provide a comprehensive overview to inform practical intervention on a global level.

Two-country research study

Research was undertaken simultaneously in February 2008 in Namibia and Tanzania. Two separate but coordinated research teams conducted interviews in the two countries with key informants and facilitated adult discussion groups, as well as gender-segmented, HIV-positive learner discussion groups in both urban and rural environments.

In both countries, the research teams were required to conduct semi-structured interviews with between six and ten key informants. The interviews were to include, as far as possible, representatives of the Ministries of Education, Welfare and Health, networks of PLHIV as well as NGOs, community-based organizations (CBOs) and faith-based organizations (FBOs). Each research team was also required to facilitate up to six adult discussion groups, drawn from teachers, counsellors, caregivers, parents and staff from NGOs, CBOs and FBOs, as well as four HIV-positive learner discussion groups.

These discussion groups were to include participants in both urban and rural environments, with the understanding that convening such groups in rural areas might prove more difficult than the equivalent process in urban areas. It was also agreed that, given the nature and sensitivity of the discussions and the age range of the participants, each of these HIV-positive learner groups would be single gender only.

A total of 156 respondents were involved in key informant interviews and group discussions. As Table 1 shows, 17 of those interviewed were key informants; 74 were adult discussion group members representing the education and health and social service sectors, NGOs, CBOs and FBOs, as well as PLHIV networks; there were 65 HIV-positive learners, children and young adults clustered in seven discussion groups, including ten orphans living in rural areas and seriously affected by AIDS.

Table 1: Sample by respondent type and urban/rural area

	Namibia		Tanzania	
Key informants	9		8	
Adult discussion group members	37		37	
HIV-positive learners and youth	30	Rural 19	25	Rural 5
		Urban 11		Urban 20
Orphans affected by AIDS	(Not separated out)		10	
Total respondents	76		80	

Most of the key informants were interviewed in urban settings, while half the adult group discussions took place in rural environments; 34 of the 65 HIV-positive learners and orphans involved in group discussions met in rural areas, in groups segmented by gender.

Separate research guidelines were developed for these groups, but were designed to ensure that interviews and discussions would, as far as possible, centre on common themes and issues. Research questions and issues for discussion, in each case, were designed to elicit views based on direct experience of the problems faced by HIV-positive learners and children, in and around the education system.[10]

Assembling HIV-positive learner groups was acknowledged to be particularly challenging. The research process was therefore sequenced to meet key informants and adult groups first, in order to develop a context for the HIV-positive learner group discussions and to help find a way to convene these groups. In the event, the problem of identifying and inviting these children to participate was addressed by engaging the support and assistance of PLHIV networks and organizations. This proved successful and also involved these network representatives in the co-facilitation and translation of discussions.

This methodology commends itself for future research of this kind. Also noteworthy was the sheer joy evidenced by HIV-positive children involved in group discussions, meeting groups of their peers in a supportive and non-discriminatory environment.

Ethical guidelines

Research conducted at the country level focused on HIV-positive learners and children, and on issues affecting the interests and welfare of these children. However, research in these areas is at an early stage internationally, and the implications for the children of discussing their experiences as HIV-positive people is not known; nor the age at which it is appropriate to involve them. Disclosure to children of their own HIV status is the prerogative of their parents, and is best thought of as a process over time. Asking HIV-positive children about their experiences may therefore amount to disclosure of their HIV status, if they have not fully understood the implications of the infection, and may affect them emotionally. The very act of asking children to tell their stories raises expectations and there is no certainty that taking part in the research will benefit them – and indeed may increase their vulnerability.

The International Community of Women Living with AIDS published guidelines on ethical participatory research with HIV-positive women,[11] which are relevant for all adults with HIV infections (although they note the need to include gender-related differences with regard to transmission and treatment in the research). They also refer to the fact that the research process may affect the psychological well-being of the individuals concerned. They propose that a stakeholders research advisory group should be convened, consisting of members of the community concerned, and others who wish to conduct the research, and that all those concerned should be viewed as researchers. While such stakeholder advisory groups were not established for the purpose of this study, the research teams took careful note of the views and suggestions of the key informants and adult discussion groups involved, before engaging in any discussion with learners and children. This was an important point of departure, as these adult groups included a cross-section of concerned professionals and stakeholders, as well as representatives of country PLHIV networks.

For the purpose of this study therefore, the ethical guidelines published by the International Community of Women Living with AIDS[12] were adopted. The guidelines are summarised in Box 1 (next page).

It was agreed that interviews and group discussions would be voice-recorded – unless a respondent refused for whatever reason – and that an assurance would be given that these recordings would be available on request should the respondent(s) require them at any stage.

While it was clearly stated that the final research report would be in English, the option to conduct both interviews and group discussions in their first language was available to all respondents. In the event, a large number of discussions were conducted in a language other than English, and the research team concerned was then responsible for the transcription and key point translation of these.

Permission to undertake research in Namibia was not required, but as a matter of professional courtesy, the Ministry of Education (MoE) was informed of the study via its HAMU. In Tanzania, it is obligatory to

Box 1: Ethical guidelines for participatory research for HIV-positive people

Research participants and the nature of their involvement in the research:

There is a need to make explicit the definition of the community/ies selected.

The likely diversity of their viewpoints should be acknowledged and upheld.

The research should be properly explained to people in the defined community, and they should have opportunities to express any concerns they may have.

They should be provided with suitable opportunities to participate.

The research should be supported by the defined community.

Purpose of the research:

The research should facilitate learning among community participants about individual and collective resources for self-determination, link them to other resources, and empower them to address the determinants of their health and well-being.

The scope of the research should encompass some combination of gender-related, age-related, political, social and economic determinants of health.

Process and context - methodological implications:

The research process should apply the knowledge of community-based researchers in the phases of planning, implementation, and evaluation.

The methods used for research data collection should be accessible by non-literate as well as literate community members, and should allow for learning about these research methods.

The process should allow the external researchers to learn about the community's visions and potential barriers to achieving those visions.

The process should be sufficiently flexible to allow for a change in research methods and focus, as necessary, and there should be procedures for appraising experiences during the implementation of the research.

The community researchers should be involved in the interpretation and synthesis of the results and the verification of conclusions.

Opportunities to address and take forward the issues of interest:

The research process should reflect the potential of the defined community for individual and collective learning and for taking subsequent action.

It should also reflect a commitment by external researchers and community researchers to social, individual or collective actions consequent to the learning acquired through research.

Nature of the research outcomes:

Members of the wider community should benefit from the research outcomes.

HIV-positive people in the community should be able to review any written or oral reports, for content, language and style, before any public presentation.

There should be a specific agreement to acknowledge and resolve any differences between external researchers and community researchers in the interpretation of the results, and an agreement between them with respect to ownership of the research data and dissemination of the results.

Source: The International Community of Women living with HIV/AIDS (ICW). 2004. Guidelines on ethical participatory research with HIV positive women. Washington, ICW.

obtain a research permit, but as the principal research organization involved (TAMASHA) was locally registered, this presented no difficulty.

Limitations of the research

Qualitative research into issues as complex and multifaceted as the educational and emotional needs of HIV-positive learners is of necessity an exploration of deeply personal concerns and sensitivities. Given the context of limited systemic support and provision at national and local levels, and the frustration and disillusionment of the children concerned, these research findings document a search for social justice. The depth of passion in child respondents, and the extent of their marginalisation, breaks the silence in a way that may be discomforting for MoEs and their development partners. The message from these respondents is clear: In spite of well-intentioned policies, and the establishment of multi-layered management structures, education has generally failed to deliver on its promise of support and inclusion.

Equally, it must be recognised that for education ministries, whose core business is teaching and learning, the overlaid stress of managing the impact of HIV and AIDS is profound. Apart from the systemic implications, ministries are expected to meet their policy obligations in the classroom – an environment peopled by the infected, affected, uncertain and distraught, over which they have little real control. It is therefore not surprising that the ground-level realities are often at variance with policy intent and the reassuring statements of senior officials. However, the mandate of education, down to the classroom level, is to provide a safe, inclusive learning environment in which children can grow through the acquisition of knowledge and skills; an environment where children have rights and special needs – including those of HIV-positive learners. On the evidence of this research study, these obligations are not generally being met, at least in the case of HIV-positive learners and many other learners made vulnerable by losing their parents or by other HIV-related impacts.

That said, this report reflects the views of a small, targeted, even self-selected sample, within two large country education sectors, and does not have the benefit of access to comparative research. While these voices must trigger grave concern, further investigation is required across a range of countries and continents. However, the mere implication of limited or even failed response after the injection and application of considerable resources into the education sector should prompt fresh interrogation of process and progress, and perhaps greater rigour in the monitoring and reporting of sector programmes.

On a more positive note, the country reports from Namibia and Tanzania provide often deeply emotive examples of caring teachers, counsellors and care-givers responding to the needs of HIV-positive learners, above and beyond the call of duty. These stories contrast vividly, however, with many more throughout the study, which reflect an astonishing disregard by some teachers for the needs and vulnerability of the learners in their charge. Such behaviour may be a characteristic of the dehumanising effects of HIV and AIDS, or indeed of any form of stigma, but has to be addressed by the serious application of rights-based policy.

Chapter 3:

Findings

"You feel so alone; you think you are the only one with this disease. My Grandmother has told me to keep it secret."

11-year-old female HIV-positive learner, Namibia

A reading of the two country studies shows a remarkable level of coincidence in the issues, concerns and views of the respondents, whether key informants or those grouped for discussion.[13] Perhaps this is to be expected. The research reflects the views of small, targeted groups with similar profiles in both Namibia and Tanzania, representing infected and affected children, PLHIV networks, NGOs and key informants from the education, health and social welfare sectors.

There may be some degree of bias, particularly from those aggrieved by their treatment in and around the education sector. However, it is important to note the level of consistency in their responses and personal experiences. The desk study summary reinforces this sense of convergence, in its appraisal of the scientific literature that has a bearing on the special needs of the children, as well as the public statements of national and international organizations dealing with the epidemic.[14]

On one level, this convergence is encouraging, as it suggests that these commonalities might facilitate the development of a common strategic response across affected regions. On another level, the fact that these issues remain so overwhelmingly prominent well into the twenty-first century is deeply troubling, particularly given the levels of funding and attention that have been focused on the impact of HIV and AIDS on education in sub-Saharan Africa.

In order to make recommendations for remedial action, it is necessary to review the findings of the desk-based research and consolidate the findings of the two-country review in order to better understand these emerging themes and their implications.

Desk-based research

There are several key points emerging from the desk-based research that emphasise the vital importance of education and the education sector in tackling the HIV and AIDS epidemic.

There is growing evidence that health promotion activities can reduce the incidence of new infections, although the overall numbers of child infections remain frighteningly high in sub-Saharan Africa. As a result, the numbers of children in residential care in orphanages, cluster homes and shelters is increasing, and a disproportionate number of these children are HIV-positive.

The school, then, becomes an important adjunct to institutional care, guiding children through adolescence towards adulthood, and assisting them with emotional and learning problems. However, unless there is a reduction in the number of infections in highly endemic areas, all systems, including education, risk being overwhelmed.

Fulfilling the needs of HIV-positive children

HIV-positive children have special needs. They have a stigmatising illness, and their lives are at stake if their illness is not identified and treated. As a consequence of the infection they are more likely than other children to be orphaned, malnourished and deprived of an education. The biological effects of HIV are severe, and the health problems of infected children can affect school entry and progress. HIV-positive children risk neurological damage, some of which is reversible when the children are on treatment. However, they are more vulnerable to opportunistic infections and schools should be especially vigilant with respect to hygiene in order to protect the children's health in crowded situations.

The United Nations Convention on the Rights of the Child includes sections that are particularly applicable to the rights of HIV-infected and orphaned children to special protection and education.[15] Although a rights-based approach is an important legal step in the support of HIV-positive children, it is nevertheless only a first step. Political support, financial resources and managerial skills have to be developed if countries are to practice what they preach.

Providing support to schools

There is a strong case for governments to cooperate in regional and international strategies for attending to the specific educational needs of HIV-positive learners. Education ministries also have a role to play in making appropriate subsidies available to NGOs working in accordance with nationally approved goals of care and education for infected children, and to enlist the assistance of appropriate civil society organizations.

Strategies are needed to attract more teachers to the profession, particularly in isolated rural areas where housing, transport and other amenities are in short supply. Teachers have daily contact with young people in high-risk age groups, and are in a position to work through risk issues with them, gradually and thoroughly over time, so that they are well informed.

In addition, HIV-positive teachers have their own specific needs. They should be supported by teachers' unions, and the school community should be trained to reduce stigma. Although disclosure to children of their status is the responsibility of parents, teachers should understand the issues so that they can respond sensitively to questions in the classroom.

Quality education for all learners requires support for teachers, administrators and other education staff; appropriate curriculum and learning materials; and links to relevant services for infected and affected children.

Maintaining the quality of education

While there are undeniable benefits to the inclusion of HIV-infected children with special needs in the regular school system, it is clearly important that the quality of education is maintained and even improved as the inclusive education process unfolds in endemic areas. The motivation and attitudes of teachers are fundamental to achieving this. They may require further training if they are to teach children with different barriers to learning, and they will have to have some understanding of the management of common behavioural and emotional problems.

School staff should be trained to keep accurate records on absenteeism and school performance, and to use these to identify children's problems, so that a strategy to assist the child can be worked out between the school and the child's family. This will be easier if teachers work within a supportive community, and this can be achieved if teachers are willing to make their expertise available to the wider community.

New programmes and examinable curricula must be developed to proactively meet learner's needs. Curriculum planners must consult widely and learn from regional and international best practice, but also use culturally appropriate local examples and illustrations wherever possible.

The families of HIV-positive children are likely to have been adversely affected by HIV and AIDS themselves, and so will be unable to offer strong support for the development of the children. Teachers and counsellors should understand the issues so that they can respond sensitively to questions and issues in the classroom. There is an onus on the wider education sector in affected countries to help support and guide these children socially, emotionally and educationally, and prepare them for adult life. MoEs must create additional counselling and psychological services posts to meet the needs of the growing numbers of infected and affected children in school.

Two-country research study

The findings of the two-country studies have been grouped into two sub-sections: challenges and responses. This first section examines some of the major challenges faced by learners and other young people struggling to cope with the AIDS epidemic in Namibia and Tanzania.

Challenges

Poverty

Poverty is cited as a limiting condition at almost every level of the learners' experience and is a key influence in the attitudes and actions of many parents. Poverty is linked to school drop-out and hunger, the latter posing a real problem for children on ART. In the case of Tanzania in particular, the systemic and social capacity to intervene is very limited because of the country's economic circumstances. In fact, the lack of NGO resources there makes it clear that their capacity to help is significantly compromised, although there were many examples of good work. Thus, intervention and remedial action at every level is likely to be constrained by the apparent lack of resources required for implementation.

There is also evidence of the effects of poverty at an institutional level. For example, in Tanzania all learners are apparently expected to pay for "extra classes outside school hours" as a means of supplementing teacher income. This seems to be less the exception than the rule, and essentially marginalises any child without the means to pay. This systemic aberration further reinforces the exclusion of the poor from proper access to education, including orphans and other children made vulnerable by HIV and AIDS.

One boy in Dar es Salaam told researchers:
"I don't have the school sweater and sports clothes and my mother can't afford to buy them for me because they are very expensive. This means I fail the subject of sports because every time I go to sports, the teacher cuts my marks and at the end of the day I fail. And they don't want to see any student wearing a sweater that is not the school uniform and if it is the cold season or I have a chest infection, I get problems."

Poverty also forces young people, particularly girls, to put themselves in situations that are extremely risky to their own health. For example, they might agree to sleep with older men, so-called "sugar daddies", in return for money for school books and stationery. This becomes a potentially life-threatening choice in an environment where HIV is so prevalent.

One 15-year-old Tanzanian female orphan living in Njombe town told researchers:
"We are tempted to enter love affairs to get money to pay for our school requirements. When a girl is propositioned and life is tough, she cannot refuse. Those who want to have sex with us are not boys or our own age, but adults."

Poverty emerged as a particular problem for Tanzania, ranked amongst the poorest countries in the world. However, its effects were also evident in the comments of Namibian respondents, particularly in rural areas. While poverty as an underlying socio-economic condition lies beyond the scope of any remedial measures to address the educational needs of HIV-positive learners, aspects of its effects can and must be targeted.

First, poverty at the household level limits and even precludes access to education, a circumstance that should be addressed by policy, and the availability of fee-waivers and bursaries at scale. Second, nutritional needs are recognised in the provision of feeding schemes, but the study suggests that these are not universally available, particularly in rural areas. The availability of at least one meal a day for vulnerable children, via the education system, cannot be negotiable, as funds exist and are reflected in country budgets. This resourcing should include provision for school uniforms (unless this requirement is abolished), shoes and stationery for those children still unable to access education through bursaries and grants.

Third, the study makes clear that key NGOs, CBOs and FBOs providing programmes and supplementation for HIV-positive learners and other vulnerable children are also under threat through lack of resources and capacity. While internal structural problems were reported to bedevil many of these organizations, it is evident that donor funds are available to support such enterprises, although these may be slowed or even constrained by complex conditionalities and reporting

requirements. The limited management capacity of these organizations may also be a factor, but these barriers to action can and must be overcome if there is to be any progress. Action to mitigate the added impact of economic hardship at every level must therefore constitute a foundation stone in any comprehensive response to the needs, not only of HIV-positive learners, but of all vulnerable children.

Urban/rural divide

A recurrent sub-theme throughout the study was the increased level of hardship and difficulty for HIV-positive and other vulnerable children in rural settings. Closely associated with the issue of poverty, respondents suggested government and NGO services were in comparatively limited supply in rural areas. This includes access to ART as well as primary health care and nutritional supplementation, including feeding schemes.

The problem is well illustrated by the example of the education system itself. Teachers are often unwilling to accept postings in rural areas, for reasons of isolation, lack of housing and transport, and, increasingly often in the face of mounting HIV-infection, distance from health facilities. This problem grows in the case of teachers with training and skills in English, mathematics and science; they are already in short supply and are able to "negotiate" their postings or, as often happens, they are poached by the private sector or other government departments. Poor distribution of books and materials in rural areas compounds the problem, as do sub-standard school and classroom conditions. In this environment, it is probably realistic to describe ALL learners (and children out of school) as vulnerable to a greater or lesser degree.

Reflecting the level of isolation encountered by HIV-positive learners in rural areas, one 10-year-old girl in rural Tanzania told researchers:
"My relatives don't know I am sick because since they brought me here to the village, they have never come to see me. Only my grandmother and some neighbours know."

In such isolated circumstances, competition for scarce resources flourishes, as do the problems of stigma and discrimination. Resolution of these problems, in the face of widespread regional poverty, will not come easily, or quickly. It is incumbent on the education sector, therefore, to look at innovative ways to assure those in need in the rural areas of some basic service delivery. This is unlikely to address the specific needs of HIV-positive learners, for example, but should be geared to addressing the basic needs of the vulnerable, including access to education, an adequate provision of trained teachers and counsellors, and a minimum level of nutritional support.

Pervasive stigma and discrimination affect the national response to HIV and AIDS in every way.

Stigma and discrimination

One of the most pervasive themes in the two-country study was that of stigma and discrimination. Every HIV-positive child interviewed in both Namibia and Tanzania cited personal and continuing experience of the negative consequences of disclosure, and emphasised greater safety in silence.

Typical of their testimony was the following from a 9-year-old Namibian boy who is HIV-positive:
"My friends will just laugh at me and leave me out of the group if I tell them I am HIV-positive. Then who will my friends be?"

These fears were the consequence of intolerant attitudes in the school and even home, severe peer pressure and the absence of responsive measures or support from school staff and the education sector as a whole. Stigma was described as "more killing" than the disease itself, and levels of denial evident in the system "could be said to promote the spread of HIV"; in short, stigma in both countries was said to be seriously affecting the national response to HIV and AIDS in every way.

Among many examples of stigma and discrimination, the reported practice in Tanzania of teachers making HIV-positive learners wear red ribbons to identify themselves was one of the most disturbing. However, anecdotal reports from learners and young people were both positive and negative, leaving a sense of ambivalence, even hope that the position is changing in some quarters. There were also unexpected subtleties in discriminatory experience. Some learners who had disclosed their status reported fewer problems than those "suspected" to be infected as a result of recurrent illness or evident "skin disease", and said they "regarded HIV as an illness like any other, which did not affect their lives". Overall, respondents said that stigma is the result of the "failure to provide comprehensive education on HIV and AIDS, and address people's misconception and fear".

However, the attitude of teachers was repeatedly described as indifferent, sometimes severely complicating the ability of HIV-positive learners to participate effectively in the learning process or access ART when required.

One 16-year-old boy from Namibia revealed to researchers:
"I told my teacher I needed to go to the ARV clinic and she told the other teachers and children that I was HIV-positive."

Several respondents cited teachers and school principals, presumably in good faith, attempting to shield HIV-positive learners from stigma by insisting publicly that they were not in fact HIV-positive. One learner from Namibia said that a newspaper had reported that she and her mother were chased away by her family when they learnt they were HIV-positive. When she got to school the next day the other children backed away from her and told her not to come too close. She was shocked and did not know what to do. Then, to her surprise, the teachers told the children that the newspaper had the story wrong, and she was not HIV-positive. It took a while for the children to react normally to her, but soon all was forgotten. She realised the teachers had done this to protect her. Now it is as if none of that happened, and she still keeps her secret to herself, not able to tell any of her peers that she is HIV-positive. She has arranged to attend the ARV clinic after school and walks from her home to the hospital every month for her medication. Only her mother knows where she is going. She has no-one she feels she can confide in, so she just tries to push HIV to the back of her mind.

This evidence from the uncompromising world of the school playground suggests that there is still some way to go before HIV-positive children can reconcile the importance of voluntary disclosure.

One girl in Dar es Salaam told researchers:
"I am in pre-Form One. No one at school knows. It would be better if they do know but I am afraid of stigma."

Interestingly, in terms of disclosure, it is often parents or care-givers who try to protect their children by forbidding them to disclose their status. It is clear, therefore, that silence is still the preferred option for most HIV-positive learners and their parents.

Ironically, some children suggested that it was better to disclose than to be "suspected" of being infected, but few reported being better off for disclosure. Others said that having sick parents led to the assumption that they too were HIV-positive, but almost all the respondents noted that HIV was only one of many stigmatised conditions.

Ministry endeavours in both countries to subsume HIV-positive learners into the wider group of orphans and vulnerable children (OVC), apparently in order to spare them further stigma, confirms recognition of the scale of the problem. That this is done – to the relief of some HIV-positive learners interviewed – demonstrates some measure of good intention on the part of the authorities, but recognises that their policy provisions and protections are not reaching ground level. Continuing attempts to limit disclosure, from parents and teachers alike, confirm that the climate for disclosure remains frosty and it is hard to see what real incentives exist for children to declare their status in such stressed circumstances.

One female respondent from Tanzania told researchers:
"One day I was on the school bus. I ran for a seat but one pupil said 'leave the seat to the dead person so she can sit down'. I cried and went to the teacher who punished the girl who said that, but I was very hurt. She said that because I am often sick."

Patently, children are not aware of their rights to privacy, confidentiality and protection from stigma and discrimination. Nor do they have any idea who to talk to about these issues; confirmation of the failure to convert policy promise into action. Many young respondents stressed the need for comprehensive information to

guide them and address "people's misconceptions and fear", rather than the often superficial "messaging" on offer. That said, the studies reported incredible resilience against the odds amongst many HIV-positive learners and young people, with several of them observing that "things are changing for the better".

One Form IV pupil in Njombe, Tanzania said:
"HIV is like any other illness. I live like any other student. Living with HIV has not affected me in any way."

Home environment

The home environment emerges as a profoundly complicating factor in this study. In fact, one of the worst cases of abuse encountered by researchers was at the hands of a child's parents in Tanzania. A boy in Standard VI was living with both parents. Although he had fungus all over his body, he had not been tested for HIV. His parents forced him to cook for himself on a separate stove and to eat from separate utensils, so that he did not infect them and others. When the teachers supported this boy, even with food and money to buy medicine, the parents went to school and told the teachers not to waste their time on the child, as he was going to die anyway.

The vast majority of the children interviewed felt that their guardians (grandmothers, sisters, etc.) cared for them well within their economic circumstances. However, this situation is clearly exacerbated by poverty and competition for scarce resources in the environment and a culture of stigmatisation that extends beyond HIV and AIDS. In short, homes are not the safe havens that might have been expected.

Poverty was a common problem among families affected with HIV and AIDS:
"Kids may be living with parents and guardians who are struggling to sustain their own lives. The kids then go hungry and are emotionally neglected," said one Namibian NGO representative.

Nutritional needs were also often mentioned, linked to the need to eat properly when on ART.

One boy from Dar es Salaam told researchers:
"I eat once a week because my aunt has no job and no one to help her. We are told by PASADA [the organization that supports them] that for the medicine (ARV) to work well, we should try to eat well. I leave the house at 6am, I take the medicine without any food and at school I have no money to buy food. That is why my health is not good, I am sick so often and when I go home, maybe I eat in the evening, just once a day, that's all."

Worryingly, foster parents and guardians of HIV-positive orphans often lack understanding and sympathy, and offer little emotional support. Indeed, very many children referred to their guardians rather than their parents, confirming the overlap between being HIV-positive and orphaned.

Common among the respondents was this testimony from a 13-year-old Tanzanian girl who is HIV-positive:
"I was sent home because I had no exercise books but when I asked my guardian for them, I was told to go and look for the money myself as I am now a big girl."

In addition to practical concerns, parents often do not know how to disclose their own or the child's HIV status to the children themselves, or to other members of the family, teachers or friends. Some respondents suggested that "discrimination starts with knowing a parent has HIV or AIDS", confirming that illness in the home – in combination with reduced household income, increased health-care costs and domestic duties – may have a debilitating effect on children there. Mothers in particular fear the resentment that may result if their children find out that they were born HIV-positive, and disclosure remains difficult, unknown terrain, even in the home.

One young girl in Tanzania said:
"At home my mother and myself have tested and been found positive. She has told me not even to tell my relatives; not even my own sister because she is afraid I will be stigmatised."

Silence is thus again the default position in the home environment, with parents fearful of both their own

and their children's disclosure, in what is patently a discriminating environment. There is clearly a link between community perceptions of one or other parent being HIV-positive and the assumption that the children concerned are also living with HIV. This "collective" stigma brackets extended families, exacerbating the internal stresses and marginalisation of infected family members.

Associated with this pervasive silence is the lack of communication about sex or reproductive health issues. Many respondents reported that they received no sex education, even at a rudimentary level, from their parents, care-givers, teachers and support organizations. Adult embarrassment or inability to deal with these issues, inside and outside the home, dramatically reduces the child's chances of avoiding or preventing any sexually-transmitted infection, including HIV. Increasing pregnancy rates among adolescents in many sub-Saharan African countries confirms this unhappy position. Clearly, any response to the needs of HIV-positive learners must encompass the wider home environment, and find a way through the veil of suspicion, ignorance and silence.

However, the testimonies included in this section risk ignoring the many good news stories of love and nurturing in evidence. While these were in the minority in this study, the resilience of affected and infected children in the sample was striking. Apart from those troubled by recurrent illness, many of them said they were "leading normal lives and had no problems, as HIV was a disease just like any other".

Orphans and vulnerable children

A variety of problems associated with poverty and the lack of parents or parental support challenge HIV-positive children, very many of whom are also orphans. In Namibia, many key informants indicated that HIV-positive learners are subsumed into the wider category of OVC. This was regarded as positive, in that the inclusion of infected children in this larger group reduces the chance of neglect, prejudice and exclusion, which appear to be the main consequences of the denial and stigma associated with HIV in Namibia.

In general, respondents seemed happier to be seen as OVC rather than HIV-positive, mainly because this entitled them to access school feeding schemes. However, they noted that their ART regimes and regular visits to clinics set them apart, even within this group.

However, orphans too are stigmatised: 90% of the orphans interviewed in rural areas in Tanzania said they were stigmatised, mistreated and, in some cases, sexually abused by their own guardians (see box). Although this is apparently widely known, the social welfare system in Tanzania is chronically underfunded and no action is taken against the alleged perpetrators. The situation in urban areas is somewhat better because of the presence of larger organizations concerned with the welfare of OVC, providing better counselling and support. Urban guardians are also more likely to access resources as a result of looking after the child, although some child respondents felt that they were being "used" to access these resources.

One 12-year-old orphaned girl from Namibia told researchers:
"I left my foster family because they said things that hurt me. Now I have a grant they want me back."

Notwithstanding these issues, the HIV and AIDS Unit of the Tanzanian MoEVT indicated that HIV-positive learners are mainstreamed into their wider plans for OVC, on the basis that this will reduce HIV-linked stigma. This approach is consistent with the ministry's stated intent to mitigate stigma and discrimination, but is predicated on levels of counselling and support not much in evidence, at least in the view of respondents. The distinguishing feature of HIV-positive children within this wider group is obviously reliance on ART, once testing has confirmed infection. In this regard at least, all those interviewed expressed some measure of satisfaction with access to treatment in Tanzania – with the caveat that access in rural areas is difficult.

The degree of coincidence between HIV-infection and orphan status amongst learners and other children remains to be accurately quantified, although some estimates exist internationally. However, this study suggests the overlap of conditions is high indeed. This is perhaps one of the motivating factors that have

Story of an orphan in Tanzania

I live with my aunt and she has several big daughters. Every day I am woken up early to clean the house on my own, and it is a big house. If I finish, I have to prepare breakfast for them. Her daughters wake up, drink tea and go to school. They always arrive early at school but I am often late because of all the work I have to do and then I am punished and even if I get to class, I am very tired. After school, my aunt tells me to come home quickly in order to fetch wood and do other household chores while her children are told to do their homework.

At home I am not given food. I am told to wait for the others to finish and then I am given the leftovers. Sometimes they let me eat with them but then they talk about me to the point where I no longer feel like eating.

Uncle often comes home drunk. I give him his food and then he wants to fondle me. If I refuse, he gets angry. If I tell my aunt, she says I am a liar and I am making up stories about her husband.

prompted ministries to subsume HIV-positive learners into the much wider OVC group. Notwithstanding this, it is also apparent that, in and of itself, being orphaned is also stigmatised at a family, community and institutional level – particularly in rural areas. Reports of abuse at the hands of guardians from orphaned respondents suggest that they are "fair game" within the community.

One 14-year-old orphaned male Tanzanian learner told researchers:
"If I ask my uncle for money, he tells me to go and ask my parents in their grave. Since that day I have been making charcoal to get money to help me."

It seems likely, though, that OVC fare better in urban areas where organizational support is more readily available. This confirms, perhaps, that the elasticity of extended rural families has finally snapped under the unrelenting pressure of poverty, HIV and AIDS.

Whether or not ministries are justified in "mainstreaming" HIV-positive learners into their plans for OVC is a moot point. On the one hand, this general categorisation may indeed reduce stigma and provide a degree of inclusivity and even peer support. Certainly, it is likely to improve access to feeding schemes and other interventions that might otherwise be beyond the reach of these learners, unless – in the face of parental disapproval in many cases – they disclose their HIV status and receive due consideration for their needs. In these extreme conditions, it is hardly surprising that they may be only too happy to be classified as OVC.

On the other hand, it does not deal with the need for HIV-positive learners to access treatment regularly and receive the additional support and understanding they require in respect of their medical and psychological condition. The calm resilience displayed by some respondents suggests that children may be better at dealing with adverse circumstances than may be imagined. However, it is more likely that their emotional scarring may become erosive or permanent if unattended by counselling and comprehensive support. How this support can be achieved in a resource-poor setting remains the over-riding challenge.

Responses

Education is repeatedly eulogised by the international development community as a "social vaccine" for HIV. Yet the two-country study found the education sector in Namibia and Tanzania wanting in many respects in its response to the epidemic.

Education sector: HIV & AIDS policy and implementation

In Namibia, the Education Sector HIV and AIDS policy was generally considered to be strong, although many respondents flagged the lack of implementation and leadership, as well as the lack of coordination between sectors and service providers. In Tanzania, the MoEVT claims that it has "given prominence to the issues of HIV and AIDS in its structures" but concedes that "there are no specific policies or guidelines relating to children living with HIV and AIDS". Instead, these are included in the general Guidelines for Implementing HIV and AIDS Life Skills Education Programmes in Schools, and contain several clauses relating to inclusion, counselling, access and confidentiality for HIV-affected or HIV-positive learners.

Namibian key informants and NGO respondents noted that, while there are structures in place to manage the issues, there is a widespread sense that the MoE is not taking HIV and AIDS seriously enough, and repeatedly attributed this to a "lack of leadership and capacity in HAMU". In Tanzania, the MoEVT stated that it has a full-time response structure in place, including focal points in every department and related educational institution, as well as a Technical AIDS Committee that reports to an AIDS Steering Committee comprising all MoEVT directors, headed by the Permanent Secretary. However, respondents noted that this Committee only meets twice a year.

Recurring criticisms of the attitudes of teachers, principals and schools across the sample in Namibia seem to confirm systemic failure to address the problem of HIV and AIDS. The study revealed a pervading sense of denial at the school level, a feeling that the best way to handle HIV and AIDS is to ignore it on a personal level, to reduce information about it to the minimum curricular requirements and to restrict discussion to AIDS Week or AIDS Clubs.

A Namibian key informant told researchers:
"The Ministry's policy is to never ask about HIV status. An interesting consequence of this is that formally and officially, HIV-positive children do not exist."

In short, the response was seen to remain "depersonalized and remote from the needs of the individuals infected and affected by the disease", contradicting any expectation that the Education Sector HIV and AIDS Policy is being comprehensively implemented. Other indications of the failure to implement policy in Namibia were cited, and included failure to make learners (including HIV-positive children) aware of their rights; failure to facilitate access to ART or support adherence; non-consensual disclosure of learner's HIV status by teachers; lack of training and capacity-building for teachers and school counsellors; and failure to develop appropriate curricula to provide requisite knowledge and understanding of HIV and AIDS.

Tanzanian respondents reported the rights and needs of HIV-positive learners are "mainstreamed" into wider planning for OVC, as the MoEVT believes that treating them as a separate group would lead to greater stigma and discrimination. The MoEVT also claims to have a range of interventions and programmes that it feels are adequate to protect and meet the rights and needs of HIV-positive learners. However, partners, employees and clients of the education system had a different view of this position, repeatedly noting that policies are "not disseminated, discussed or agreed". Despite these guidelines, learners and teachers living with HIV are regularly, even routinely, subject to stigma and discrimination. Claims that teachers and counsellors were trained are disputed by learners and teachers themselves, and many remarked that counselling was only really available at hospitals and through NGOs.

Typical of the response from PLHIV networks in Tanzania was this testimony:
"We have no guidelines. We have heard there is a national AIDS policy but we have not seen it and we do not know what is in it."

Based on the evidence, there appears to be a substantial gap between what ministries of education in both countries claim to have put in place in terms of HIV and AIDS response compared to the various observations and experiences of their clients and partners. While some key informants pointed fingers at specific targets in the education establishment, the extent of the perceived failure by these ministries to meet their obligations in this regard suggests that the problem is wide-ranging and complex.

Indeed, there is no doubt that policy and guidelines exist, and cover most of the issues that best practice requires. Structures are clearly in place and are increasingly decentralised, with regulated if limited reporting; oversight committees and other meetings are also clearly held, although the frequency and depth of these may be less than desirable. Nevertheless, ministry officials seemed confident that they were on top of the problem and had met all their obligations and responsibilities. Whether these statements are based on assumption, reports or a belief in the unchallengeable primacy of policy is unknown. What is clear is that implementation, in the experience of those most affected by its success or failure, is in limited evidence.

The question is why should this be so when everyone involved has so much to gain from successful intervention?

In short, however pressing the issue of HIV-positive learners – and of the wider impact of HIV and AIDS – it is likely that education managers still do not see response as core business. Education systems in sub-Saharan Africa are routinely stretched to simply deliver basic education, and challenged by often dysfunctional management systems, inadequate human and material resources, unreliable data and limited training. However, while HIV and AIDS make this situation much worse, the impact of the disease remains masked by lack of data and investigation, and does not appear to be taken seriously as a systemic management problem. Few ministries have HIV and AIDS-sensitive data alerting them to impact, and even if they had such data, their response – as evidenced here – would probably be to say they have done everything required of them. The fact is that HIV and AIDS is no longer a headline issue in a competitive environment, and is largely sustained by donor insistence and the involvement of NGOs and HIV and AIDS management units and their structures. That this response does not always filter down to the school level, particularly in rural areas, should come as no surprise.

Teacher training, policy guidelines, and efforts to address stigma and discrimination are all part of an enabling school environment for all learners.

However, between these two poles, it must be said that there are very many stories of dedication by teachers, principals and counsellors who are doing their best to make schools better, safer places for all – including HIV-positive learners. The same applies to the many NGOs and other CBOs and FBOs that supplement the capacity and resources of education ministries to deliver a more personalised approach to the needs and concerns of HIV-positive and other vulnerable children. In other words, there are many people and organizations involved whose success is due less to policy than their own drive and determination to make a difference.

School and teaching environment

In Namibia, a number of schools had clearly made some effort to reduce school fees, provide school feeding for OVC and promote HIV prevention. However, the consequences of infection represent a set of problems that few schools seem either prepared for, or eager

to deal with. Respondents suggested several reasons for this. First, teachers are unwilling or untrained to deal with open discussion on the topic; disclosure is discouraged to avoid the potential for stigma; education on HIV and AIDS is not taken seriously; and policy is not clearly understood or implemented. Reported incidences of teachers spreading information on learner's HIV status, linked to confidential disclosure or clinic visits, represent an extraordinary compromise of learner confidentiality and a disregard for policy and human rights at the school level.

One male respondent in Dar es Salaam told researchers:
"The teachers know that I am sick and living with HIV. When I am late at school the teachers take no action but if I am with my fellow students they are beaten or punished so that they are not late again but they do nothing to me. They don't even ask me why I am late although it is true that sometimes it is because I am sick. I don't see why the teachers leave me alone when I am late. The teachers seem to be afraid of me because I am living with HIV and they don't help me. They should be asking me why I am late."

A number of HIV-positive learners and young adults noted that school counsellors are "around", but are to all intents and purposes invisible or inaccessible. Many respondents indicated that teachers had very little training and were not equipped to deal with the problem in school.

In Tanzania, the gulf between the views of the MoEVT and its clients is most evident. Apart from its Guidelines for Implementing HIV and AIDS Life Skills Education Programmes in Schools, the MoEVT claims to have several interventions in place in schools and teacher colleges, in association with partner organizations. These include the integration of AIDS education into the primary school curriculum, supported by teacher training and manuals, as well as extra-curricular activities such as health clubs and two HIV and AIDS Days per term. According to the MoEVT, two trained counsellors should provide services in every school and in primary schools there should be peer educators in Standards 5 to 7; school counselling and HIV and AIDS committees should be in place to facilitate parental acceptance of PLHIV. Ministry officials claim that curricula are "state of the art in prevention and impact mitigation" and that "early warning and diagnosis of children living with HIV and AIDS" is included in this.

However, very many respondents inside and outside the MoEVT contested this view, citing lack of teacher training and failure to integrate any sexual or reproductive health education into the curriculum. Where there was evidence of the integration of life skills, respondents remarked that "the dosage is too small to have any effect". However, while learners, NGOs, commissions and even teachers were more or less critical of this failure, it is important to reconcile this apparent under-delivery with the impoverishment of the system and its overburdened staff and curriculum. What emerges from these contrasting views is that the ministries concerned have good intentions and even some measure of prioritisation in place; what is required now is recognition of the ground-level realities and the urgent and comprehensive initiation of remedial action.

It is at this level that the failure to implement policy promises is most evident. Ministry claims in both countries of high levels of teacher training, availability of counsellors, and establishment of structures, programmes and support systems were repeatedly refuted by both system clients and partners. In fairness, however, this generalisation does not do justice to the many teachers and counsellors who work above and beyond the call of duty, but confirms that these heroes and heroines are in short supply. Several HIV-positive learners cited extraordinary stories of compassion and material support from teachers and counsellors, including being taken into the homes of these remarkable people.

One 9-year-old Tanzanian girl who is HIV-positive told researchers:
"The teachers know my status and every day when I go to school they buy me a cup of milk in the morning. And if I don't go to school, the teachers send a friend of mine to find out if I am sick or I have another problem."

Another Tanzanian girl said:
"Teachers know my status, they were told by my grandmother. If I don't come to school the teacher sends my friend to find out if I am sick or not and if the teacher is free, she comes to visit me as I live near the school."

By contrast, there are many reports of teachers unwilling to get involved or even culpable in the unauthorised disclosure of learners' HIV-status. Even given the probable bias of young people, angry and disillusioned with the perceived failure of the system to accommodate their needs, these anecdotes confirm not only that policy

and guidelines have not been implemented, but that the most fundamental rights-based regulations are often ignored. The apparent impunity that these teachers feel also reflects the failure of local management systems and school controls. Some principals are apparently unaware or disinterested, suggesting that a positive culture of teaching and learning may also be absent in many settings. Indeed, it is the implied lack of empathy and caring that is perhaps most disturbing. Teachers in high HIV-prevalence countries could be expected to be deeply sensitised to the issues through personal experience, and should be intuitively providing support and understanding in the classroom. Unfortunately, all too often this is far from the reality.

A Tanzanian representative of PLHIV networks told researchers:
"Teachers have no capacity to help the pupils. We see many students are sent home if they are sick, so teachers cannot help them. Even if a child has a headache, the teachers cannot even give them a Panadol."

The variability of these experiences confirm – as with the education process itself – that much is dependent on the personalities involved. However, since such a range of experience continues to be reported, it is necessary to circumscribe the conduct and behaviour of everyone concerned by regulation, within an effective legal and policy framework. More to the point, this framework must be given effect, to ensure that aberrations of the kind reported in this study cannot occur again without serious recourse. It is noteworthy, for example, that none of the study respondents – including ministry officials – mentioned monitoring or reporting of policy implementation. Yet evidence of reduced school fees and expanding feeding schemes for OVC and HIV-positive learners suggest that there is some good news, and perhaps it is this that motivated many of the young people interviewed to suggest that "things are getting better".

Information and curriculum content

Most HIV-positive learners in Namibia said that their main sources of information on HIV-related issues and support were Ministry of Health and Social Services (MoHSS) doctors, clinic sisters, counsellors and care-givers, as well as the media. There was consensus that little information was available at schools and that learners were unprepared to deal with HIV and AIDS. Respondents stated that only the most basic facts about HIV and AIDS material were taught in the curriculum, but that issues like means of infection were not discussed, "effectively promoting the spread of HIV". HIV-related programmes were reported to be voluntary and extra-curricular, and respondents claimed that these were seldom taken seriously.

One Namibian NGO representative told researchers that political will could make a huge difference:
"A firm message from the President and Minister of Education would go a long way towards legitimising the integration of HIV issues into the school curriculum."

Several respondents also made the point that limiting the integration of HIV and AIDS into life skills lessons would not help much, as this subject is treated "flippantly" because it is neither mandatory nor subject to examinations. One key informant suggested that there seemed to be some reluctance to fully integrating HIV and AIDS into the curriculum, further limiting potential access to a comprehensive understanding of the pandemic.

Most respondents – and particularly young adults – felt strongly that HIV and AIDS should be mainstreamed into the curriculum, to provide clear and unambiguous information to all learners, as a matter of urgency. They suggested that schools need guidance in the delivery of comprehensive age- and gender-appropriate SRH education. They also argued that partnerships with other ministries and NGOs would be useful to the MoE in terms of implementing effective HIV-related programmes.

In Tanzania, awareness about HIV and AIDS and its transmission is said by official sources to "be almost universal, with educational campaigns available on a regular basis". Respondents refuted this, saying that these campaigns were about "messaging" rather than real education, with the result that, even in urban areas, "knowledge is only skin deep". HIV and life skills are supposed to be integrated into the current school curriculum: at primary schools in Science and Social Studies; and at secondary schools in Biology and Civics at O-level, and in General Studies and Biology at A-level. Respondents observed that such integration into an already very full curriculum is extremely difficult in practice. Pupils almost universally said that they were not taught SRH or life skills, but wished that they were. Primary school teachers in rural areas said that SRH was not a part of the syllabus, but hoped that this would change.

A Tanzanian primary school teacher told researchers: "AIDS is not on the syllabus. Maybe in the new syllabus being prepared, but for now there is no topic on AIDS."

This criticism is supported by the evidence of wide-ranging stakeholder consultations currently underway in Tanzania to develop a national life skills framework. One of the main findings is that, although life skills are supposed to be integrated into these subjects, this is not happening – or seen to be happening. Many adult respondents concluded that this lack of education places all learners at risk of HIV-infection. And with particular reference to HIV-positive learners, even the few references to sexual and reproductive health do not take into account their particular SRH needs as they enter puberty.

The reported failure of the education sectors in Namibia and Tanzania to communicate with and inform their learners of the facts is of great concern. But however culpable these country systems might be, it should also be recognised that a debilitating level of "AIDS fatigue" dogs efforts to develop, communicate and receive such information. In Africa at least, several generations have been weaned on billboards, posters and media reports to the point that such messaging may have become background noise. In such circumstances, criticism is easy and may even be accurate relative to the intake of behaviour-changing knowledge. As one young Namibian remarked: "HIV and AIDS information is given in such a boring way, not appealing to young people. It needs to be youth-friendly, not just top-down from old people."

Meeting the testing and treatment needs of children and ensuring "child-friendly" services remains a significant challenge.

It is for these reasons that the voices of these young respondents should be carefully listened to, for the message is direct and uncompromising: Make issues of human sexuality, reproductive health, HIV and AIDS – including its prevention, treatment and management – examinable subjects in the formal curriculum. The sub-text from these young people is wise and equally direct: Do it not only for us, but also to help make the uninfected and unaffected better understand the issues and stop the destructiveness of stigma and discrimination.

Testing and treatment

The majority of children in the Tanzanian sample discovered they were HIV-positive when they were already at school. Testing was often suggested by a third party, sometimes a teacher, following frequent bouts of observed illness. Once tested and confirmed HIV-positive, these children accessed ART from the same health or NGO sector centres as adults but did not have access to "child-friendly" facilities.

The need for child-friendly, confidential counselling and testing facilities was repeatedly stressed, as the lack of confidentiality was seen as a major problem, both by the children and their parents, leading to further stigma and discrimination. For example, most children are known to be HIV-positive as a result of being seen at the local ARV clinic, and most are shunned by their peers at school. There is little confidentiality in small rural communities, and word quickly spreads about who is attending the ARV clinic.

There seemed to be general levels of satisfaction with access to treatment, although the frequent interruption of drug supplies, particularly in rural areas, suggested that this service was also stressed by economic stringencies. It was also clear that testing and treatment in rural areas was more difficult due to the distances, transport and other costs involved.

Multisectoral support

While HIV-positive learners and children in Namibia face difficulties at home and at school, they do receive substantial support from ART counsellors at hospitals and clinics, and from a variety of non-governmental groups. Respondents suggested that the most effective support comes from "personalising the HIV-positive condition in a social context, in which a child can be confident, accepted as a worthy person, and have the same rights as everyone else".

The study revealed many examples of the breadth of these interventions, with volunteers selflessly working amongst struggling families, projects formulated to respond to the ravaging effects of the disease, and the medical staff members of clinics in many cases going the extra mile to support their patients in innovative ways. Several NGOs and programmes were identified in this regard and attracted variable but generally positive comment. Learners and young adults were quite incisive in their comments, noting that voluntary school-based programmes had limited value. Many respondents appreciated the more "personalised approach" of NGO programmes, with several citing the AIDS and Me and Circles of Support (IBIS) programmes as examples of good practice.

In Tanzania, there was considerable discussion of the role of civil society and its organized structures in support of HIV-positive learners and other OVC. There is a perception of an ever growing number of organizations of people living with HIV, the majority of which provide counselling, material support, solidarity and education. In Tanzania, the national network has more than 60 member organizations playing a key role in the response to HIV. However, the recurrent problem of institutional poverty limits the role of these organizations, leaving them dependent on financial aid either from the Tanzanian Commission on AIDS (TACAIDS), which coordinates the multisectoral response to HIV and AIDS, or from donor organizations. When they have the resources, they provide clothes, school uniforms and other items to children living with HIV, along with other children who have been affected by AIDS or are vulnerable in other ways. Thus they play a key role in ensuring that HIV-positive learners are able to continue to go to school. In this way, they effectively supplement the MoEVT's role – albeit with very limited resources and capacity.

Many of the learners and young people interviewed were virtual veterans of multisectoral and NGO support programmes, but few credited the education sector as a key provider.

One Namibian hospital doctor told researchers: "We talk to our adolescent patients about what they learn at school, but it is clear that very little information on HIV and AIDS comes through the education system."

Within the government cluster, the health sector – including many NGOs working in partnership with the ministry – was consistently rated as a good provider of services, ranging from counselling to ART and support services. In fact, it appears that young people are getting more information from the health sector than the education sector, if only in response to questions. In their ranking of available programmes, HIV-positive learners were particularly well-disposed

to the “personalised approach” of some of these. This sub-text reveals how much in need these young people are of programmes that treat them as “worthy persons, (with) the same rights as everyone else”.

There was considerable comment about the sustainability of NGOs, especially from key informants. They cited fragile, politically divided structures, perennially stressed by financial instability, and noted that even some of the larger organizations were fragmenting due to internal divisions. That the key and sometimes only providers of programmes and support to HIV-positive and other vulnerable children appear to be so susceptible to structural failure is worrying in the extreme. Without them, support may founder, as it seems that government ministries do not have the capacity – or perhaps even the appetite – to expand their range of services. It is ironic that financial and management stress in these NGOs should be such a major problem, given the volume of resources that donor agencies claim to direct their way. It begs the question of whether these resources are reaching their destination; whether they are trapped in bilateral pipelines; or whether it is access to these very resources within NGOs that is creating division and collapse.

Whatever the case, the loss of the NGO presence in this equation cannot be countenanced, particularly in rural areas where they are often the only source of support services. Finally, in overwhelmingly endorsing the need for multisectoral partnerships, respondents reported a real sense of frustration that the education sector appeared unable or unwilling to emulate the health sector in its successful development of productive and dependable relationships.

Chapter 4:

Lessons learned and recommendations

"I see there are lots of other kids the same as me; that feels better; by sharing I have got new ideas about how to cope with HIV."

11 year-old female Namibian HIV-positive learner

Summary of Lessons Learned

One of the most pervasive themes in the two-country study was that of stigma and discrimination. Respondents said that stigma is the result of the "failure to provide comprehensive education on HIV and AIDS, and address people's misconception and fear". Every HIV-positive child interviewed in both Namibia and Tanzania cited personal and continuing experience of the negative consequences of disclosure, and emphasised greater safety in silence. Children are not aware of their rights to privacy, confidentiality and protection from stigma and discrimination. Nor do they have any idea who to talk to about these issues; confirmation of the failure to convert policy promise into action. Continuing attempts to limit disclosure, from parents and teachers alike, confirm that the climate for disclosure remains frosty and it is hard to see what real incentives exist for children to declare their status in such stressed circumstances.

This study suggests the overlap between HIV-infection and orphan status amongst learners and other children is high. Lack of parents or parental support challenges HIV-positive children. Ministries in both countries have subsumed HIV-positive learners into the wider group of OVC. The inclusion of infected children in this larger group reduces the chance of neglect, prejudice and exclusion, which appear to be the main consequences of the denial and stigma associated with HIV in Namibia.

However, orphans too are stigmatised: 90% of the orphans interviewed in rural areas in Tanzania said they were stigmatised, mistreated and, in some cases, sexually abused by their own guardians. Classifying HIV-positive learners as OVCs does not deal with the need for them to access treatment regularly and receive the additional support and understanding they require in respect of their medical and psychological condition.

Poverty is cited as a limiting condition at almost every level of the learners' experience and is a key influence in the attitudes and actions of many parents. Poverty is linked to school drop-out and hunger, the latter posing a real problem for children on ART. A recurrent sub-theme throughout the study was the increased level of hardship and difficulty for HIV-positive and other vulnerable children in rural settings. Closely associated with the issue of poverty, respondents suggested government and NGO services were in comparatively limited supply in rural areas. This includes access to ART as well as primary health care and nutritional supplementation, including feeding schemes.

The home environment emerges as a profoundly complicating factor in this study. In fact, one of the worst cases of abuse encountered by researchers was at the hands of a child's parents in Tanzania. The vast majority of the children interviewed felt that their guardians (grandmothers, sisters etc.) cared for them well within their economic circumstances. However, this situation is clearly exacerbated by poverty and competition for scarce resources in the environment and a culture of stigmatisation that extends beyond HIV and AIDS. Worryingly, foster parents and guardians of HIV-positive orphans often lack understanding and sympathy, and offer little emotional support. Indeed, very many children referred to their guardians rather than their parents, confirming the overlap between being HIV-positive and orphaned.

Associated with the pervasive silence surrounding HIV-positive learners is the lack of communication about sex or reproductive health issues. Many respondents reported that they received no sex education, even at a rudimentary level, from their parents, care-givers, teachers and support organizations. Adult embarrassment or inability to deal with these issues, inside and outside the home, dramatically reduces the child's chances of avoiding or preventing any sexually-transmitted infection, including HIV. Clearly, any response to the needs of HIV-positive learners must encompass the wider home environment, and find a way through the veil of suspicion, ignorance and silence.

Conclusions

At first glance, the issues raised by respondents in Namibia and Tanzania leave an overwhelming sense that, in general terms, education has failed to deliver on its promise of support and inclusion for HIV-positive learners and other vulnerable children. On balance, it is probably fair to say that, while MoEs may have fallen well short of their declared intent in policy implementation terms, at least in the view of these respondents, there are also very many examples of devotion and dedication amongst teachers, counsellors, principals and managers within these systems. There is no doubt that policy and guidelines exist, and cover most of the issues that best practice requires. Structures are clearly in place and are increasingly decentralised, with regulated if limited reporting; oversight committees and other meetings are also clearly held, although the frequency and depth of these may be less than desirable. Perhaps the larger question is whether or not MoEs can ever realistically hope to implement, monitor and report their wide-ranging policy obligations and promises. Given the difficulty of simply providing basic education at acceptable levels, the expectation that education could additionally provide a "social vaccine" against HIV and AIDS might be unduly optimistic.

In overwhelmingly endorsing the need for multi-sectoral partnerships, respondents reported a real sense of frustration that the education sector appeared unable or unwilling to emulate the health sector in its successful development of productive and dependable relationships. The repeated observation that MoEs had failed to develop and formalise sector partnerships comes into sharp focus, suggesting that avenues for some early resolution of these problems identified by respondents may be open and accessible. These and other options are discussed under the following section on recommendations, but before turning to these, it may be useful to reflect, finally, on one particularly important feature of this study: this is, in many respects, one of the first times that the development world has paused to monitor the views of infected and affected children in the school system, in respect of HIV and AIDS programmes and provision.

That the outcomes are as sobering as they are is less a condemnation of the education system than an overdue recognition that response is not as simple as it may have seemed in the halcyon days of policy development. Rights-based, comprehensive policies abound in Africa, but this study confirms that bridging the gulf between their declaration and implementation is no easy matter. That, in short, is the challenge that lies ahead if education is to play its role in managing and mitigating the impact of HIV and AIDS.

Summary recommendations

These recommendations integrate those made in the two country studies, and add additional layers of detail and focus. Most importantly, they seek to respond directly to the areas of concern that have been highlighted by the evidence of respondents in both Namibia and Tanzania. In addressing these, it should be remembered that under each heading there are options for immediate, short-, medium- and long-term action. In other words, while there are a number of important interventions that should be actioned now, aspects of these recommendations will take time, planning and considerable resources to implement.

In the latter regard, and given the limited success of implementation to date, the question arises of how the implementation of these recommendations can be more effective? The answer, simply put, is that the evidence presented in this study should focus fresh attention on the problem of implementation in general, and involve independent partners in the oversight of it, in future. In addition, the revitalisation of regular monitoring and reporting of policy implementation should be a non-negotiable task for HIV and AIDS management units, and the addition of independent oversight – to include PLHIV network representatives – should help ensure this happens.

Policy, regulatory frameworks and guidelines

In light of the apparent failure of policy implementation, at least in the view of the respondents in this study, it is imperative that effect be given to sector HIV and AIDS policies, regulatory frameworks and guidelines. However, to achieve this, it is recommended that:

1) An independent national commission should be established in each country to assess the extent of policy and guideline implementation at every level of the system, and report failures where they have occurred. This should generate a detailed review of implementation status in relation to the spirit and letter of the country policies and guidelines concerned, and ensure that the educational needs of HIV-positive learners and other affected children are adequately addressed.

2) Terms of reference should include provision for the commission to make recommendations for revision of these policies and guidelines where required, to better facilitate practical, decentralised implementation. Membership of the commission should include NGO and development partners, as well as PLHIV network representatives.

3) Once complete, decentralised and prioritised implementation planning should be required at the district level, with clear allocation of responsibility, timelines and budget requirements. These plans should be developed interactively with relevant development partners, including NGOs, CBOs and FBOs, and formal agreements on roles and responsibilities entered into.

4) A limited number of key implementation monitoring indicators should be developed and a regular reporting and dissemination format agreed.

5) A core group of the independent national commission referred to above should be institutionalised as an independent oversight committee to review this monitoring and reporting on a regular basis, and comment where necessary or appropriate.

6) Based on these policies, simple guidelines should be developed in appropriate language options on the rights of infected and affected learners (and teachers). These should be displayed in every school at an accessible point and provide comprehensive details of where to obtain counselling, treatment referral and other support services.

7) Sanctions and disciplinary procedures for violations of policy-derived regulations and guidelines should be reconfirmed and disseminated to every teaching and non-teaching employee of the MoE.

HIV and AIDS management

The role, function and effectiveness of HIV and AIDS management units with these MoEs were extensively questioned by respondents, not least because of their conflicting reports of activity and response. Since these units are, by definition, the MoE's lead units on HIV and AIDS, the apparent failure of policy implementation monitoring and reporting must also lie at their door to some extent. It is therefore recommended that:

1) The independent national commission tasked with reviewing policy implementation should also review the operations and performance of MoE HIV and AIDS management units and their structures. The commission should provide an oversight report and recommendations on any restructuring or redirection it deems necessary, to ensure these units play an effective lead role in coordinating and managing response.

2) Following and depending on the content of this report, the HIV and AIDS management units in each case should be responsible for coordinating and reporting the implementation monitoring process, based on agreed indicators. In addition, in light of the further recommendations below, these units should be responsible for the quarterly or trimesterly reporting of all other HIV and AIDS-related activity in the sector.

Reduction of stigma and discrimination

In an ideal world, this problem might be resolved through the promotion of a culture of tolerance and understanding in schools, in which OVCs and HIV-positive learners can be confident and accepted as worthy citizens, without stigma or discrimination. However, as respondents in this study confirmed, stigma runs deep and will require sustained action to reduce it to manageable proportions. Thus, while policy declarations or communications campaigns will provide a context, it must become a focus for fresh attention and the clarification of learner rights. This means the unequivocal adoption of disciplinary action and sanctions against any person deemed to incite or increase stigma and discrimination within the education sector. It also means the adoption of practical mechanisms to reduce the exposure of HIV-positive and other affected learners to such stigma and discrimination. It is therefore recommended that:

1) HIV-positive learners and other children affected by HIV and AIDS should be integrated for practical purposes, including access to feeding schemes, fee waivers, bursaries and other support systems, into the wider group of OVC, confirming the approach now in evidence in Namibia and Tanzania.

2) Within this wider group, HIV-positive and other children affected by HIV and AIDS enjoy the rights due to them in terms of the education sector and national policy on HIV and AIDS, including unimpeded access to counselling, medical treatment and other associated support services.

3) MoEs should make every effort to promote a culture of tolerance and understanding in schools, and should explore best practice in other countries in this regard. Apart from the promotion of human rights and responsibilities, this should explore all of those issues of human sexuality and typecasting that are perenially ignored, through enlightened teaching and relevant and accessible materials in schools. This should also require the commitment of teachers to work within the policy framework and ensure social justice in the classroom.

Counselling, testing and treatment

On the evidence, teachers are often unable or unwilling to play their part in support and guidance in the classroom. There may be good reasons for this, including embarrassment, competing agendas and work overload, all of which reinforce the need for adequate counselling at school level – including some measure of teacher orientation. It is therefore recommended that:

1) Every teacher, in pre-service or in-service training, should receive a comprehensive orientation module on HIV and AIDS, with particular attention to policy and the rights of the child, including those HIV-positive or affected by HIV and AIDS. This module should also include guidance on care and support as well as treatment literacy. Teachers should also be sensitised to early signs of learner problems, including symptoms of HIV, in order to guide or refer the child appropriately. These modules should be linked to, and equip teachers to present new examinable materials in the curriculum, as discussed below.

2) The training of counsellors should be accelerated where necessary to ensure the provision of at least one counsellor, but preferably two, in every school, including those in rural areas. In recognition of the high numbers of small schools with limited enrolment, this provision could be supplemented by volunteer teachers additionally trained and equipped for this task, via a rigorous selection process.

3) Clear and accessible guidelines should be established on referral to ensure that all teachers and counsellors are fully informed of their options. In addition, the MoE should establish and disseminate a database of all programme support and service organizations, including contact details and geographic location.

4) HIV-positive learners (and teachers) at the secondary level should be given the opportunity to train as peer educators, and, where appropriate provide support to school counsellors. Materials and modules for this purpose should be developed and made available.

5) Voluntary counselling and testing (VCT) and ART facilities should be universally available with a reasonable distance of every school, and should be "child-friendly" with an absolute assurance of confidentiality and privacy.

6) Once such VCT and ART facilities are universally available, policy and legislation should be revised to allow and encourage all children over the age of 12 to test at their own discretion.

Curriculum and information

The study confirms that an underlying cause for much of the trauma, stigma and marginalisation is lack of comprehensive, "down-to-earth" information. Secondly, almost every respondent noted that, until this subject area is an examinable part of the syllabus, it will continue to be treated "flippantly". It is therefore recommended that:

1) Gender and age-appropriate sexual and reproductive health, HIV and AIDS and life skills materials should be incorporated without delay into the curriculum as an examinable subject, to increase access to comprehensive knowledge and understanding. This curriculum revision should also deal with the sexual and reproductive health needs of HIV-positive learners and other affected young adults and draw on international best practices, but with due regard for local customs and practices.

2) A curriculum guidance panel should be established to support this process, and should include NGO partners and PLHIV network representation. Mechanisms should also be found to regularly test HIV-positive and other learner reaction.

Nutrition

The critical role of adequate nutrition in support of ART also makes this a non-negotiable element of any comprehensive response. Moreover, the extent of vulnerability due to a basket of associated causes suggests that the need for nutritional support is wide-ranging and should encompass whole districts, for example. It is therefore recommended that:

1) Sustainable feeding schemes should be provided to all schools across vulnerable districts, to guarantee every learner one nutritious meal per day. These should also be accessible to out-of-school children in the district, and used to motivate their (re)enrolment. At the very least, in the event that economic constraints preclude feeding at scale, one meal per day must be guaranteed to those children designated OVC – including HIV-positive learners.

Programmes providing nutritional support and basic care are important for the well-being of children affected by AIDS.

2) Supplementary systems should also be developed to cover periods of school and public holidays, at which time learners would not ordinarily be in school. These supplementary systems should also address the quality of food in boarding schools and other hostel institutions, and responsibility for the monitoring of this should be clearly allocated and confirmed.

Multisectoral partnerships

This study makes it abundantly clear that the education system cannot cope with the added complexities of HIV and AIDS management on its own. It is also clear that the extensive networks of NGOs, CBOs and FBOs – including PLHIV organizations, have not been embraced or formally contracted to provide support services and supplement capacity, to the necessary extent. For this reason, it is imperative to change this culture of limited engagement within MoEs and ensure a consolidated approach to response. Thus, MoEs should be encouraged to enter into partnerships with other social-cluster ministries – such as health and welfare – as well as these civil society networks. This also implies that MoEs must help facilitate the funding of external service provider programmes, through the commitment of their own budgets and motivation of donor agencies to support these. It is therefore recommended that:

1) MoEs should develop detailed databases of service providers and their programmes of support in the fields of HIV and AIDS, orphaning, vulnerability, nutrition, counselling and related areas of activity. This database should be designed to facilitate the negotiation of partnerships and be widely and comprehensively disseminated to local levels to assist schools in referrals.

2) Based on this organizational and programme information, MoEs should enter into a range of formal partnerships with other social-cluster ministries and civil society organizations to supplement their capacity and address policy implementation requirements. Within these agreements, roles and responsibilities should be carefully delineated to avoid confusion and duplication.

3) MoEs should recognise national PLHIV networks and ensure their involvement as programme partners and sector advisers.

4) Development agencies and donor partners should play a major facilitating role in ensuring that these supportive partnerships are developed and formalised.

5) On the evidence of success, MoEs should support these sector partners to take viable programmes to scale, inside and outside the classroom, and help facilitate the resourcing or funding for such scaling.

Poverty

While it is self-evident that conditions of national and regional poverty cannot be addressed within the ambit of this study, its debilitating effect and cumulative impact on the lives of HIV-positive learners and all vulnerable children make some mitigating response a priority. Given that any such response must be within the capacity of the education sector, this will, of necessity, be limited to action at a local, even household level. It is therefore recommended that:

1) Based on policy and other guidelines, principals and school administrators should be sensitised to the need to extend fee-waivers, bursaries and other grants to HIV-positive learners, orphans and other vulnerable children. Where government policy provides for universal, free primary education, such waivers should cover the invariable school-level fees still charged out of hand by the schools themselves.

2) School principals as well as school counsellors should be encouraged to make every effort to assist learners and their families or guardians to access any available child-welfare or other grants, from whatever source. In the event such access is blocked by lack of documentation, such as birth certificates or IDs, school principals and counsellors should be encouraged to assist in sourcing these.

3) MoEs should accelerate engagement and partnerships with civil society organizations to further assist, especially in the provision of school uniforms, shoes and stationery, for example. In short, the welfare of infected and affected children should become a focus of attention at the school level, without detracting from the routine functions of teaching and learning.

Endnotes

1 WHO/UNAIDS. 2008 Report on the Global AIDS Epidemic. Geneva, UNAIDS.

2 Ibid.

3 UNAIDS. 2007. 2007 AIDS Epidemic Update. Geneva, UNAIDS.

4 World Bank 2006.

5 WHO/UNAIDS. 2008 Report on the Global AIDS Epidemic. Geneva, UNAIDS.

6 Ibid.

7 Zanzibar was not included in the study.

8 WHO/UNAIDS. 2008 Report on the Global AIDS Epidemic. Geneva, UNAIDS.

9 See full text of UN Convention on the Rights of the Child at http://www.unhchr.ch/html/menu3/b/k2crc.htm

10 In addition, these questions and issues were designed to reflect themes explored in the UNAIDS Inter-Agency Task Team (IATT) on Education. 2006. Education Sector Global HIV & AIDS Readiness Survey 2004: Policy implications for Education and Development which researched related issues in 71 countries worldwide in 2004. This was done to facilitate some comparison of self-reported Ministry of Education statements in 2004 with the views of education system clients, managers and partners in 2008. While no direct comparative analysis can be inferred, the overwhelming concurrence of the views expressed in this 2008 study confirms the value of such baseline reference.

11 The International Community of Women living with HIV/AIDS (ICW). 2004. Guidelines on Ethical Participatory Research with HIV Positive Women. Washington, ICW.

12 See the International Community of Women Living with AIDS website at www.icw.org.

13 The full Namibia and Tanzania country research reports can be found on the UNESCO website at http://unesco.org/aids

14 The desk study (UNESCO. 2008. Supporting the Educational Needs of HIV-Positive Learners. Paris, UNESCO.) may be found in full at http://unesco.org/aids

15 See full text of UN Convention on the Rights of the Child at http://www.unhchr.ch/html/menu3/b/k2crc.htm

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This report is a commissioned review of best practice as well as an exploratory study in two countries – Namibia and Tanzania – to understand how the education sector should support HIV-positive learners at school. The increase in the number of children and young people living with HIV poses new challenges to the education sector. The report identifies the specific challenges faced by the education system in responding to the needs of HIV-positive learners and develops a set of recommendations and guidelines about how best to support them.

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