



United Nations
Educational, Scientific and
Cultural Organization

Supporting the educational needs of HIV-positive learners:

a desk-based study

EduSect **r**
AIDS Response Trust

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with EduSector AIDS Response Trust

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This desk-based study of available literature and service provision regarding HIV-positive children and young people was written by Peter Badcock-Walters, Director of the EduSector AIDS Response Trust (ESART), in collaboration with Jane Kvalsvig. It was designed as a precursor to a two-country research study in Namibia and Tanzania. A final consolidated report summarising the desk-based research and the two country studies has also been written. All these reports are available in full on the UNESCO website at <http://www.unesco.org/aids>.

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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	Education Sector 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
TACAIDS	Tanzanian Commission on AIDS
TANOPHA	Tanzania Network of Organizations of People Living with HIV and AIDS
UNAIDS	Joint United Nations Programme on HIV and 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

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 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.

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 disturbingly high in sub-Saharan Africa. At a time when the numbers of children in residential care in orphanages, cluster homes and shelters are increasing, a high proportion 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 education¹. 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 in enlisting 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 members of the school community should be sensitised through awareness-raising and training in order to reduce stigma and discrimination. 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.

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 if they are willing to make their expertise available to the wider community.

New programmes and examinable curricula must be developed to proactively meet learners' 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 concerns raised in the classroom.

In conclusion, there is an onus on the wider education sector in affected countries to help support and guide HIV-positive 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.

Chapter 1:

Introduction

The EduSector AIDS Response Trust (ESART) in South Africa was commissioned in November 2007 to produce a stock-taking exercise which drew together international best practice on support for HIV-positive learners, children and young people. This desk study was designed as a precursor to a two-country research study in Namibia and Tanzania. Separate reports on each country study and a summary report can be accessed from UNESCO's website at <http://www.unesco.org/en/aids>.

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 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. In this review, some attention has been given to how responsibility is apportioned and what the mechanisms are for facilitating a collaborative approach.

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

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.

Chapter 2:

International practice and evidence

International policies and conventions

The United Nations Convention on the Rights of the Child has been signed by all member states with the exception of the United States of America and Somalia. It is based on four fundamental principles: non-discrimination; upholding the best interests of the child; the survival, protection and development of children to the maximum extent possible; and participation (the right of children to be heard)¹.

The rights that point the way to what is required for HIV-infected children are: survival and development (Article 6); non-discrimination (Articles 2 and 30); special protection and assistance if deprived of the family environment (Articles 20 and 22); the rights of people with disabling conditions (Article 23); and education (Articles 28-29). HIV-infected children 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. Moreover the nature of their infection puts them at risk of disabilities.

Given the education focus of this review, it is important to look at Articles 28 and 29, which deal specifically with education and go beyond simply allowing children into a classroom (see Appendix A). State signatories to this international convention are obliged to undertake all appropriate legislative, administrative and other measures in order to implement these rights². HIV infections can have disabling consequences, and here too Article 23 makes provision for special care that goes beyond simply accepting the children into an education system (see Appendix A).

Although they may have different emphases with respect to children's rights, both the African Charter on the Rights and Welfare of the Child (1990) and the South African Children's Charter (1992) join the Convention on the Rights of the Child with similar protective clauses, indicating substantial agreement on these essential rights.

These conventions and charters then have to be ratified by member states, and all new laws have to take account of them. Although they represent powerful international, regional and national statements in support of the right to education of HIV-infected children, the next

set of factors in realising the rights are situated in the government's will to pursue the matter with urgency, the country's resources and the management skills in the relevant service agencies.

Lessons from the past, and emerging practice

The most important lesson learned from the past is the way in which an early and whole-hearted response at the level of a national government can avert the main force of the HIV epidemic. Hsu maintained that this essentially involves the government's respect for human rights³. He examined the way in which a rights-based approach by some governments was able to make a significant impact on the course of the epidemic in their countries.

The Brazilian government gave an important lead in translating the rights of HIV-positive people into practice. Hsu attributed the success of the government action to the fact that there was an early concerted response, systemic advocacy of human rights in all strategies, multisectoral mobilisation, transparency, and a balance between prevention and treatment in the approach. Abadia-Barrero describes the effects this response had on the lives of HIV-infected street children, giving them hope for the future⁴.

In the case of Thailand, Hsu noted that political leadership and budgetary provision for the campaign were important factors in initiating a timely response. An open acknowledgment of the practices in society that drove the epidemic enabled prevention programmes to target vulnerable groups successfully. In Thailand, these driving factors were identified as sex work, injecting drugs and trafficking in women and children. There was considerable multisectoral cooperation, with commerce and industry joining government in the campaign. Sadly, the lack of cooperation between law enforcement officers and health officials in targeting the injectors of illicit drugs meant that this aspect of the programme was less successful and this led Hsu to emphasise the importance of cutting through administrative barriers.

In Africa, Uganda, one of the world's least developed countries, mounted a very visible and valiant campaign against the transmission of HIV. Once again, political

leadership, transparency and a multisectoral response were thought to be key factors.

The lesson from the past is that, although a rights-based approach is an important legal step in the support of HIV-infected children, and has been endorsed by almost all countries, it is nevertheless only a first step. Political support, infrastructural and financial resources and managerial skills have to be developed if countries are to move from simply paying lip service to children's rights towards practising what they preach.

Regionally, it should also be acknowledged that what happens in one country affects its neighbours, influencing both infection levels and strategies for prevention and treatment⁵. There is a strong case for governments to cooperate in regional and international campaigns to fight profiteering in the pharmaceutical industry and to set up early warning and rapid response systems, as pioneered by the South-East Asian communities⁶.

It goes almost without saying that within countries there is a need to set up effective monitoring systems so that the size and intensity of a health threat is understood and adequate responses can be planned. Developed countries are at a comparative advantage given that they have a far better supply of skilled personnel, sentinel sites and budgeting processes to support intervention as well as a well-informed population that can respond more effectively to the threat posed by the epidemic.

All of these lessons can be applied to the specific educational needs of HIV-positive learners, the subject of this review. There should be improved cooperation across countries so that important foci of common concern can be addressed in good time and before the infections spread. Within countries, responses should be driven by a rights-based approach; there should be imaginative political leadership and an open acknowledgment of problems. There should be cooperation across government departments involving civil society, with roles and responsibilities clearly defined and understood. In education ministries, the mechanisms for cooperation should be put in place at national, provincial and local level, and continued right down to individual schools and teachers, and accountability for action should be made clear at each level. These broad guidelines are not controversial, but neither are they particularly helpful. The size of the problem and the resources required to address them vary considerably from place to place. A much more

detailed understanding is therefore required of the systems involved, one that takes account of different levels of country development.

Role of government and NGOs in multisectoral responses

Support for parenting and stimulation programmes in the home and for early education sites often fall to the non-government sector in many countries but are an important and intrinsic part of education. Mechanisms need to be put in place for supporting them and ensuring accountability. Many orphan care programmes for children of all ages are run by faith-based or non-profit organizations. These valuable contributions from civil society extend the coverage of services to HIV-infected children. It is noted, however, that these are often undertaken in association with ministries of social welfare and may in fact involve service delivery contracts.

Government ministries therefore have a role to play in making appropriate subsidies available to non-government organizations that are doing work in accordance with nationally approved goals of care and education for children. They can uphold the quality of the interventions by monitoring and evaluating their programmes and by providing or subsidising good quality training for community workers in the non-profit sector. They can make sure that basic services like clean water and sanitation are available to organizations dealing with children. More importantly, they can plan and act in partnership to supplement government provision, particularly in rural and informal settlement areas in urban centres.

By encouraging the involvement of community workers in promoting the care and development of young children, there is increased likelihood of early identification and treatment of HIV-infected children and a consequent improvement in the prognosis for the child. The implication is that government and the NGO/ CBO/ FBO community – representative of civil society – are mutually dependent and should have a shared agenda for action.

Roles of PLHIV networks and groups

In a declaration published on their website (www.rapnap.org), *Now more than ever*, the Network of African People Living with HIV (NAP+) states clearly that a rights-based approach is the only way to achieve universal access to treatment and prevention. It cites the case of Brazil as one in which the epidemic was slowed by placing human rights at the forefront of government activity and planning. They put forward ten reasons why a rights-based approach should be central to the attack on the epidemic. Of particular relevance to this document is their public acknowledgement that women and girls are particularly vulnerable, and that the rights of children and youth have been largely ignored. Regionally in Africa, the network has a central secretariat in Nairobi, Kenya, and three sub-regional secretariats (Harare, Abidjan and Yaoundé).

Members of the organization make it their business to seek out information on HIV and AIDS and to promote healthy living. They also have the experience of living with the infection, and therefore they are well placed to monitor and assist with the development of curricula for school-age children, particularly those in early adolescence, so that they are well-informed of the risks before they become sexually active. This is one of the cases where civil society organizations can add value to formal education campaigns by presenting real-life stories to add to the immediacy and impact of more theoretical information.

Summary and key points

- Governments that are signatories to the United Nations Convention on the Rights of the Child, and have ratified it, are legally obliged to show that they have plans to realise the rights of all children, including HIV-infected children, and that they are making progress towards this goal.
- In the terms of the Convention, the rights of all children to education are extensive. For example, Article 29 directs that the child's personality, talents, and mental and physical abilities should be developed to their fullest potential.
- Although international conventions and charters on children's rights are powerful statements, government action and an adequate allocation of resources are required if the needs of HIV-infected children are to be met.
- In a few countries, the main force of the epidemic appears to have been mitigated by timely and comprehensive government action. Strong political leadership, effective policy and legal frameworks, multisectoral mobilisation, adequate planning and resourcing (based on reliable data) and a transparent process are thought to be key factors.
- Governments can cooperate regionally to fight drug profiteering and to set up early warning systems that monitor changes in the incidence of infections. Monitoring systems within countries should be developed to ensure the availability of adequate resources.
- Mechanisms should be developed to facilitate cooperative action across government departments, and between government and civil society agencies.
- This cooperation should happen at national, provincial and local level, and continue right down to individual schools.
- PLHIV networks are rights-based organizations that are well placed to assist with the development of curricula for school-age children, particularly those in early adolescence, so that they are well-informed about risks of infection before they occur. They also have an important monitoring role in ensuring that the rights and needs of HIV-positive children and learners are understood and observed.

Chapter 3:

Children and HIV

HIV impact and scale of the problem

The estimated number of HIV-positive children across the developing world in particular is disturbingly high. The most recent UNICEF report records an estimate of 2.5 million children under the age of 14 who are HIV-infected. Nine out of ten of these are in sub-Saharan Africa⁷.

The UNAIDS update report cautions against a simplistic view of the prevalence rates reported for a country and notes that “even within a country there may be a series of multiple, changing and overlapping micro-epidemics”. In the case of South Africa, provinces have very different prevalence rates with the province of KwaZulu-Natal being the epicentre of the epidemic with a prevalence of 39.1% being reported in antenatal clinic attenders, as against 15.7% in the Western Cape province⁸. The rates for black Africans are 6 to 7 times higher than for others, while for females aged 15–29 the rate is three to four times higher than for males in the same age group. These inequities suggest that it would be wise to understand these epidemiological forces and to target the groups most at risk with interventions carefully designed to meet their needs.

UNAIDS and UNICEF reports over the years concentrate mainly on health issues, mortality, treatment and control, but with the advent of antiretroviral treatment for children other issues can come to the fore. International agencies and national governments are starting to recognise the central role that schools should play in preparing both infected and uninfected children for a world where AIDS threatens not only their lives but also their emotional well-being and their cognitive development.

The United Nations Report on the Millennium Development Goals notes, amongst the successes, that progress has been made in getting more children into primary school and that child mortality has decreased globally⁹. Sub-Saharan Africa, as a region, however, is

lagging behind in the goal of achieving universal primary school enrolment by 2015. Worldwide the number of people dying from AIDS has increased, and the report concludes that prevention measures are not keeping pace with the growth of the epidemic. While under-five child mortality has decreased globally, in HIV hotspots like South Africa it remains at very high levels.

Special needs of HIV-positive children

The biological effects of HIV include malnutrition, anaemia, recurrent and chronic illness, and specific neuro-developmental effects. Children with symptomatic HIV disease may suffer from disease-associated morbidities such as respiratory infections, malnutrition and diarrhoeal disease. Like other children with chronic diseases and disabilities, their health problems can affect school entry and progress.

HIV-positive children are subject to different classes of special needs. The first relates to the infection itself and the neurological damage it inflicts. The second relates to the opportunistic infections and the disturbances caused by their frequency and severity. The third relates to the family environment, with the likelihood of bereavement, poverty, changes in caregivers and all the other disturbing life events that HIV-positive children share with the HIV-negative children of infected parents. The difference in this case is that the family stresses and pressures are complicated for the HIV-positive children by the fact that they have to cope with their own illness as well.

Neurological damage

As reported in an overview of the special needs of HIV-positive children¹⁰, children who are HIV-positive risk neurological insult¹¹. Infected children may have hearing impairments, language and motor skill deficits, verbal and memory deficits, impaired visual-spatial integrative ability, poor executive function, hypotonia and/or hyperactivity. Some of this is reversible when the children are on treatment, but there is substantial evidence of residual problems in school-age children, including attention deficit disorder and hyperactivity.

The clinical conditions in children most likely to be noted in the school situation include recurrent infections and failure to thrive¹². Anand notes that the course of central nervous system infection is characterised by delays in development, loss of acquired motor, speech, adaptive and social skills and decreased interactions with the environment. Coplan and co-workers found evidence of language deterioration, which usually improved after the initiation of antiretroviral therapy¹³.

Early diagnosis and treatment, or good medical care (where antiretroviral treatment was not available) seemed to have a protective influence in some cases, but the fact remains that in highly endemic areas, there will still be an increased need for special education services.

Frequent infections and absenteeism

The fact that some HIV-positive children progress slowly in school and are older than other children in the class may be due in part to the fact that they are frequently unwell, or have to attend clinics for treatment purposes, and may have difficulty in keeping up with schoolwork. HIV-positive children on antiretrovirals have a reasonable expectation of surviving to adulthood, and need preparation for employment, independence and responsible sexual relationships.

Even children who are not themselves HIV-positive, but come from HIV-affected families, are often unable to attend school when they are needed to assist at home. It should be possible for curriculum planners to produce home learning programmes and home projects for children who are unable to attend school.

These resources may help children to pick up again on schoolwork if they are made grade-appropriate.

HIV-clinics and children's wards in hospitals should also be stocked with attractive and age-appropriate toys and learning materials so that children who are unwell or obliged to spend hours waiting for treatment monitoring at least have some pleasant distractions, and ones that are developmentally valuable.

Children with HIV are more vulnerable to communicable diseases. In high prevalence areas, it is important to be especially vigilant about hygiene in schools and preschools to protect children as far as possible from opportunistic infections. Clean water supplies, hygienically kept toilets and hygienic preparation of school meals are always important in schools, but standards need to be particularly high in schools with HIV-positive children.

However, the reality is often quite distant from this ideal, particularly in resource-poor settings. In practice, such access and support are often complicated by local conditions, including fear of exposure to stigma and discrimination. Anecdotal evidence from PLHIV networks in southern Africa, for example, suggests that access to treatment and support for young people is fraught with problems, judgmental attitudes and personal trauma.

Lack of early stimulation for HIV-positive children

Children who are brought up in households disrupted by illness and death, and who themselves may be sickly and often hospitalised, will probably lack the early stimulation that has been shown to be a key factor in cognitive development. Very young children react to emotional situations without necessarily understanding the implications.¹⁴ There is a tendency for bereaved children to internalise problems and be depressed and withdrawn, thus reducing beneficial social interaction.¹⁵ Every opportunity should be taken to remedy this. A variety of early education programmes exist in many countries, often from the non-government sector. They range from home and community-based parenting or grandparenting programmes, to centre-based preschool programmes. However, parents or alternative carers in HIV-affected households need to be made aware of the programmes in their neighbourhood and should be

encouraged to participate. Education and social welfare ministries should coordinate, monitor and support these services so that they are more widely available and are of a reasonable standard.

Children in institutions

Children in institutions represent a special case for educational support. While most international agencies focus on the negative aspects of institutions as homes for children, some of the children's homes offer care and educational support of a higher standard than that available in the children's own very poor communities.¹⁶

The reality in resource-poor settings is that the number of places providing residential care for children in South Africa is increasing rapidly, and a disproportionate number of the children are HIV-positive.¹⁷ This report suggests "widespread abuse, neglect and abandonment of children to be the major reasons for their entry into the residential care settings, and that HIV and AIDS and poverty are part of a complex causal pathway rather than the dominant reasons for admission". The authors note that the knowledge of HIV in these settings was uneven, in spite of the high numbers of HIV-positive children in residential care.

In another study of HIV-positive children in residential homes in South Africa, Domek¹⁸ noted that many children were susceptible to upper respiratory infections, and some were partially deaf and needed hearing aids. Most homes did not have access to a psychologist or, if they did, it was minimal and thus contact time was reserved for seriously disturbed children.

While residential care may be the only option for large numbers of children who are HIV-positive, and the quality of the care may be high, the problem still remains that residential care may not be able to provide children with the links into the community. This means that when the time comes to leave the institution they have no home to go to, and are not accustomed to handling money or preparing food and are without a number of the other skills that are needed for life outside an institution. The school environment then becomes an important adjunct to institutional care, through formal and informal learning experiences, social contacts and experiences, guidance through adolescence toward adulthood, and assistance with learning and emotional

problems on the way. This should include the social, sexual and reproductive health information needs of ALL children, and make provision for any additional and specific information and guidance needed by HIV-positive learners.

Treatment compliance

Like other children with chronic ailments, children on antiretrovirals will have to take medication every day. However, unlike diabetics, there will be no immediate and obvious consequences if they forget to take their medication. Ultimately though, failure to comply will have serious health consequences and the child will die. This constant need to take medication is a difficult responsibility for a child. Teachers may have to support the process tacitly, without drawing attention to it, if they are aware that the child is on a daily regime of medication. This also implies the need for sensitivity to the associated needs of the child and assurance of confidentiality and support. However, conditions in many affected education systems suggest that many teachers may not have the capacity, skills, time or personal inclination to assume this role as part of their classroom responsibilities. More to the point, it is often argued in these systems that this role should fall to counsellors, medical professionals and parents or guardians rather than teachers; this view ignores the lack of such counselling and medical support in resource-poor settings and is often motivated by personal reluctance to address issues associated with sexuality and HIV.

Education and prevention

Unless there is a reduction in the incidence of new infections in the education sector in developing countries, all systems involved with HIV run the risk of being overwhelmed. The South African Department of Education has set out broad guidelines for educators (see Box 1).

Many young people have their first sexual experiences while they are still of school-going age, and should have the knowledge or means to protect themselves against infection, to avoid consequences that could be life-threatening, both for themselves and for a child

born from an early pregnancy. However, in addition to the comprehensive sexual and reproductive health information required by ALL young people, HIV-positive children and learners have special needs in respect of their sexual and reproductive lives as PLHIV.

While teachers see children on a daily basis, and are theoretically better placed to discuss these issues and work through them gradually over time than primary health care professionals, this may not always be addressed. In fact, evidence from many affected regions suggests that teachers are often reluctant to engage these issues due to feelings of embarrassment, inadequacy or personal value systems; these issues may be compounded by cultural guidelines or traditional roles within local communities. It is therefore vital that the roles of teachers, and those of other counselling and health professionals, community workers, parents, guardians and caregivers are clearly considered and proscribed. In this way, a context and connection can be established to support the teacher's role in the classroom and compensate for any shortcomings in addressing the complex issues associated with HIV, its prevention and management at this level.

Workforce issues

There is a 'brain drain' phenomenon whereby trained workers in the fields of health and education leave less developed countries to seek employment in developed countries. Superimposed on this in highly endemic countries is the impact of the AIDS epidemic. There are increased deaths amongst health and education professionals, increased absenteeism from those infected, and those whose family members are infected and require assistance. Under these circumstances, the organizational environment needs to elicit commitment¹⁹. Among the strategies suggested are: the expansion and stabilisation of the workforce; and explicit workplace policies for those affected by the epidemic that include psychological and financial support, and non-discrimination.

These issues will be taken up later in the review, but is important to note here that teachers cannot be expected to assist learners effectively when they are not fully informed about transmission, testing and treatment, or are themselves the target of discriminatory remarks or policies.

Box 1: Guidelines to educators – South African Department of Education

Educators must set an example of responsible sexual behaviour. In so doing, they will protect their families, colleagues, learners and themselves.

- Because educators are well educated, they can grasp the facts about HIV and AIDS and help spread correct information about the disease and its effects.
- Almost every young person attends school, so educators have a great opportunity to discuss the disease and help the young to protect themselves from becoming infected, getting sick and dying.
- Educators are in frequent touch with parents, and can therefore spread the message about HIV and AIDS deeply into the community.
- Educators can help create an environment in the workplace where people can be open about their HIV status without fear of prejudice or discrimination.
- Educators can find creative ways to support their ill colleagues and learners, and make the school a centre of hope and care in the community.

Source: Department of Education, South Africa, 2002

Box 2: HIV-positive Teachers consultation

UNESCO held a technical consultation in Nairobi, Kenya, in 2006. Among the recommendations to support HIV-positive teachers were the need to:

1. Ensure access to treatment, care and support
2. Provide support for teachers by teachers on a day-to-day basis at school level
3. Develop partnerships between HIV-positive teachers' networks and teachers' unions to support teachers' rights
4. Train members of the school community (teachers, school board members and parents) to reduce the stigma associated with HIV.

Source: UNESCO. 2006. Supporting HIV-positive teachers in East and Southern Africa. Technical Consultation, 30th November - 1st December, Nairobi, Kenya.

Universal precautions

Although there is little or no evidence of transmission of HIV during normal activities in schools or preschools, all children need to be treated as potentially HIV-positive in the course of wound management in the classroom, playground or sports field. Universal Precautions in this regard have been published by UNESCO on its website²⁰.

However, the development of guidelines for implementing these precautions had only been completed in 16% of high-prevalence countries by 2004²¹. Although some progress has been made since then, it is sobering that this 'foundation stone' of good – indeed essential – HIV management practice has been largely ignored close to three decades into the impact of HIV and AIDS on education systems.

Appropriate ages and stages

In an ideal world, one might anticipate that early education practitioners would be available and best-suited to work with young parents in high-risk age groups. In such a situation, assuming these practitioners were well-informed and supplied with posters and pamphlets, as well as the local address of

Voluntary Counselling and Testing (VCT) facilities, they could assist with the transfer of information at formal and informal meetings with parents in order to reduce the incidence of new infections and to prevent mother-to-child transmission.

The reality, certainly in large parts of sub-Saharan Africa and southern Africa in particular, is that early childhood development is far from generally systematised or accessible, especially in rural and resource-poor settings. Consequently, early education practitioners might not be available for this role in many areas, although other role players are to be found. These include often very effective formal and informal community-based childcare associations and networks. However, the reality is that young parents and children in the 0–5 age group are more likely to have contact with primary or community health care workers or social workers than education professionals. As a consequence, much of the information these young parents require may be provided in the context of nutritional or health input rather than via an educative process *per se*.

Another reality is that in many cases these young parents, specifically the mother, may not be available or in evidence for whatever reason, leaving older family members (i.e. grandmothers and aunts) to care for these young children. This may be a complicating or confounding factor as this very common family or community care-giving system may limit reliance on

professional inputs and guidance, in favour of more traditional values or approaches.

These issues and constraints do not change the fact that such early childhood development in the hands of trained professionals is vital for any number of reasons, including the building of the cognitive skills required for later education. It is equally vital, in the AIDS-era, to reduce prevalence and equip those involved with the knowledge and practical skills required to facilitate this. For example, with proper treatment it is possible to reduce the risk of vertical transmission dramatically, so it is vitally important that early education practitioners, along with other community workers concerned with children, transmit life-saving information to parents. It is important that, in the course of their work, they encourage open and accurate information about the epidemic, and strongly discourage myths, rumour-mongering, and discriminatory remarks about HIV-infected people. Training for early childhood education practitioners – as well as all the other players concerned – should prepare them for this role.

Very young children in highly endemic areas are often aware of the words HIV and AIDS (or their local, slang equivalent) and the negative associations these might appear to have. Even 3–5 year olds are starting to discriminate against children who they perceive as different.²² Creating an atmosphere where children's questions are answered in an age-appropriate manner, explaining acceptance and understanding, sets the scene for free and open discussions at school, as the child gets older, on sexual and reproductive health issues and HIV, and ultimately for discussions about personal choices and protection against the infection.

Children's educational programmes on radio and television (such as the Takalani Sesame Programme in South Africa), which treat HIV and AIDS as chronic conditions like any other, assist with demystifying the epidemic for the very young. This is a useful preparation for later school-based programmes on prevention of infection.

Primary school teachers

While it is desirable for primary school teachers to have professional support in devising suitable programmes for young children that provide a comprehensive understanding of the epidemic, most of the information, care and support that primary school teachers can provide will be in the course of their normal teaching duties in the classroom.

Here, information on HIV, together with sexual and reproductive health, constitute but one of many competing subject areas in an already crowded curriculum, further complicated by the problem of teacher shortages and absenteeism. Taken together with the personal attitudes or concerns of the teachers concerned, this may reduce the level of opportunity for learners to acquire and interrogate the information they need. It is also vital, at this early age, to allow children to discuss and question gender stereotypes so that they start to value gender equity, an important precondition to the empowerment of women, and a key factor in the protection of women and in preventing sexual exploitation of women, one of the points made in the South African five-year strategic plan for fighting the epidemic.²³ The challenge will be for education systems to create an enabling environment in which such curriculum 'competition' makes space for these subjects and issues, and to ensure that teachers at this and other levels have sufficient training and materials to deliver the requisite information.

Higher primary school and secondary school

For some parents, sex education at school has raised the spectre of encouraging sexual activity and promiscuity amongst the young. For teachers who may themselves be parents and share some of these fears, the situation of dealing with angry parents is daunting. Every effort should be made to defuse tensions, so that the teachers can do their duty in informing learners about matters that affect them, particularly in endemic areas where children risk contracting a deadly infection if not well-informed about the risks – and shown how to protect themselves²⁴. Studies have confirmed that school programmes that give learners information about safe sexual behaviour do not encourage them to become sexually active²⁵. However, school is not always a safe

place for young girls, and careful surveillance needs to be undertaken to ensure that vulnerable female children are protected from sexual violence²⁶.

Sensitively presented and age-appropriate sex education programmes will help both infected and non-infected learners to acquire the confidence needed to make safe choices as they mature sexually. Fortunately there are now many teaching aids such as the *HIV and AIDS myth buster*²⁷, media programmes (such as *Soul City* <http://www.soulcity.org/za>), and agencies employing young people (*Love Life* <http://www.lovelife.org.za>) or HIV-infected people (PLHIV networks) to assist school teachers to give clear information in a way which is likely to hold the interest of young learners and present accurate information.

Some of the materials and curricula assume that the recipients of the message are not themselves HIV-infected. This is understandable because until recently children born with HIV infections were not expected to live long. However, it has now been recognised that there is a substantial group of “slow progressors” who survive to school-going age, even where antiretrovirals are not available, as well as a growing number of children on antiretroviral therapy. Educational programmes that do not include these children and assist them to manage their own emerging sexuality, risk alienating them and they may be then be a danger both to themselves and to others. Because disclosure is not a prerequisite for school enrolment, all children should be made aware of how HIV-positive individuals need to manage their sexual activities safely, on the assumption that there may be HIV-infected children in the classroom who will need this information. It may also assist those uninfected learners who later have a sexual partner that they know is infected, to protect themselves.

Higher levels of education are intrinsically desirable for children in the school systems of any country, but are particularly important in developing countries where skills shortages hamper economic growth. Higher levels of education have also been associated with safer sexual behaviours and delayed sexual debut²⁸, and this constitutes yet another good reason to try to retain learners longer in formal schooling. The World Food Programme promoted education through its collaboration with UNESCO in feeding schemes in 11 countries on the explicit assumption that education has an important role to play in decreasing sexual risk-taking²⁹.

Treatment access for children, and disclosure in an education context

Monitoring and early warning

All the evidence points to the fact that, the sooner HIV infections are diagnosed, the greater the chances are that a child will survive and thrive, and fewer neurological complications will arise. Current guidelines advise that all pregnant women attending antenatal clinics should be tested, and that the infants of HIV-positive mothers should be tested as early as six weeks of age. However, large proportions of mothers and children remain untested. Early education practitioners, associated health care and other professionals, and school teachers should be alert to the possibility that children who are frequently ill should be referred for HIV testing – subject of course to appropriate procedures and the agreement of their parents or guardians. The Integrated Management of Childhood Illness (IMCI) and the Ten Questions Plus (TQP) have simple and sensitive algorithms for screening children for possible referral. The signs and symptoms of HIV infection (such as oral thrush) are listed, for example. If the school and preschool system can be linked to a school health programme with trained primary health care workers, this would assist with the early identification and referral of possible infections. Where this facility is absent, teachers should be aware of the dangers, and informed of referral procedures so that they can communicate these to parents of children who appear recurrently sickly.

It is often the case that an infected parent is frightened of the consequences of the infection and the stigma attached to it, and unwilling to admit the likelihood of infection, even to him or herself. In these circumstances, it is the difficult duty of those who have recognised the situation, to reassure and support the parent, and to support them through the referral and testing process as well as the initiation of treatment. While not every teacher may feel capable of performing this function, it is important that every school has someone who is well informed about HIV, trained in how to approach the parent over this sensitive matter, and motivated to assist them to find help.

Box 3: A checklist of referral services

- testing and counselling services
- primary care or NGO clinics for HIV, including treatment for opportunistic infections
- peer support groups and post-test clubs
- income-generating groups or micro-credit organisations
- orphan or vulnerable child support services, including those that assist with school fees
- home-based care programmes and those involved with food distribution to vulnerable households
- sexual and reproductive health services, including STI diagnosis and treatment and contraceptive advice
- preventing mother-to-child transmission services
- suppliers of condoms and injecting equipment
- drug substitution treatment services for injecting drug users.

Source: International HIV/AIDS Alliance³⁰

Referral: Linking education with health and other service providers

A key issue in prevention and treatment is to set up an effective referral register for all teachers, parents or learners who require HIV services. This should be widely communicated, encompassing not only counselling and testing, and other treatment and prevention matters, but also services that will assist children and their families to deal with other ancillary aspects of disease such as home help for families thrown into turmoil, and access to financial or nutritional support. The International HIV/AIDS Alliance list basic services (see Box 3), and suggest that a list like this is most helpful for referral purposes when it is coupled with local information about where it can be obtained, exactly what services are offered, and the quality of the service.

Guidelines on the management of disclosure of the child's status to the school

Within an education system, there are two very different issues relating to disclosure of infection status: disclosure to the school or preschool of a child's or teacher's infection status, and disclosure to a child of his or her infection status.

With respect to disclosure to the school, it has to be said at the outset that disclosure should open the way to support, but this may only happen in an accepting environment. All too often disclosure results in discriminating practices and hurtful remarks. As leprosy and cholera were spoken of in the past, so people with HIV today are sometimes spoken of in demeaning terms and moral judgments are made about them³¹.

For these reasons, it is important that teachers are proactive in creating a climate of acceptance within the school. Higher rates of disclosure have been linked to communities that had more access to government and non-government social services, and more opportunities to take leadership roles in organizations like PLHIV networks³². The International Centre for Research on Women has released a revised toolkit for reducing stigma, based on their research in Ethiopia, Zambia and Namibia, and the finding that stigma stems from misinformation and moral judgments about people who get HIV³³. It deals with the principles of devising a

programme to reduce stigma and includes modules on stigma and children, and stigma and young people.

Disclosure to children

Disclosure regarding the nature of their affliction to the children themselves is the responsibility of the child's parent or alternative guardian or caregiver, and should not be usurped by a teacher. However, teachers should understand the issues around disclosure to children and be able to respond sensitively to children's questions, and to assist parents/caregivers if asked. This is not easy. Until recently, when antiretroviral therapy became available in developing countries, most children did not survive beyond the age of five. Most organizations working with infected children devoted their energy to palliative care rather than to disclosing their HIV status to the children.

Using ethnographic methods, Abadia-Barrera and Larusso described how HIV-infected children of different ages in an institution in Brazil were confused and mistrustful when there was poor communication and an absence of developmentally appropriate information³⁴.

“Children younger than 6 learn to accept medication taking, and to silence illness-related questions. Seven to 9-year olds perceive that the word AIDS and/or being sick are considered negative attributes, but are confused about how these relate to their lives. Preadolescents’ growing awareness of the relationship between their lives and negative social values associated with AIDS produces shame and anger. Adolescents exhibit a poor understanding of the implications of HIV and AIDS for their lives and cynicism toward AIDS care, their future, and information about risks to their health.”

In developed countries where experience with antiretroviral therapy for children has a longer history relative to developing countries, and disclosure processes can be guided by professional psychologists, disclosure to children has generally been found to be beneficial to their adjustment³⁵. It was also thought that appropriate disclosure outside of the immediate family might confer some benefits to the child in terms of psychological and physical health, but more research is needed. A process-oriented approach to disclosure, whereby information is given over time, is the favoured approach, but there is insufficient detailed information available at present about how to control the flow of

information to children in an age-appropriate manner. The National Institutes of Health in the United States posted this policy summary on their website:

“Treatment for human immunodeficiency virus (HIV) infection has enabled more children and youths to attend school and participate in school activities. Children and youths with HIV infection should receive the same education as those with other chronic illnesses. They may require special services, including home instruction, to provide continuity of education. Confidentiality about HIV infection status should be maintained with parental consent required for disclosure. Youths also should assent or consent as is appropriate for disclosure of their diagnosis.”

Limited research is available from developing countries on how HIV-positive parents disclose their own status to children, and whether they then have children tested. A study in Uganda conducted through key informant interviews with members of an AIDS support organization found that, although infected parents worried that their children might also be infected, they were reluctant to disclose their status to their children for fear of an emotional reaction from them³⁶. They usually only had children tested if they showed symptoms of HIV, and then informed children of their status. Counsellors confirmed that they were without training and guidelines on disclosure.

A survey amongst healthcare workers and parents in rural Eastern Zimbabwe also noted that the standard Western “couple approach” for disclosures was probably not appropriate, and that there was a need to develop culturally adapted approaches³⁷.

Research in Thailand with the parents of children with perinatally acquired HIV-infection once again emphasised the very real difficulties that parents have in telling children about their HIV status, and emphasised the importance of developing guidelines³⁸.

Taken together, it is clear from these reports that there is a lack of detailed and culturally appropriate information about disclosure to children, although there is agreement that age-appropriate information should be given over a period of time. Much more research is needed into how the process of disclosure to children should be conducted if teachers are to be trained to handle children's questions in the classroom regarding their own or their friends' HIV status, and to give supportive advice to parents or caregivers.

Psychosocial support to teachers, learners and caregivers

There are different models of psychosocial support for children and these can be used to conceptualise and plan services within the education system or within the community. The Regional Psychosocial Support Initiative for Children affected by AIDS (REPPSI) report³⁹ lists five models:

1. *The Head-Heart-Social Model*, which explores how feelings and emotions alter the individual's interactions with others. This could be applicable to teacher-learner interactions, caregiver-child interactions, or the HIV-infected child's interactions with his or her classmates.
2. *The Well-being Model*, which consider the well-being of the child in a holistic way with overlapping elements.
3. *The Resilience Model*, which is concerned with developing resilience for children living in difficult circumstances by building on the strengths in his or her environment.
4. *Circles of Support Model*, which targets the gaps in support at the family, community or government service level that can be filled by support from other levels.
5. *The Pyramid Model*, which concerns multilayered support building upwards from broadly-based community programmes, to mid-level and more focused child need programmes, and finally to specialist mental health services.

The REPPSI report gives practical guidelines that can be of assistance to teachers in rendering social support to vulnerable children, and as such will assist them to give the all important daily support.

Summary and key points

HIV impact and the scale of the problem

- Although there is growing evidence that health promotion activities in some countries have been successful in reducing the incidence of new infections, the overall numbers of child infections remain disturbingly high.
- Within countries, there is an unequal distribution of infection and it would be advisable to target the groups most at risk with interventions designed to meet their needs.

The special needs of HIV-positive children

- 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, which may manifest as hearing, speech and learning problems, or hyperactivity. Some of this is reversible when the children are receiving ARV treatment. Early diagnosis and good medical care seem to have a protective influence.
- HIV-positive children are often unwell and may fall behind in their schooling for that reason. Home learning projects would help the children to keep up with their classmates. HIV clinics and children's hospital wards should also be stocked with attractive educational toys and learning materials.
- HIV-infected children 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.
- Children who are sickly, and are brought up in households disrupted by illness and death, will probably lack the early stimulation needed for optimal cognitive development. Early education programmes should seek out vulnerable caregivers and children, and encourage their participation.

- 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. Residential care may not be able to provide the children with the links into the community that they will need when they reach adulthood. The school then becomes an important adjunct to institutional care, guiding children through adolescence towards adulthood, and assisting them with emotional and learning problems.
- Treatment compliance is a difficult responsibility for infected children, and teachers should support them in this, without drawing undue attention to the issue.

Education and Prevention

- Unless there is a reduction in the number of infections in highly endemic areas, all systems, including education, risk being overwhelmed. 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.
- HIV-positive teachers cannot be expected to assist learners effectively if they themselves do not have access to treatment, care and support. Their rights should be supported by the teachers' unions, and the school community should be trained to reduce the stigma.
- A copy of the Universal Precautions should be on hand in every school, together with the simple essential supplies needed to clean wounds. Even very young children should be educated about how to protect themselves.
- If they are well-informed and supplied with posters and pamphlets, early education practitioners and other community workers can provide information to others and help to prevent new infections in adults and mother-to-child transmission.
- By creating an atmosphere where young children's questions are answered in an age-

appropriate manner, teachers set the scene for later free and open classroom discussion on the nature of HIV, sexuality and prevention of infection.

- Educational children's programmes on television and radio can help to demystify the epidemic.
- Primary school teachers should promote values of gender equity in classroom discussions. This is an important precondition to the empowerment of women.
- Parents may object to sex education at school, and high school teachers will have to try to defuse the situation so that learners can be taught about safe sex.
- Girls should be protected from sexual violence at school.
- Teachers can use teaching aids, media programmes and the assistance of agencies such as PLHIV networks to help them give out accurate information in a way that is likely to hold the interest of young learners.
- Sex education materials and curricula should not assume that the recipients of the information are not HIV-infected. It is important that infected children learn how to manage their own sexuality, without being a danger to themselves and to others.
- A key issue in prevention and treatment is to set up an effective referral register for all teachers, parents or learners who require HIV services.

Treatment access for children, and disclosure in an education context

- All the evidence points to the fact that the sooner HIV infections are diagnosed, the greater the chances are that the child will survive and thrive, and fewer neurological complications will arise. Teachers should be aware of this and informed of referral procedures so that they can communicate

these to parents of children who appear sickly.

- A key issue in prevention and treatment is to set up an effective referral register for all teachers, parents or learners who require HIV services. This should be widely construed, encompassing any local services that might help the children and their families.
- Disclosure of a child's HIV status to school personnel is not mandatory, but can open the way to support. Often, however, disclosure results in discriminatory practices and hurtful remarks.
- To counter this, it is important that teachers create a climate of acceptance within the school.
- Disclosure to children of their status is the responsibility of the parents, but teachers should understand the issues so that they can respond sensitively to questions in the classroom.

- Brazilian research has shown that children who lack information about their infection status can become confused and negative in their attitudes.
- Responsible disclosure to children of their own HIV-positive status can be beneficial to their adjustment, and a process-oriented approach is favoured.
- Taken together, it is clear from these reports that there is a lack of detailed and culturally appropriate information about disclosure to children. Much more research is needed.

Psychosocial support to teachers, learners and caregivers

- There are different models of psychosocial support for children and these can be used to conceptualise and plan services within the education system or within the community. The REPPSI report gives details of these and guidelines about how teachers could use them in rendering social support to vulnerable children.

Chapter 4:

Education sector response

Systemic management of HIV impact

UNAIDS has responded to the pervasive nature of the impact of the AIDS epidemic by developing the concept of mainstreaming for the education sector, and by producing a toolkit to assist development agencies to ensure that the concept is fully understood and appropriate action has been taken⁴⁰. In essence, mainstreaming requires that concerns about HIV and AIDS become integrated at every level of the structure of the education system and in all its functions, and that education about AIDS is not just a section of the life skills course delivered to learners at a particular stage in their schooling. Mainstreaming means that the response to the epidemic is to be seen everywhere in the education system, from early education to high school and tertiary education, and to encompass administrators, teachers, learners, texts and attitudes.

While various multi- or bilateral development agencies may use slightly different definitions of mainstreaming, the base concept that HIV and AIDS prevention, mitigation and management must be part of the routine function of all education systems at every level and in every sub-sector is now widely accepted.

The Mobile Task Team on HIV&AIDS and Education (MTT, HEARD) noted in 2005 that for well over two decades, HIV and AIDS had been making a direct and indirect impact on education systems in many parts of the world, but particularly in sub-Saharan Africa. It notes that: “the tragedy of this period is that these education systems, especially those in the most severely affected countries, did not recognize the incremental impact of the epidemic or respond early enough to mitigate this impact. When they did begin to address it, many responded in a narrowly conceived way, often confined to curriculum change. Even today, many systems still do not fully recognize the major threat that HIV and AIDS poses to their ability to ensure sustainable educational provision, responsive to personal and social needs”⁴¹.

The MTT goes on to say, however, that: “this situation is changing: As they recognize the increasingly erosive effects of the epidemic, education system managers increasingly understand HIV and AIDS as a development issue requiring a wider and more comprehensive response. They have begun to realise that the primary impact of

the epidemic has been to explode the scale of existing systemic and management problems. As these systems experience increasing AIDS-related educator attrition and absenteeism, declining learner enrolment and retention and compromised ability to meet EFA and Millennium Development Goals, education policy-makers, planners and managers within them are coming to terms with HIV and AIDS as a serious management challenge that requires a systemic response”.

The implication of this is that HIV and AIDS response must be mainstreamed within the wider context of education planning and management, so that all decisions are informed by, and take full account of, these critical issues. In other words, that HIV and AIDS response must be located within the system and recognised as a routine function of management at every level. This implies that a clear understanding of the dynamic HIV and AIDS situation must guide and inform every aspect of policy, planning, budgeting and implementation. In this regard, there is now international understanding that, for a response to be comprehensive, it must address five key themes.

These are:

- Enabling environment ;
- Prevention ;
- Treatment, care and support ;
- Workplace issues ;
- Management of the HIV and AIDS response.

Inclusivity and education quality

UNESCO defines inclusive education as “a developmental approach to the learning needs of all children, youth and adults, especially those who are vulnerable to marginalization and exclusion”.

The advent of antiretroviral therapy for children means that more children who are HIV-positive will enter and be retained in the school system. As already noted in this report, these children are vulnerable to marginalisation in several ways: they may be subjected to discriminatory remarks and social isolation because of their HIV status; they may have a physical or mental disability that makes

it difficult for them to participate fully in the school's educational and sporting programmes; they may be suffering emotionally from the traumas associated with bereavement and/or removal to a new home; or they may be frequently absent from school because of illnesses and the need for treatment. While there are undeniable benefits to the inclusion of children with special needs in the regular school system, in resource-poor schools with large classes and under-trained teachers, it is difficult to meet the special needs of HIV-positive teachers and learners.

The consequence of these difficulties is that HIV-positive learners are likely to have compromised levels of access to education, which in turn will compromise the quality of what education they do receive. This problem, taken together with their own higher rates of absenteeism, learning difficulties, nutritional shortfalls, medical and family stress, may seriously impact both inclusivity and quality. For this reason, special attention must be paid to the needs of these HIV-positive learners, in addition to the special needs of other vulnerable or marginalised learners.

Changing roles in the classroom

It is clearly important that the quality of education is maintained as the inclusive education process unfolds in HIV-endemic areas where there are HIV-affected teachers and learners in the schools. The motivation and attitudes of teachers are fundamental to achieving an inclusive education system, and they will require the support of health and mental health professionals for problems that they feel unqualified to address. This points to the need for an inclusive multisectoral approach in which social sector ministries work in a well-informed partnership with their NGO and development colleagues. While such cooperation and partnership may sometimes be the exception rather than the rule, it is important that all schools are kept informed of referral services in their area so that teachers can be confident that they can obtain good advice for themselves, and give out accurate information to parents. This task should be the responsibility of an official in the ministry of education, in close cooperation with partners and networks.

One of the most important consequences of HIV impact on the education system and its clients and employees is that it fundamentally changes the dynamics of classroom activity and relationships. Teachers outside the developed world, by and large, perform their duties in sub-optimal conditions, particularly in the most resource-poor settings. Such settings are often coincidentally more vulnerable to HIV impact, and so place the business of teaching and learning at great risk.

Simply put, already resource-poor and often dysfunctional systems now face the added strain of direct and indirect HIV impact on teacher recruitment and training (both pre-service and in-service), enrolment, retention, transition, quality and output.

At the classroom level, this translates to increased pressure and competing demands on teachers, who are often themselves directly or indirectly affected by HIV. These impacts may include personal or family infection, death, funeral and related bereavement issues, additional workload to compensate for similar impact on colleagues – and the emotional and professional stress of teaching growing numbers of orphans and other vulnerable children. In the KwaZulu Natal province of South Africa and Lesotho, for example, combined single and double orphaning rates are now in the range of 33–35% of enrolment⁴².

For HIV-positive learners, this scenario may further reduce the capacity of teachers to pay sufficient attention to their learning and psychosocial needs, and exacerbate the problem.

Teacher training and support

Teachers require further training if they are expected to teach children with different barriers to learning, and some with quite severe disabilities. In order to be effective, teachers will have to have some understanding of the management of common behavioural and emotional problems, like attention deficit disorder. At present many of the guidelines for teachers are too broad and abstract to be of practical assistance in day-to-day classroom situations. One option is for training (and some measure of responsibility) to be shared by the health and education ministries, to ensure the development of a coordinated school health programmes and the creation of health-promoting schools.

Administrative staff should be trained to keep accurate records on absenteeism, school performance, and anthropometry. This should not be construed as an onerous and even pointless exercise, but should be used to provide important trend data and early warning of a child's problems, so that a strategy to assist the child can be worked out between the school and the child's family. This basic approach must unfortunately be seen in the context of often inadequate, out-of-date or even dysfunctional record-keeping at the school and system level, suggesting that information system reform and discipline is an urgent priority for both HIV-response and system functionality.

School managers may also need training to deploy staff more effectively where children with different needs share a classroom, and no special teaching aids are provided, and to develop policies relating to stigma. This may be difficult in settings where teaching staff are in short supply or otherwise overtaxed.

At other levels in the ministries of education, more posts should be created for psychological services so that new programmes and curricula can be developed to meet children's needs proactively. All too often, crisis management is the order of the day for children in distress. If university departments of psychology and psychiatry are alerted to the need for master's level clinical and educational psychology and psychiatry courses, they can devise coursework tailored to the demands of the situation, and recruit suitable students. In a study of the way in which the South African early education system needed to assist HIV-positive children, key informants pointed out that, although training services existed, there was little liaison between government departments and universities with respect to training needs to meet the crisis⁴³. Attention to detail in education planning would boost the capabilities of the system.

Even if sufficient resources cannot be found to provide additional or relief staff, information sharing and supportive partnerships of the kind described can and should be developed at comparatively little cost.

Demand and supply: the human resource equation

HIV and AIDS have had a measurable impact on the supply and provision of teachers in most, if not all, affected countries. While attrition rates are driven by a number of factors (including resignation, medical boarding etc.), mortality as a single cause has grown proportionately to become a very significant issue. One reason for this is the increasing loss of young teachers in the 25 to 45 age band, and the loss of a disproportionate percentage of female teachers. While AIDS-associated opportunistic infection as a cause of death is not widely recorded, it is sufficient to recognise for the purpose of planning that the dramatic rise in mortality in these younger age bands can be largely attributed to the disease.

However, it is important to note that, even in highly-affected countries like South Africa, the gross (all causes) mortality rate is nowhere near as high as once speculated or assumed.

In the most comprehensive research yet undertaken on teacher attrition and mortality, the South African Labour Relations Council (ELRC) commissioned an 8-year study of an annual average of 360,000 teacher personnel records, triangulated against the National Death Register. This showed that the proportion of gross attrition due to mortality increased from 7.0% in 1997/98 to 17.7% in 2003/04⁴⁴. Similarly, the proportion of terminations due to medical reasons grew from 4.6% to 8.7% over the same period. However, while the crude mortality rate in this teaching workforce climbed from 0.39% in 1997/98 to 0.57% in 2003/04, it still only reached 1.04% in the country's worst-affected province (KwaZulu Natal) with antenatal clinic prevalence rates of close to 40%. In other words, while teacher mortality will have a severe impact on teacher supply and provision, it is not a doomsday scenario – particularly where most teachers know their HIV status and have access to ART.

Attrition, including mortality, represents permanent loss from the system but is only part of the human resource equation. Temporary loss, principally through absenteeism of one kind or another, contributes to variable amounts of lost contact time in the classroom and consequent reductions in quality. Again exacerbated by the impact of HIV and AIDS, absenteeism is on the rise in many affected countries but is hard to quantify due to poor or irregular record-keeping and analysis. Reasons for absenteeism include illness, maternity, study or compassionate leave (including personal trauma and funeral attendance), vacation, special leave and growing incidence of workshop or training attendance. Length and frequency of these leave 'episodes' may be increased in rural locations as teachers there often seek medical and other services in urban areas. Current research in Namibia suggests that this could be as high as 15% in some regions, but accurate data and a comprehensive teacher demand and supply model would be required to pin this down further. It is also fair to say that both temporary and permanent loss of teachers from the system is indirectly due to reluctance to work in deep rural areas, poor salaries and limited career prospects.

The effect on a system already stressed by other systemic pressures, including large classes and lack of resources, is to reduce still further the support and dedicated time HIV-positive learners can hope to receive.

Options to alleviate this problem include increased recruiting and training, improved service conditions and incentives, relief teacher strategies (including the introduction of teacher aides to assist) and improved support systems and partnerships at the local level – particularly in terms of counselling and other specialist services. Another option is to offer housing, transport and other forms of incentive or subsidy, but the reality of resource constraints militates against this. Mandatory community service for the graduates of universities and teacher training colleges might be considered, as might recruiting teaching staff from other countries, although this may simply increase the regional problem. A more realistic option, particularly in the AIDS-era, might be to increase the retirement age and help retain experience in the system.

Curriculum and materials development

While curriculum development, including issues of life skills, sexual and reproductive health, has advanced significantly due to improved access and better models, many affected countries seem reluctant to learn from one another. Instead, considerable resources are expended on duplicating perfectly functional models of best practice within a given region, possibly reducing the capital and recurrent means to implement, monitor and improve such curricula.

While it is not suggested that affected countries should simply 'import' curricula and materials from developed countries, which do not fit the needs and expectations of learners and teachers in developing countries, these countries should at least consult widely, and if necessary adapt appropriate curricula and materials locally. Critically, to meet the needs of HIV-positive learners, this should be done with input from local specialists and groups, such as the PLHIV networks, to formulate key messages and include relevant local examples. Language clearly needs to meet local and regional needs, particularly in respect of sensitive or complex biological issues. Graphics and visual material may be of great importance in this regard, and illustrations should be done by local artists wherever possible – within quality controls and guidelines. Related instruments developed to assess the cognitive, social and emotional functioning of children should also be culturally appropriate, so that they can provide sufficiently sensitive indicators of intervention needs.

Integrated community and sectoral partnerships

Teachers will have an easier task if they work within a supportive community. This can be achieved if teachers are willing to make their expertise available to the wider community, by giving talks and running workshop on matters of common interest. Partnerships can be developed at local level with local NGOs specialising in health or education, or between schools, clinics and social welfare agencies, so that cooperative action is possible when needed. If cooperative arrangements were forged with community workers in the fields of

child protection and care, they would be able to visit the homes of children who were exhibiting signs of distress in school, and bring support services to bear on the problem.

Summary and key points

- UNAIDS has responded to the pervasive nature of the impact of the AIDS epidemic by developing the concept of mainstreaming for the education sector. In essence, mainstreaming requires that concerns about HIV and AIDS infiltrate every part of the structure and functions of education systems.
- While there are undeniable benefits to the inclusion of children with special needs in the regular school system, in resource-poor schools with large classes and under-trained teachers, it is difficult to meet the special needs of HIV-positive teachers and children.
- It is clearly important that the quality of education is maintained as the inclusive education process unfolds in HIV-endemic areas where there are HIV-affected teachers and learners in the schools.
- The motivation and attitudes of teachers are fundamental to achieving an inclusive education system.
- The teachers require further training if they are to teach children with different barriers to learning, and some with quite severe disabilities. In order to be effective, teachers will have to have some understanding of the management of common behavioural and emotional problems, such as attention deficit disorder.
- Administrative staff should be trained to keep accurate records on absenteeism, school performance, and anthropometry and these should be used 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.
- At other levels in the ministries of education, more posts should be created for psychological services so that new programmes and curricula can be developed to meet children's needs proactively.
- In some countries, there has been attrition in the teaching professions. The shortage of teaching staff is most often noticeable in deep rural areas where housing, transport and other amenities are in short supply. A variety of strategies have been mooted to attract more teachers to the profession.
- All too often, developing countries are supplied with curricula and materials from developed countries that do not quite fit the needs and expectations of learners and trainees in developing countries. Although curriculum planners should consult widely, they should also use culturally appropriate local examples and illustrations wherever possible.
- Teachers will have an easier task if they work within a supportive community. This can be achieved if teachers are willing to make their expertise available to the wider community.

Notes

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Appendix A

The United Nations Convention on the Rights of the Child: articles and items relevant to education policy for HIV-infected children

Article 28

1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:
 - (a) Make primary education compulsory and available free to all;
 - (b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;
 - (c) Make higher education accessible to all on the basis of capacity by every appropriate means;
 - (d) Make educational and vocational information and guidance available and accessible to all children;
 - (e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates.
2. States Parties shall take all appropriate measures to ensure that school discipline is administered in a manner consistent with the child's human dignity and in conformity with the present Convention.
3. States Parties shall promote and encourage international cooperation in matters relating to education, in particular with a view to contributing to the elimination of ignorance and illiteracy throughout the world and facilitating access to scientific and technical knowledge and modern

teaching methods. In this regard, particular account shall be taken of the needs of developing countries.

Article 29

1. States Parties agree that the education of the child shall be directed to:
 - (a) The development of the child's personality, talents and mental and physical abilities to their fullest potential;
 - (b) The development of respect for human rights and fundamental freedoms, and for the principles enshrined in the Charter of the United Nations;
 - (c) The development of respect for the child's parents, his or her own cultural identity, language and values, for the national values of the country in which the child is living, the country from which he or she may originate, and for civilizations different from his or her own;
 - (d) The preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of sexes, and friendship among all peoples, ethnic, national and religious.

Article 23

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of

charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

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This report is a desk-based study of available literature and service provision regarding HIV-positive children and young people. It was designed as a precursor to a two-country research study in Namibia and Tanzania. A final consolidated report summarising the desk-based research and the two country studies has also been written. All these reports are available in full on the UNESCO website.

For more information on UNESCO's work on HIV and AIDS, visit the website:
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