

## **Annex 5**

# **The Increasing Role of the Education Sector in Caring for HIV Affected and Infected Children and Adolescents in Botswana**

**An Issues Paper**

by

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## **Executive summary**

Botswana's position is special: the country with an outstanding record in addressing the HIV epidemic now faces the next consequence of its success, a pathfinder role in managing the quality of prolonged lives of its next generation.

The education sector has recognised essential internal and external roles within the multi-sectoral response to HIV&AIDS (Bundy, 2002). In the new era of drug treatment, schools not only have a primary role in keeping the uninfected from infection, but now also a secondary essential contribution in supporting the increased numbers of infected young people of school age. Modelling demonstrates that due to Anti-retrovirals (ARV) and Prevention of Mother to Child Transmission (PMTCT), the number of HIV positive children is expected to increase then decline over the next 15 years, beyond which there will be very few infected children if PMTCT is maintained at near 100%. It is estimated that between the years of 2007 and 2025, the education sector in Botswana will have to cope with around 19,000 HIV positive school age children. Similarly, on current trends, an increasing proportion of their teachers will also be HIV positive and taking ARVs. Thus the internal role of the education sector in supporting its teachers has become even more important.

The support provided by schools will be invaluable not only to the education sector itself, but also the health sector, as better educated children will be able to make better decisions concerning health leading to a healthy, educated and productive generation of Botswana.

This paper serves to highlight the key issues now facing the education sector that are explored at three levels: Government, School and Community.

## **Context and Background**

It is estimated (UNAIDS, 2006) that there were 270,000 people living with HIV&AIDS (PLWHA) in Botswana in 2005. The adult (15-49) prevalence was 24.1%, globally the second highest. This huge prevalence is associated with a

large mortality: 18,000 people are estimated to have died from AIDS in 2005. Botswana has been more successful than other SSA countries in treating its HIV positive population: in 2005, 55,829 people were treated of 84,000 who are estimated to need treatment (WHO, 2005).

In the new era of drug treatment for HIV infection and prevention of mother to child transmission (PMTCT), countries with successful PMTCT and paediatric ARV programmes (CHIPS, 2007) have witnessed a single cohort of PLWHA pass from birth to adulthood (Figure 1). Previously, many HIV positive children were born to HIV positive mothers due to negligible provision of PMTCT. These children also died at high rates because ARVs were scarcely available to treat them. In Botswana, this is no longer the case; as provision of PMTCT and ARV access for children is becoming more widespread, more babies are born free from HIV, and more HIV positive children are surviving into adulthood.

This has consequences for the education sector: as ARVs are successfully provided to children, the number of HIV positive school-age children passing through the system will increase. Although this number will begin to decrease again as more children are born free of infection. In total, around 19,000 HIV positive school children are expected to pass through the education system before 2025. In 2010, there will be a peak of around 135,000 orphans, some of whom will be HIV positive, this number is expected to increase then diminish over time.

The education sector has recognised essential external and internal roles within the multi-sectoral response to HIV&AIDS (Bundy, 2002). In light of this cohort phenomenon, the external role has become twofold: supplying children with education while supporting their health and development, including supporting these children through early adolescence and preparing them for any possible challenges they may face, including sexual and family life (Cooper et al., 2007). It will not be easy to address the sexual needs of adolescents who are completing primary or secondary education and who have lived with HIV from their birth (Hekster and Melvin, 2005): the concept is likely to challenge teachers' assumptions on HIV and society and to provoke a dislocation of thought that must be faced and overcome. Nevertheless, these young people will go on to have sexual relationships and families. European experience (CHIPS, 2007) since the introduction of highly active combination anti-viral treatment in the mid 1990s has shown that all this is possible and can be made safe, from the point of view of HIV transmission, with precautions for sex and PMTCT interventions for birth.

Similarly, on current trends, an increasing proportion of their teachers will also be HIV positive and taking ARVs. Thus the internal role of the education sector in supporting its teachers has become even more important.

To achieve this, likely areas for review will be in school health policies, curricula, teacher training and monitoring and evaluation to include these HIV care and support related issues. Specific advances in pedagogy will be in adapting health and nutrition and family life education (FLE) to affected

children’s developmental stages, as well as in preparing children with HIV for their future sexual and family lives. New strategies for enhanced learning on these subjects might usefully explore how to integrate information of special relevance to those living with HIV into a broad education for young people’s health, wellbeing and development.

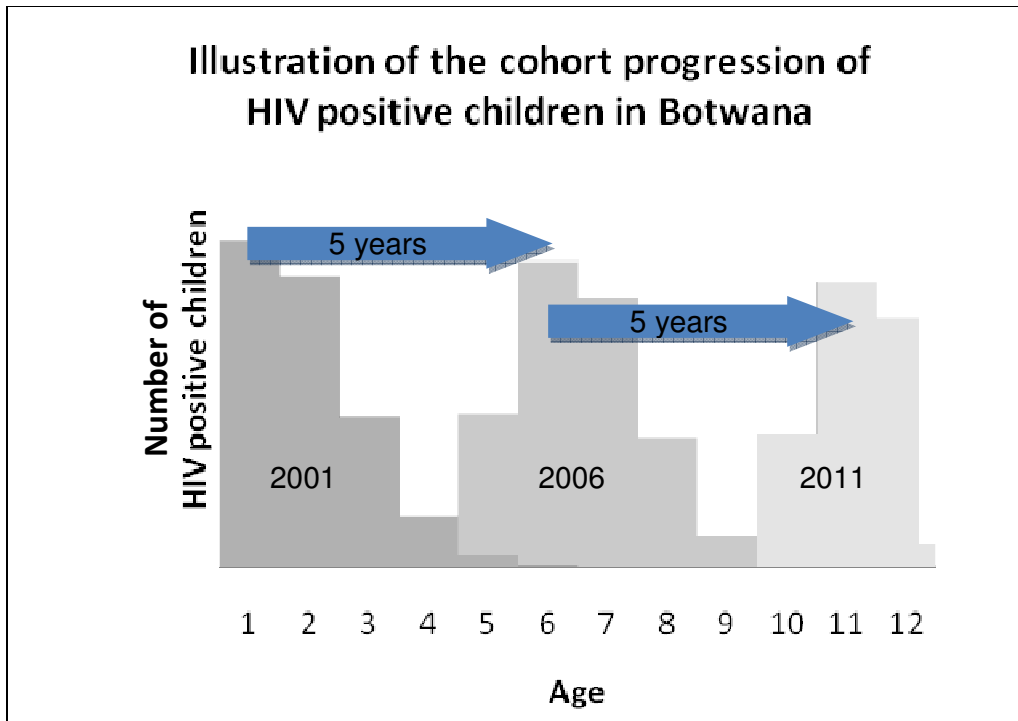


Figure 1. Illustration of the cohort progression of HIV positive children in Botswana. This figure is illustrative and no real data were used. In 2001, ARVs were not given to children, and HIV positive children usually died in the first few years of life. Consequently there were few HIV positive children over the age of 3. Since 2001, ARV provision has increasingly kept HIV positive children alive who are now aging and passing through school. At the same time, more HIV positive mothers began taking PMTCT drugs and therefore fewer HIV positive children were born. If these two regimens are maintained, over the next 15 years an HIV positive cohort of children will pass through school in Botswana.

The Ministry of Education has addressed the HIV&AIDS challenge through several initiatives which mainly include mainstreaming across the sector (see Annex A).

### **What are the consequences of effective PMTCT and ARV on the education sector in Botswana?**

As Botswana continues to improve access to PMTCT to pregnant women, the incidence of infection in newborn babies will be reduced and so the numbers

of HIV positive children born will also decline. Concurrently, if access to ARVs for children continues to mirror successes in treatment delivery to adults (UNAIDS, 2006), child AIDS deaths will decline. Consequently the numbers of children living longer with HIV will increase, mirroring the prolongation of life in adults living with HIV, and enable them to complete their schooling and live onwards. These two effects, i.e., the preservation of the life of children infected with the virus with ARVs, and the reduction in the production of HIV positive children achieved by PMTCT, will result in a single cohort of HIV positive children passing through Botswana schools.

### **The Models**

Three models were used to generate the projections presented in this paper:

1. A mathematical model, allowing an estimation of the size of the expected HIV positive and treated school-age cohort, from a 2005 baseline, allowing for the effects of PMTCT and ART uptake in children.
2. The orphan module of Spectrum (the UNAIDS suite of mathematical model, predicting demographic impact of HIV), allows estimation and projection of the most likely number of orphans expected due to AIDS and due to other causes.
3. The Ed-SIDA model which projects the impact HIV on education was used to calculate numbers of teachers by infection status where all teachers requiring ART are assumed to take it from 2007 and to estimate cost effectiveness of facilitating access to treatment.

## **Impact on Supply and Demand in Botswana**

### **Impact on Demand**

The scenario modelled was an increase from 2005 baseline to 100% by 2010. The numbers of infected youth (10-14 year olds) are predicted to reach a peak of about 4,400 in 2010, then decline to 1,400 by 2025 (Figure 2).

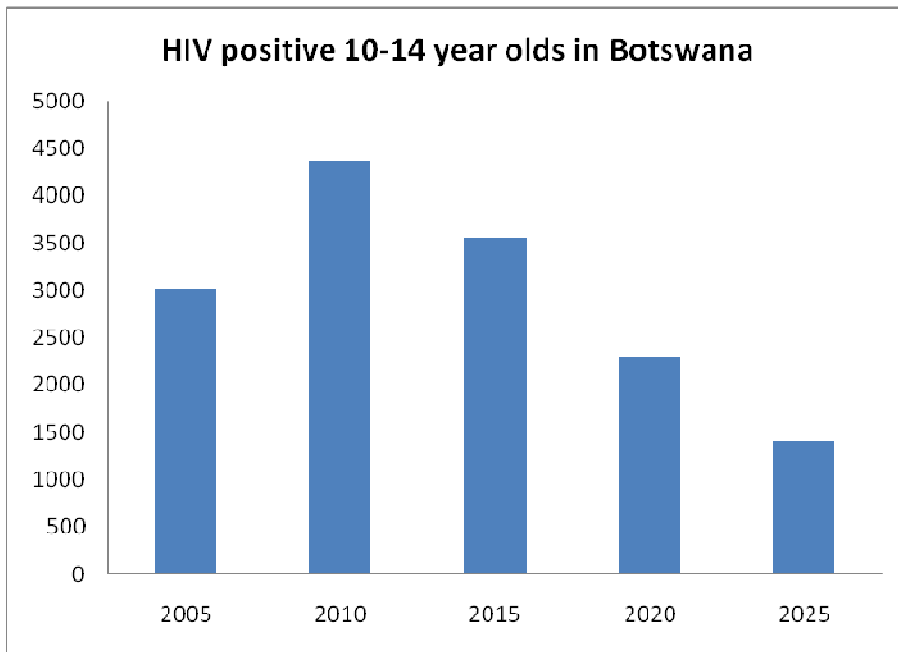


Figure 2: Predicted numbers of HIV positive 10-14 year olds in Botswana, 2005-2025.

These children who are infected are a subset of all the children affected by HIV. One measure of the number of children affected by HIV is the number of those who have experienced the death, due to AIDS, of one or both parents (Figure 3). These vulnerable children, some of whom will also be infected with HIV, are also predicted to reach a peak in 2010. This peak will be about 135,000 and decline to 2005 levels of about 126,000 by 2015.

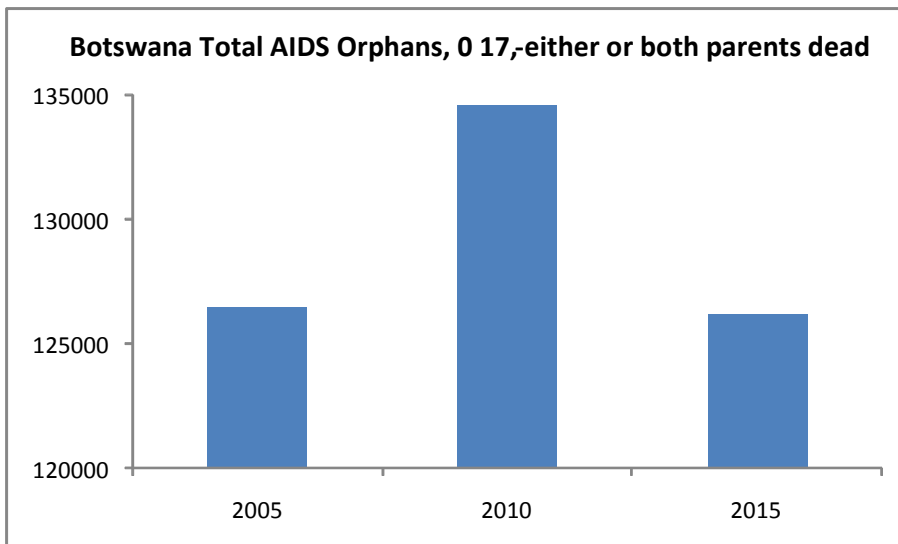


Figure 3. Number of children aged 0-17 whose mother and/or father has died from AIDS in Botswana, 2005-2015.

### Impact on Supply

In this scenario (under UNAIDS predicted prevalence rates for Botswana) all teachers who require ARVs are taking them. Figure 4 shows that prior to the introduction of ARVs (2003) the number of teachers dying was increasing. As would be expected, since the introduction of ARVs the number of teacher deaths is reducing reflected in the constant number of cumulative AIDS deaths and the continuing number of HIV positive teachers remaining alive and continuing to teach.

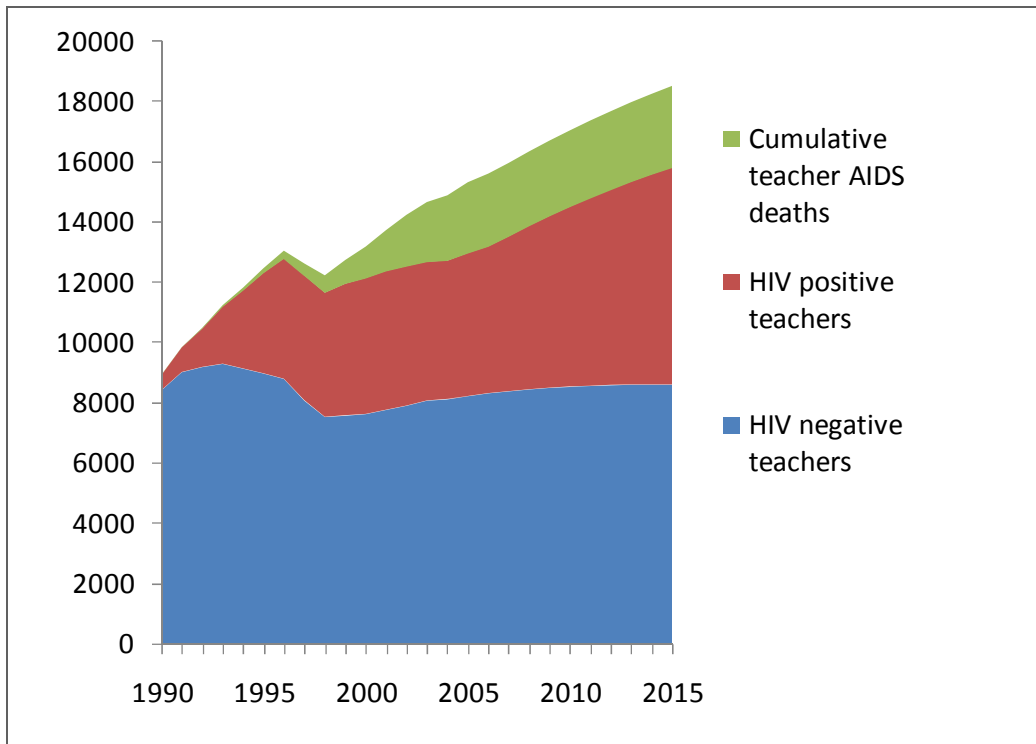


Figure 4. Projections of the number of teachers themselves infected with HIV, if ART treatment continues to be made available to them

In the absence of an ARV program, the HIV positive area of the chart would reduce and the cumulative AIDS deaths area would increase proportionately.

### **Cost-effectiveness of care, support and treatment of this cohort of teachers and children in Botswana**

The Ed-SIDA can also output cost predictions when economic data are added to the input. This model assumes there are 4 costs of HIV to the education sector: (1) Voluntary Counselling and Testing (VCT) (which the ministry can choose to provide or not), (2) covering for teachers absent due to AIDS illnesses, (3) training teachers to replace those that have died from AIDS and (4) contribution towards the funerals of teachers who have died in service.

Providing VCT is cost effective to the education sector if accompanied by Ministry of Health provision of ARVs. The cost-effectiveness of facilitating the

VCT of teachers can be illustrated by considering two alternative scenarios between 2005 and 2015: (1) all teachers are tested and treated, (2) no teachers are tested or treated (Figure 5). If the MoE spends resources on providing VCT to all teachers between now and 2015, the overall cost of HIV to education will shrink over the 10-year period from \$1.7M in 2005 to \$0.36M in 2015; if it chooses not to test any teachers and treatment is discontinued, the overall cost will increase to an enormous \$3.2M in 2015, largely due to the training of new teachers necessary to replace those teachers dying of AIDS illnesses.

It is estimated that the cumulative cost of teacher AIDS deaths and illnesses between 2005-2015 is \$4.85M if the teachers who need it are treated with ARV, and \$34.17M if no teachers are tested or treated. As VCT is estimated to cost \$0.39 M over the ten year period, the net saving associated with VCT and ARV provision is \$29M to the education sector.

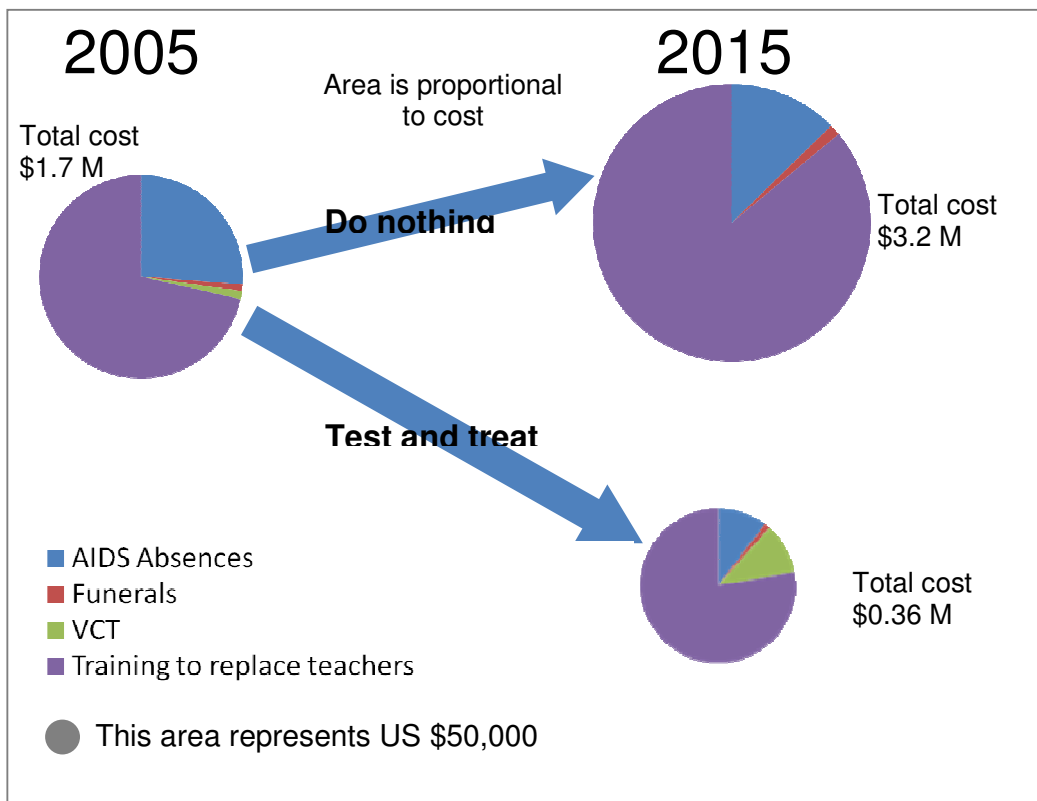


Figure 5. Cost of HIV to the education sector in Botswana of two scenarios between 2005-2015: testing and treating 0% or 100% of teachers. It is more cost-effective to the education sector to provide VCT to all teachers than not. Note that the area of the pie charts is proportional to the total cost they represent.

**What are the implications of effective PMTCT and ARV of concern to the education sector in Botswana?**

Discussions of the above projections and estimations with the education sector stakeholders resulted in the identification of emerging issues.

### **The learner**

1. Infected people, including children, have a right to confidentiality that is supported by worldwide interpretation of medical ethics (Faunce, 2005). Do teachers have a right to know which children in the class are HIV positive? Many teachers wish for infected children to be identified to them.
2. Medical and psychological consensus is that disclosure of a full diagnosis to a child is a progressive process in which the child develops understanding in stages; first learning of the need to increase their immune defence through taking medicine and culminating in the naming to them of the virus they carry as HIV, at around the age of 11 years (American Academy of Pediatrics, 1999). An individual's disclosure should come from the family (Mellins et al, 2002), supported by health workers, for the best results in subsequent mental health. However, the general learning on health and HIV and support in the class room for all the children will undoubtedly provide crucial support and preparation. How can teachers support this disclosure process?
3. How much autonomy should young people have, particularly regarding access to VCT (the high age of legal consent in Botswana (21 years) is a barrier)? Adult legal guardians are often absent. Is autonomy also an issue in understanding the development of children? Sometimes traditional ideas of adult authority over young people are incompatible with the need of children to take responsibility progressively for their own care, including medication.
4. How can appropriate care and support be delivered to all vulnerable children, including HIV infected and affected children? Should existing guidance and counselling services be strengthened?
5. What is the impact on the education of children who are frequently absent because they are unwell and sometimes because they need to attend clinics frequently?
6. There will be a broad range of intellectual ability among HIV positive children and while many will retain good cognitive function, it is recognised that average development and cognitive ability is somewhat delayed in the infected cohort (Blanchette et al, 2002). Anti-viral treatment may not entirely abolish this effect (Sacktor et al, 2002). What changes are necessary to accommodate this range of cognitive abilities?
7. How can HIV positive children be best prepared for the gender and sexuality related challenges of adolescence?

8. Should HIV specific lessons be taught as a stand alone subject or should they be integrated? Integration is not only programmatically efficient, but is also consonant with our knowledge of children's cognitive development (Miah, 2004). Life skills must be built on knowledge of human health, appropriate to the age and development of the child. Knowledge of HIV and the body's defences against viral infection is best delivered when incorporated into general health education and health promotion. Child psychologists believe that emphasis on strengthening defence through good hygienic practice and nutrition, then adding the need for anti-retroviral treatment as a further part of this, is far more easily assimilated by the child than constant stress on the invasive threat of HIV. Family Life Education and Health and Nutrition curricula should take account of this.
9. There is a need for increased sensitivity among teachers to the vulnerability of children directly affected by HIV in their family. Among those who are affected are many children who are themselves infected by the virus, an increasing proportion of whom will be taking ARVs every morning and evening at home.
10. How can the impact of stigma and discrimination of HIV infected and affected children be addressed?

### **The teacher**

1. Is a human rights based approach lacking in the education sector? If so, is this something that should be focused upon in staff development?
2. Teachers are said to lack the knowledge and skills needed to handle confidential information. How can they be better equipped to do so? How can their own confidentiality be ensured?
3. Teachers are unlikely to recognise accurately whether a child is infected or not, and may also know little of the family background, but teachers can nevertheless recognise when a child is vulnerable. How can capacity be strengthened to provide the expected support to vulnerable children?
4. Does the general health and nutrition curriculum adequately address the learning needs of vulnerable children? How can teachers' capacity be strengthened in order to deliver this?
5. Teachers have questions on their mandate in care for the vulnerable children. What support are teachers expected to provide to vulnerable children? What legal protection does a teacher have

regarding their care and support of vulnerable children outside the school environment?

6. What support should teachers expect to receive in implementing their activities? How will these be monitored?
7. How can the education and health sectors improve coordination to better facilitate access to VCT for education staff?
8. Increasingly, teachers have access to ARVs. There will be many classrooms in which a teacher on ARVs is instructing pupils on their immune defences and virus suppression while knowing that the lesson is relevant to their own condition. What support, including guidance and counselling services, can teachers who are HIV positive expect?

### **What are the first steps to addressing these issues?**

It is clear that there is a need for debate on these issues. The education sector has created a research think tank to explore specific areas and provide an evidence base to inform decisions (see annex B). These issues should be considered at three levels: Government, School and Community.

A) What changes are needed at the Government Level?

#### **Policy and planning**

##### 1. Joint policy

There is a need to develop a policy defining the joint roles and specific responsibilities of the Ministry of Education, the Ministry of Health and the Ministry of Local Government, in relation to the care and support of HIV affected and infected teachers and staff.

##### 2. Education Policy

An evidence based revision of the education sector specific policy on school health, nutrition and HIV&AIDS should consider the following issues regarding the care and support of HIV affected and infected learners for inclusion:

- stigma and discrimination in the school setting;
- present and future gender and sexuality challenges of the students;
- child protection;
- confidentiality;
- appropriate guidance and counselling services;
- guidelines for appropriate care and support;
- life skills and knowledge based teacher training to respond to these needs.

##### 3. Workplace policy

Comprehensive education sector specific workplace policy is needed, considering the following issues relating to care and support of teachers:

- teacher and education staff confidentiality;
- stigma and discrimination;
- guidelines for teachers outlining appropriate care and support activities;
- care and support for teachers affected and infected by HIV;
- guidance and counselling services for education staff;
- guidelines for access to VCT and treatment for education staff.

#### 4. Monitoring and Evaluation

School health, nutrition and HIV&AIDS prevention program M&E tools need to incorporate the specific issues of care and support.

#### 5. Teacher training programmes

Teacher training programmes need to be strengthened in terms of care and support issues for learners, teachers and staff and on the sexual, family and future relationship needs of adolescents who are living with HIV from their birth. In addition to effective training, a range of other factors are also necessary, including the provision of comprehensive support and resources for the activities.

#### 6. Curriculum development

Curricula should be revised to ensure that knowledge is delivered at the appropriate age. For the youngest children some knowledge of the immune system should be imparted in developmentally appropriate concepts. For the 11 year old a full understanding of HIV infection is the aim. Ideally, at this age most children who are themselves infected should know this and know the name of the virus that their body carries: HIV. The curriculum will also need to address the sexual, family and future relationship needs of adolescents living with HIV from their birth.

#### 7. Support programmes

The Guidance and Counselling programme and the National Lifeskills Framework must be implemented and addressed through a comprehensive student support programme that mobilizes all student support needs. Included will be the necessary information, the methods of education and communication and all the dimensions relevant for a broad service delivery.

#### 8. Costings

Cost options should be appraised for Ministry of Education strategies and human resource needs to scale up prevention, VCT, treatment, care and support within the Education system, e.g. full time guidance and counselling coordinators vis-à-vis HIV&AIDS at regional level.

B) What changes are needed at the School level?

## 9. Policy

All schools should have health and nutrition policies. These should be standard copies of Government policy, modified for local community needs, including care and support of HIV infected and affected students and health and nutrition education specifically useful to the child living with HIV.

The establishment of Schools as Centres of Care and Support is critical. This will capacitate the community led programmes in continued community child support (see C below).

Although many children on treatment are well, others have only partial suppression of viral replication and may have some symptoms and signs. These children, nevertheless, are less sick than they would be if they were not on anti-viral treatment at all. However, they are subject to complications and absence from school – sometimes

## 10. A supportive role for “anti-AIDS clubs”?

A new role for teachers in the anti-AIDS clubs could be to monitor the wellbeing of the learners and engage in discussions arising from general health teaching and specific teaching on HIV in the formal school setting. In this role, the clubs would not only be conveying approved messages, but would be acting in a communal way to support the more vulnerable children, without identifying them individually. This form of partnership between teachers and students, rather than the acceptance of a relationship based entirely on authority and instruction, is essential in order to engage the most distressed and vulnerable students.

## 11. A supportive environment for children living with HIV&AIDS

Disclosing a child’s HIV status is the responsibility of the family, working with the health service. However, the school can provide a supporting environment by providing the educational preparation in which this disclosure can be made. Additionally, teachers can be supportive of unavoidable absenteeism of children infected and affected by HIV&AIDS.

## 12. Adherence to Anti-Retroviral Treatment.

One of the ways in which educators can most effectively partner health workers is in encouraging children to understand, in a way appropriate to the developmental stage they have reached, why there must be 100% adherence to the medicines prescribed. Adherence – sticking to the treatment – is one of the greatest challenges in the drug treatment of HIV infection. It means

taking the prescribed dose of the three anti-retroviral chemicals every day, seven days a week. This should receive prominence in the FLE curriculum.

### 13. Sex and family/future relationships for the adolescent living with HIV.

The teacher and the school will play an important role in supporting adolescents address the sexual, family and relationship needs, including those adolescents who are completing primary or secondary education and who have lived with HIV from their birth. To support this, teachers will require training and a revised curriculum.

#### C) What changes are needed at the Community level?

Schools are an integral part of any community and have a responsibility to respond to the needs of that community. Community members should play a key role in monitoring, overseeing and supporting school-based HIV&AIDS activities to ensure that these respond to the needs of the community. Members should include community leaders, e.g. council of elders, faith leaders, parents, e.g. through a PTA, local partners, e.g. NGOs, and local government representatives.

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