SUPPORTING THE EDUCATIONAL NEEDS OF HIV-POSITIVE LEARNERS IN NAMIBIA

by

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ACRONYMS and ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral (ARV) Therapy
ARV	Antiretroviral
CAA	Catholic Aids Action
CBO	Community-Based Organisation
COS	Circles of Support
ESART	Education Sector AIDS Response Trust
ETSIP	Education & Training Sector Improvement Programme
FBO	Faith-Based Organisation
HAMU	HIV and AIDS Management Unit
HIV	Human Immunodeficiency Virus
MoE	Ministry of Education
MoHSS	Ministry of Health and Social Services
NGO	Non-Governmental Organisation
NIED	National Institute for Educational Development
OVC	Orphans and Vulnerable Children
PLHIV	People Living With HIV
RACE	Regional AIDS Committee on Education
RAISON	Research and Information Services of Namibia
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund

SUMMARY

Information for this study was derived from 76 respondents who contributed to interviews and group discussions in February and March 2008. Nine of these were key informants; 37 were adult discussion group members representing the education and health and social service sectors, NGOs, CBOs and FBOs, as well as country PLHIV networks; and 30 were HIV-positive learners, children and young adults interviewed during three discussion groups. The key informants were interviewed in urban settings, while half the adult group discussions took place in rural areas. Nineteen of the 30 HIV-positive learners were brought together in a single discussion group in a rural town, with the balance split between two groups which met in an urban setting. Researchers from RAISON Namibia were assisted in the facilitation of group discussions with HIV-positive learners by members of Namibia's PLHIV network who also helped with translations.

A number of important insights into the scale and scope of challenges faced by HIV-positive children were gained. These are summarized here within a range of themes:

Education sector HIV & AIDS policy implementation and management:
The Education Sector HIV & AIDS policy was generally considered to be strong, but lacking in implementation, leadership and coordination between sectors and service providers. While management structures were noted as being in place, there was a widespread sense that the Ministry of Education (MoE) is not taking HIV & AIDS seriously enough, this being repeatedly attributed to a "lack of leadership and capacity". Recurring criticism of the attitudes of teachers and principals across the sample seem to confirm systemic failure to address the problem. This study also uncovered an insidious sense of denial at school level, a feeling that the way to handle HIV & AIDS is to ignore it on a personal level. Information about HIV & AIDS is limited to the minimum requirements of the curriculum, while discussion is confined to activities during Aids Week or by Aids Clubs that remain depersonalized and remote from the individuals infected and affected by the disease. HIV-positive learners are not made aware of their rights and their specialized needs are not supported, including for example access and adherence to ART. There are incidents of non-consensual disclosure of learners' HIV status by teachers; there is a lack of training and capacity-building for teachers and school counsellors; and an absence of appropriate curricula to provide requisite knowledge and understanding of HIV & AIDS.

Multi-sectoral support:
While HIV-positive learners and children face difficulties at home and at school, they do receive substantial support from ART counsellors at hospitals and clinics, and from a variety of non-governmental groups. Respondents suggested that the most effective support comes from "personalizing the HIV-positive condition in a social context in which a child can be confident, accepted as a worthy person, and have the same rights as everyone else". This study revealed many examples of the breadth of these interventions, volunteers selflessly working amongst struggling families, projects formulated to respond to the ravaging effects of the disease, and clinic staff often going the extra mile to support their patients in innovative ways. Learners and young adults noted that voluntary school-based programmes had limited value.

Many informants appreciated the more personalized approach of NGO programmes, citing the *AIDS and Me* and *Circles of Support* programmes as examples of good practice.

However, they also noted the fragile nature of the non-government sector and the fragmentation of several leading NGOs. Some key informants noted the success of the Ministry of Health & Social Services (MoHSS) in establishing multi-sector partnerships and lamented the apparent inability of the MoE to do the same, even with other government sectors. It was noted that HIV-positive children in rural areas have less access to medical treatment, counselling and other resources that are more available in urban centres.

Stigma and disclosure:

The most pervasive, recurrent theme to emerge during the research was that of stigma and discrimination: Every HIV-positive child interviewed cited personal and continuing experience of the negative consequences of disclosure, and emphasized greater safety in silence. These fears were the consequence of intolerant attitudes at school and even at home, severe peer pressure and the absence of responsive measures or support from school staff and the education sector as a whole. The attitude of teachers in this regard was repeatedly described as indifferent, and severely complicated the ability of HIV-positive learners to participate effectively in the learning process, or to access ART. Several respondents cited teachers and school principals attempting, presumably in good faith, to shield HIV-positive learners from stigma by insisting publicly that they were not in fact HIV-positive. This indicates that there is still a long way to go before HIV-positive children can accept the importance of voluntary disclosure.

The school and teaching environment:

While some schools have reduced fees and provide school feeding for orphans and vulnerable children (OVCs), and promote HIV prevention, the overall consequences of infection present a set of problems that few schools seem either prepared for, or eager to deal with. Respondents suggested several reasons for this: teachers are unwilling or untrained to deal with open discussion on the topic; disclosure is discouraged to avoid the potential for stigma; education on HIV & AIDS is not taken seriously; and policy is neither clearly understood nor implemented. A number of HIV-positive learners and young adults noted that school counsellors are “around”, but are invisible or inaccessible to all intents and purposes.

Information and curriculum content:

Most HIV-positive learners said that their main sources of information on HIV-related issues and support were doctors, clinic sisters, health counsellors and care-givers, as well as the media. Respondents stated that only the most basic facts about HIV & AIDS material were provided by the curriculum, and that HIV-related programmes are voluntary and extra-curricular, and thus seldom taken seriously. Most respondents – particularly young adults – felt strongly that HIV & AIDS should be mainstreamed into the curriculum to provide clear, unambiguous information to all learners. They further suggested that schools need guidance in the delivery of comprehensive age and gender-appropriate sex and reproductive health education. Partnerships with other ministries and NGOs were proposed as being useful to the MoE for its effective implementation HIV-related programmes.

The home environment:

The home environment emerged as a profoundly complicating factor in this study: Parents often do not know how to disclose their own or the child's infection to the children themselves, or to other members of the family, teachers or friends. Mothers fear the resentment that may result if their children find out that they were born HIV-positive, and disclosure remains difficult, unknown terrain even in the home. Foster parents and guardians of HIV-positive orphans often lack understanding and sympathy, and offer little emotional support. Sex education for infected children is largely neglected by parents, teachers, care-givers and even support organizations, including the health sector. This is a dangerous situation considering the numbers of HIV-positive children approaching sexual maturity and their need for a clear understanding of the implications of the disease. Apart from the apparent fear and embarrassment that parents appear to feel, many respondents cited antagonism from their siblings and other family members, leading to practical isolation in the home.

Orphaning and vulnerability:

A variety of problems associated with poverty and the lack of parents or parental support also challenge HIV-positive children, many of whom are orphans. Many children in the HIV-positive groups talked about their comparatively small physical size, in spite of often being older than their classmates, and cited their reliance on medication and poor nutrition for their apparent frailty. Key informants and other respondents often reported that HIV-positive learners are subsumed into the wider category of OVCs. This was regarded as positive, since the inclusion of infected children in this larger group reduces the chance of neglect, prejudice and exclusion, which are the main consequences of the denial and stigma associated with HIV in Namibia.

INTRODUCTION

This study was initiated in November 2007 when UNESCO commissioned a stock-taking exercise to draw together international best practice on support for HIV-positive learners, children and young people. The EduSector AIDS Response Trust (ESART) in South Africa was tasked with developing the desk study, ethical and research guidelines and questions, a sampling strategy and providing technical support to two country teams. This was followed by studies in Namibia and Tanzania. The research in Namibia was undertaken by Research and Information Services of Namibia (RAISON) during February and March 2008.

The research was designed to address the following questions:

- What barriers face HIV-positive learners in accessing education and staying at school?
- What challenges are faced by teachers and schools in supporting HIV-positive learners?
- How can HIV education programmes be adapted to suit the sexual and reproductive health needs of HIV-positive learners?
- How does the education sector need to adapt to meet the needs of HIV-positive learners?

This report constitutes the qualitative country report for Namibia, which in turn forms part of ESART's consolidated summary report which:

- Describes the various educational and HIV-related needs of HIV-positive learners and young people;
- Provides examples of successful strategies and case studies;
- Gives emphasis to the voices of HIV-positive learners and young people; and
- Draws together conclusions and recommendations for the education sector, UNESCO, researchers and the region more generally.

METHODOLOGY

The researchers conducted semi-structured interviews with nine key informants, including staff of the Ministries of Education and Health & Social Services, PLHIV networks as well as NGOs, CBOs and FBOs. Thirty-seven members of adult discussion groups were drawn from teachers, counsellors, caregivers, parents and NGO/CBO/FBO personnel, 30 HIV-positive learners participated in learner discussion groups. The discussion groups included participants from both urban and rural environments.

Many of the group members were contacted through the PLHIV network. Esther Sheehama, a member of the International Community of Women Living with AIDS (ICW), worked as a research assistant and assisted with the recruitment of members of discussion groups. While recruiting adults was relatively easy, HIV-positive learner groups proved the most difficult to assemble. Parents and caregivers were reluctant to allow their children to participate in research, citing fears of breach of confidentiality, and the fact that many children were not aware of their diagnosis. The networking skills of the research assistant eventually won over, and the caregivers support group members agreed to allow their children to participate, after they themselves had experienced a group session and realized that the research followed a strict ethical code. The guidelines used are those published by ICW on ethical participatory research with HIV-positive women (www.icw.org), which are relevant to all people infected with HIV. The involvement of the PLHIV network was in fact central to identifying and inviting the participation of HIV-positive learners, young adults, caregivers and several other key informants, and ensured the practical application of ethical guidelines. The interactive environment provided by this facilitative link further ensured that stigma was not reinforced in any way. It is indeed difficult to see how these meetings could have otherwise been arranged, and it provides an important model for future research and intervention.

Interviews and group discussions were voice-recorded, except where some respondents refused or were uneasy about being recorded. While the final report was always intended to be in English, the option to conduct both interviews and group discussions in an alternative language was available to all respondents. Key point information was later translated into English.

Research guidelines, questions and issues for discussion were developed for key informants and adult and HIV-positive learner groups, and were designed to ensure that interviews and discussions would centre on common themes and issues, as far as possible. Research questions and issues for discussion sought to capture the direct experience of the problems faced by HIV-positive learners and children in and around the education system. The questions were used flexibly to hold the flow of each interview and group session intact.

Limitations of the research include the small size of the sample, the difficulty of recruiting participants due to the sensitive nature of investigation, the potentially invasive study of extremely sensitive and personal subject matter. There was also the potential to raise expectations of change or service delivery, especially for people who have desperate needs for support, and to elicit feelings that have no way of being dealt with when the meeting is over. The focus group meetings with the learners demonstrated the distinct value of sharing common problems and providing the participants with the realization that they were not alone in this condition, an experience that was often new to them. Realising the great need these children have for contact with each other, the researcher undertook to assist the PLHIV facilitators to host further support group meetings.

FINDINGS

> ***"You feel so alone; you think you are the only one with this disease. My Grandmother told me to keep it secret"*** HIV-positive learner, 11 year girl

Information and views from the respondents provided a number of insights into the scale and scope of the challenges faced by HIV-positive children. The findings are explored here within a range of themes, and are later drawn together into a set of conclusions and recommendations (see page 17).

Education sector HIV & AIDS policy and implementation:

> ***"The Ministry's policy is to never ask about HIV status.***
> ***An interesting, indirect consequence of this is that formally and officially,***
> ***HIV-positive children do not exist"*** Key informant

While the policy position of the Ministry of Education (MoE) was considered to be robust, many respondents referred to the paucity of implementation. The unwritten policy of silence around naming HIV, while justified by the need for caution in avoiding the potential for stigma, has the effect of creating a vacuum around implementation. An MoE informant suggested that HIV infection causes children to become part of a larger group of vulnerable children who may require special care and remedial treatment, thus making HIV a component of vulnerability. But there is no formal engagement with this issue at school level. This was confirmed by educators at schools who emphasized that the duty of the school is to protect its learners by not identifying their status, which means there are no special arrangements or allowances for HIV-positive learners. In fact, there is a deafening silence around HIV (and its impacts on teachers and learners) at school level. There is thus no indication of how many learners are positive, although a survey at one school revealed high numbers of orphans which made the teachers suspect high levels of HIV infection. Many schools implement the policy for Orphans & Vulnerable Children (OVC) which theoretically extends the meaning of vulnerable children to include children with disabilities or learning difficulties, the neglected and abused, the HIV-positive, and indigenous minorities. However, while OVCs are exempted from school fees and benefit from school-feeding programmes, no allowances are made for HIV infected or affected children because they cannot be identified. Thus, for example, HIV positive children only benefit from OVC allowances if they qualify as orphans.

The MoE directorate of HIV & AIDS Management Unit (HAMU) was established with the main aim of implementing the National HIV & AIDS Policy for the education sector. The policy deals with prevention as well as treatment, care and support, and impact mitigation. It explores ways of managing responses to HIV & AIDS, and emphasizes workplace issues to ensure that all employees in the education sector receive accurate information on HIV & AIDS. This includes information on advocacy, counselling, testing and prevention methods. Regional AIDS Committees for Education (RACE) assist with implementation of the policy, for example through an annual HIV & AIDS Awareness week, World AIDS Day and the Condom Awareness Day in cooperation with the Ministry of Health & Social Services

(MoHSS). HAMU mobilises all the directorates in the MoE to participate in HIV & AIDS activities, collaborates with the National Institute for Educational Development (NIED) in ensuring the integration of HIV & AIDS and life skills across the curriculum, and coordinates the *Window of Hope* and *My Future is My Choice* programmes.

However, HAMU staff admit to being hampered by limited capacity, budget constraints and a lack of clarity of their function in the Ministry. RACE coordinators are constrained by lack of transport in the regions. Regional School Counsellors are supervised to train and manage school counsellors in their respective regions. Each school, of which there are about 1,700 in Namibia, is supposed to have a trained counsellor. This is an un-paid appointment where extra counselling duties are assumed by a teacher, who is usually nominated by the school principal. There is often no assessment of whether the teacher has a disposition appropriate for being a counsellor. Furthermore, the identity of the counsellor is not always made known to all learners, and so a child in need of help might not know that a counsellor is at hand.

"The two biggest problems of dealing with HIV and its consequences in schools are the pervasive atmosphere of intolerance and emotional abuse in schools, and the lack of training for teachers in counselling…In such an environment, HIV-positive children dare not disclose their status. School principals need to be trained to create caring environments in their schools, and school counsellors need to take a more active interest in assisting vulnerable children." **(Key informant – MoE)**

Multi-sectoral support:

"We talk to our adolescent patients about what they learn at school, but it is clear that very little information on HIV & AIDS comes through the education system" ARV clinic doctor

From the perspective of health support, doctors interviewed at an urban ARV clinic concede that the HIV-positive children known to clinic staff attend school and are able to manage their disease by adhering to their medication regime and routinely visiting the clinic. *"Since 2004 when ARVs became available, it has been possible for HIV+ children to live lives relatively free of illness, as long as adherence is good."* **(ARV clinic doctor)** However, due to illness early in life, these children are often small in stature, may not be strong enough for physical exertion in school sports, and are behind their peers at school. They complain to the doctors about their friends outgrowing them, about stigma if their status is known, and even about rejection by family members. There have rarely been cases at this clinic of neurological effects or severe learning problems. Children adapt well to school life if they have good support from the home, but many children are orphans staying with caregivers who do not take good care of them. Nutrition is a particular issue, as children need adequate food to be able to handle the harsh medication. There are many instances where children do not appear well-nourished and doctors refer their caregivers to NGOs for nutritional support.

Children attending this urban clinic are encouraged to take responsibility for their own medication, and the clinic runs special days for the attendance of adolescents without their caregivers. The emphasis is on promoting independence and commitment by patients so that they can take responsibility for their own lives and actions. This is done through the clinic in an atmosphere of support, as many of these children feel rejected at home or at school, and need to know where to turn for help.

The doctors cautioned that regular access to ARV clinics may be difficult due to distances and living conditions in rural areas, and adherence may not be as high there. While all HIV-positive children theoretically have access to free treatment, some clinics have charges that patients are unable to pay, and these are not always waived as they should be. The doctors emphasized the importance of greater collaboration, co-ordination and linkage between ministries, especially in getting "HIV messages" effectively across to the youth. In particular, the MoE and MoHSS need an integrated approach in establishing skills training for pre-service and practicing teachers relating to HIV management, and in developing ways of mainstreaming HIV in schools.

Extensive support for HIV-positive children comes through the NGO sector in Namibia. *"We do not separate HIV-positive children out of the OVC umbrella, but we can say that many of the OVCs we deal with live without parents and have to care for younger siblings. Others live with sick and dying parents, or with older relatives or foster parents who are often unable to provide care normally needed by school-going children. We assist with school fees, uniforms and food support. But there is a high dropout rate among OVCs …they disappear usually with no follow up by their schools. We have noticed that children who are going for ARV treatment at clinics are better monitored by health counsellors, who follow up if they miss a checkup, and they refer them for welfare assistance. Teachers do not follow-up, maybe because they have large classes, but they don't seem to care anyway."* **(NGO respondent)**

Respondents linked to PLHIV networks, Catholic Aids Action (CAA), IBIS, Urban Trust and Treatment Action Campaign described the services they render to school children and their parents and caregivers. These include support with school fees, school uniforms, applications for welfare grants, nutritional support, activity programmes and referrals to various services. A major contribution is the establishment of support groups for adults infected and affected by HIV. This study's use of focus groups for children, recruited mainly from caregivers in adult support groups, had the effect of catalyzing children's support groups, facilitated by PLHIV networks.

"Many HIV interventions have evolved outside of the education system, like the AIDS and Me *and* Circles of Support *programmes which HIV-positive people appreciate for their personalized approach. They are not yet accepted by the education sector, rather being seen as detached projects that are not relevant to education. We admit that IBIS [development NGO] is in a weak position politically and financially to make an impact in the formal sector, but we have put in a major proposal to HAMU for the implementation of our successful programmes in schools. We have had no response from HAMU."* **(Key informant – NGO)**

This study revealed many examples of the breadth of civil society interventions, in particular the PLHIV volunteers working to help struggling families in both urban and rural areas. With minimal income, these young people devote their time to organizing support groups, assisting

HIV-positive people to obtain medical services and social security, following up individual cases reported as having problems, assisting children with school problems, and referring people to appropriate organisations and services. One volunteer had even taken in an HIV-positive orphan to her meagre home because she was having problems with her foster family.

Stigma and disclosure:

"My friends will just laugh at me and leave me out of the group if I tell them I am HIV-positive. Then who will my friends be?" HIV-positive learner, 9 year boy

Considerable stigma may arise as a result of HIV disclosure. For example, parents often do not want to tell their children that they are infected because the children may tell their friends. Likewise, mothers are afraid of being blamed for having passed on the infection to their children. Thus parents and caregivers have in many cases not disclosed the child's status to the child or to the school. This is confusing for a child who is expected to take medication twice a day and attend an ARV clinic monthly. The MoHSS policy is to leave the matter of disclosure to the parents and/or the child, and the MoHSS will not inform the school. But "*…disclosure remains difficult, unknown terrain, and nobody really knows how to disclose this information to a child. There is no perfect formula as different people respond in different ways to disclosure. We are now developing a curriculum to train our staff on the best approaches to disclosure. People who disclose their infection publicly, or even just to their friends, colleagues or teachers, may suffer many consequences. The consequences are also uncertain and many people feel it is best to keep quiet."* (**Key informant - MoHSS**) This is even more relevant to children because of peer pressure and the need to conform behaviourally. Children want to be 'cool' and comparable to their peers; they do not want to look different or to be seen as behaving differently. Infection and its consequences are often hard to hide, for example as a result of physical blemishes, the regular need to take medicines and visit clinics for check-ups, and being absent from school and reduced learning performance. Children are perceptive and often cruel to each other, and teachers and school principals have been known to discriminate because a child is often absent or performing poorly.

Learners in the rural focus group talked about the consequences of disclosure; they are all orphans on ARV treatment. Most of them are known to be HIV-positive as a result of being seen at the local ARV clinic, and most are shunned by their peers at school. There is little confidentiality in this small rural community, and word quickly spreads about who is attending the ARV clinic. The learners know that their rights to education are the same as those of all other children, but being HIV-positive brings difficulties and some learners expressed deep resentment and hopelessness about their condition. One learner said that she was avoided by her friends once her status became known, because they assumed her coughing would infect them. Another said that no-one would sit with her at break because it was assumed that she could put blood in their food. Another learner said he was excluded from games because his peers thought he could infect them through contact. Guidelines about disclosure evidently do not exist in their schools, since the learners complained that teachers spread the word once they know a child to be HIV-positive. Two learners said they have been deeply unhappy at their schools since their status was disclosed and spread around by teachers, as their peers then started to avoid or tease them. They want to go to a different school and keep their status a secret.

A learner in the urban focus group said that she has been pushed aside, rejected even by people in her family who know her status. She has to eat her food and wash her clothes separately as her family fear infection. Another learner said that a newspaper had reported her and her mother as being chased away by her family when they learnt they were HIV-positive. When she got to school the next day the other children backed away from her and told her not to come too close. She was shocked and did not know what to do. Then, to her surprise, the teachers told the children that the newspaper had the story wrong, and she was not HIV-positive. It took a while for the children to react normally to her, but soon all was forgotten. She realised the teachers had done this to protect her. Now it is as if none of that happened, and she still keeps her secret to herself, not able to tell any of her peers that she is HIV-positive. She has arranged to attend the ARV clinic after school and walks from her home to the hospital every month for her medication. Only her mother knows where she is going. She has no-one she feels she can confide in, so she just tries to push HIV to the back of her mind. She was relieved to meet other HIV-positive children in the focus group, and was keen to attend further meetings.

The school and teaching environment:

"I told my teacher I needed to go to the ARV clinic and she told the other teachers and children that I was HIV-positive" - HIV-positive learner, 16 year boy

Respondents reported that it was difficult to assess specific impacts of HIV in the school setting because the status of the children is not known. Teachers consulted during this study were not aware of problems relating to treatment or access to treatment, and they had not been approached by parents or children for help related to HIV & AIDS. *"We don't know who is HIV-positive in this school because of confidentiality, so HIV is not discussed, apart from short sections of the syllabus."* **(Primary school teacher)** The contention is that parents are afraid of disclosure due to the stigma attached to the disease, and so silence prevails. Teachers at two schools observed that poverty is rife in the communities around the schools, and that many children drop out due to disruptive conditions at home, especially in the case of parents having alcohol-related problems. Poverty and a lack of food constitute another reason for dropping out, especially as school-feeding programmes are only for orphans or are not available at all.

Many respondents noted a resistance in the education system to dealing with the consequences of HIV infection. Possible reasons given included teachers themselves being in denial about their own HIV status; teachers being unwilling or untrained to deal with open discussion on the topic; disclosure being discouraged to avoid the potential for stigma; education on HIV and AIDS not being taken seriously; and policy not being clearly understood or implemented. *"I sense a kind of paralysis in the management of the pandemic to the extent that many teachers are in such denial that they themselves are actually sick and dying rather than accessing treatment."* (**NGO respondent)** Learners reported little confidence in the benefits of informing teachers of their status, and indicated that while school counsellors are "around', they are often either unknown or unwelcoming. None of the learners was aware of any meaningful psychosocial support system that they could approach with their problems, apart from non-governmental agencies.

Information and curriculum content:

"A firm message from the President and Minister of Education would go a long way towards legitimizing the integration of HIV issues into the school curriculum" NGO representative

Two HIV information programmes have been developed for schools: *My Future is My Choice* and *Window of Hope*. The *Window of Hope* after-school programme aims to teach 10 to 14 year-olds about HIV & AIDS prevention before they become sexually active, equipping children with the self-esteem, knowledge and skills to protect themselves against HIV & AIDS and to care for others, providing a critical window of opportunity to deliver prevention messages and prepare young people for the challenges posed by HIV & AIDS. *My Future is My Choice* is an interactive and participatory curriculum for secondary schools, providing information on sex organs, sexually transmitted diseases and sexuality, and encouraging questions that adults and parents would normally not permit. All schools are required to offer these programmes but participation is voluntary because they are not integrated into the formal school curriculum. Due to sensitivities surrounding HIV & AIDS and sexuality, both programmes run in the afternoons and parents have to give their written consent before their children may participate. Respondents reported that while the programmes are well-intentioned, they often lack relevance and participation, tending to recite facts without personalizing them, while teachers are negative about promoting these programmes. They receive training but there is little follow-up and no encouragement from leadership. HIV-positive learners said that their main sources of information on HIV-related issues and support were MoHSS doctors, clinic sisters, health counsellors and care-givers, as well as the media. There was consensus that little information was available at schools and that lessons did not prepare learners to deal with HIV & AIDS. *"HIV and AIDS information is given in such a boring way, not appealing to young people. It needs to be youth-friendly, not just top-down from old people"* **(Young adult informant)** One key informant suggested that the National Institute for Education Development (NIED) seemed unwilling to fully integrate HIV & AIDS into the curriculum, further limiting potential access to a comprehensive understanding of the pandemic. As another informant said: *"The educational needs of HIV-positive learners are addressed more tangibly by civil society than by the formal education sector."* Another NGO respondent suspects that many teachers are indeed willing to deal with HIV but are unsure of how to go about this.

This contention was borne out by teachers interviewed at a rural school, who said they taught general information on HIV & AIDS as a cross-curricular concept in Life Science and Agriculture. But there is no personalization of the condition, it is only taught in a theoretical way and related to people 'out there'. *My future is My choice* is supposed to be offered to learners extramurally, but it is not implemented at this school. AIDS Clubs are supposed to meet twice a month, but none had met in the first semester of 2008, which was then almost at an end. The teachers admitted the problem of HIV to be huge in their rural area, but they need training to be able to deal with this issue, and they have no idea of how to go about raising awareness and encouraging disclosure. *"We sometimes suspect a learner is dealing with HIV, like one case of a child whose mother died and she had no-one to support her. The class mates got together to help her with food, and the principal helped her contact a relative in Windhoek. But no-one mentioned HIV."* **(Secondary school teacher)** The school counsellor said she feels inadequate as she may not give the right help or deal with learners' issues in the right way. She needs training to support learners in revealing their status and taking appropriate action, as well as in dealing with stigma. *"I know the problem is out there, and there must be many learners who are affected by it, but I don't know where to start, or how to cope if these issues are raised, so I just avoid the topic."* **(Secondary school counsellor)** The teachers suspect that many people in surrounding communities are infected, and it is thus important to get through to learners to open up discussion and maximize the possibility of prevention. But they have no guidelines on how this can be done.

Doctors at the urban ARV clinic expressed concern at the lack of school-based initiatives for open discussion on sexual education, HIV and stigma. *"Information provided at schools should be comprehensive, explaining the difference between HIV & AIDS, age appropriate primary prevention, facts about transmission, VCT and adherence. Peer educators should be more visible in schools so that they can really engage with other young people who resist being talked down at by adults. The typical adolescent sense of omnipotence, 'I will not catch the virus', needs to be challenged through adolescent-friendly approaches where feelings can be expressed and understood. Practical questions need to be dealt with that perhaps will not be presented at clinic visits, such as 'Why am I small, why am I not menstruating like my friends, why am I behind at school, how shall I disclose to my friends?' "* **(ARV clinic doctor)** And while sexual education for teenagers is clearly not being handled by schools, it is also not well-catered for by the health services. Adolescent patients who make inquiries about birth control are referred to the family planning clinic as if they are adults. This points to the absence of adolescent-friendly services at hospital and school levels.

Young adult respondents felt that HIV should be mainstreamed in schools by being written into the syllabus in detail to offer clear information to all learners, and to open discussion points for teachers to follow up with learners. This would also help children who are not HIV-positive to understand the condition and to respond more appropriately to peers. HIV testing should also be promoted through schools, as too few young people are being tested. All of this would help normalise the condition and could reduce stigma. It should also encourage responsibility amongst sexually active young people. Furthermore, the approach to the disease needs to be personalized to promote engagement with the issues. The example of the personalized IBIS approach called *AIDS and Me* was mentioned as an effective way to get people to really consider their involvement and responsibility in the pandemic. Improved information would also help to debunk the myths around HIV, as much of the fear of the disease is fuelled by inaccurate media information and by rumour. *"Kids need accurate information because they hear so many mixed rumours about HIV, like it comes from baboons, or homosexuals and prostitutes…and it travels through kissing or sharing food."* **(Young adult respondent)** The dominant culture around these young people further entrenches negative attitudes since that are not permitted to discuss anything to do with sexual practices with the adults of the community. Children are getting their sex education from the media and from peers, and often have inappropriate ideas as a result.

The home environment:

> ***"Kids may be living with parents and guardians who are struggling to sustain their own lives. The kids then go hungry and are emotionally neglected"*** NGO representative

Members of the rural caregivers' group agreed that HIV-positive children do have particular problems: they are embarrassed about being HIV-positive, they do not always understand the facts of the disease, they fear death, and feel isolated from other children because they are stigmatised. One parent explained how her youngest child is HIV-positive but her older children are not, and they beat and reject their sibling, even sleeping with a partition in the shared bed due to their fear of being infected. Another parent's response was to suggest that the older children may feel that the infected child is favoured by the parent, so there should be more open communication in the family. She suggested that parents should engage in discussion with their children rather than following the tradition of silence on the subject of sex or HIV. *"School only gives the basics, we parents should also talk to our kids more, not wait for teachers …they don't know everything anyway."* **(Caregiver respondent)**

Parents need help in dealing with questions like how and when to disclose to their children. They complain about children refusing to take ARVs because the reason for the medication is not known to them. Parents are also unsure of whether to disclose to the school as this has consequences of confidentiality which may result in the child suffering stigma. Learners in hostels are in conflict about whether to disclose, thus few of them are assisted by hostel staff to remember medication and to access clinics for monthly check-ups. Psychosocial support for HIV-positive children is generally lacking where there is no active family support. Some children just stay in hospitals because their parents die there and there is no one to take care of them, or they live in child-headed households. Some may attend school but often drop out, especially if there is a lack of food. There are also few structures in schools or the community to really inform children about the disease and its consequences. There is no system available to help children express their needs, and no space for them to learn and interact over issues related to the disease. *"I want to help my foster child, but I have my own three children, and the foster grant is small, so how can I give him what he needs and neglect my own children?"* **(Caregiver respondent)**

Orphaning and vulnerability:

> ***"I left my foster family because they said things that hurt me. Now I have a grant they want me back"*** Orphaned learner, 12 year girl

Children in the rural focus group said that they feel different to their peers: not having parents, having a lifelong disease, needing to take medication daily, feeling ill at times, and not being able to take part in much sport. All this leads to a feeling of isolation. One girl said she used to be clever at school, but since she started on ARV treatment she manages less well at school. She does not mention this to the doctor since he does not ask her how she is coping. Another learner said she is unsure of what to do about taking ARV medication while on a week long school excursion: who to ask for help with remembering times, and how to take it discreetly to avoid being teased. Teachers on the whole are not sympathetic, and the learners did not feel they could ask their teachers for help. One learner said there was no use speaking to teachers about one's problems as *"the teachers don't care"*. One of the learners said she went to the PLHIV activist in her area in desperation when her foster family was being particularly rejecting, and she was offered a place there. She now lives with the activist who has arranged a grant for her. Another learner left his foster family and lives with the Red Cross representative, also receiving a grant. A learner started to cry and said he wants to leave his foster family. They do not give him enough food, and insist that he prepares his small allocation of food separately as they fear being infected. He is often beaten. A PLHIV activist was summoned by the neighbours when they noticed how badly he was being treated, but not much has changed. None of the schools in this rural area offer school feeding schemes.

Respondents at CAA, who provide services to OVCs, have the impression that learners who are healthy physically and mentally and have supportive homes, can manage in schools, but those with special needs are not catered for. Learners with dying parents have psychosocial needs, or if they are struggling to adapt to the side effects of medication they may lack energy and need rest periods. These needs are not accommodated, however. Another major social issue faced by children in many communities is the effect of alcoholism, with its accompanying tendency to promote abusive and promiscuous behaviour. The after-school programmes run by CAA reveal that many children are victims of abuse, as shown by their behaviour and what they say. While these children can find a safe haven at this after-school site, there is little vision for how to intervene and mitigate the effects of their difficult living environments. For example, the CAA after-school programme in Windhoek was set up with the purpose of providing a space where children could come and get assistance with their school work. However the reality is that children from the local schools refuse to bring homework and stopped coming to the centre when that was the proviso. The manager therefore dropped that requirement, making schoolwork voluntary. The manager's impression of the local urban schools is that they are overcrowded and under-resourced which makes progress extremely difficult. The children also often have behaviour problems because they come from homes where alcohol is abused, and they themselves are victims of abuse. There is also little academic stimulation and children are promoted automatically whether or not they perform well. The manager cited a lack of self-esteem as a glaring problem. *"It takes a village to raise a child…but these days there is no community support around a child, in this area they are just on the street if they are not at the after care centre."* **(NGO respondent)**

CONCLUSIONS AND RECOMMENDATIONS

"I see there are lots of other kids the same as me; that feels better; by sharing I have got new ideas about how to cope with HIV" HIV-positive learner, 11 year girl

The overriding impression provided by this research is that medical services related to HIV & AIDS are relatively efficient, infected children generally have access to treatment and the supportive services of the NGOs, FBOs and PLHIV networks. But a quite different picture emerges from learners' experiences at schools, where there a sense of denial prevails, with the feeling that the way to handle HIV is to ignore it on a personal level, and to reduce information about the disease to the minimum curricular requirements. Discussion is restricted to Aids Week or Aids Clubs that remain quite depersonalised and remote from the individuals infected and affected by HIV. Many of the learner respondents explained how they had to hide their status, to lie about their medical needs and their inability to keep up with sports, how they felt intense shame about being HIV-positive, a condition of disgrace to be hidden from their school mates who would mock them if they knew. Then there are those whose condition is known in their schools, who described their lives as a kind of hell, of rejection and derision by peers, of harsh treatment by teachers. Their unqualified advice was to get HIV/AIDS information mainstreamed in the school system to achieve a better understanding of the issues around the disease, and less irrational stigma. The prospect of support groups for young infected people was welcomed, with good role models talking about the disease to help dispel the negative myths that have grown up around the disease, using youth-friendly approaches.

It would seem that many HIV positive learners have to cope with a disjuncture in the experience of home, clinic and school. On the one hand, they receive detailed information about their disease from the medical side, being engaged consciously in their treatment programme, and given responsibility for taking medication according to a rigorous daily schedule. From the home side, they may be assisted by a family member to access clinical facilities and to take medication timeously, while also having to deal with the implications of transmission of the disease and how they became infected. On the other hand, beyond the walls of clinic and home, all this information and understanding is seemingly forced underground. There appears to be a silent agreement to hide their status, to conduct their lives as if their condition does not exist or, in the case where it is known, to hang their heads in shame.

"These are our children…living in our midst…
we should be saying, isn't this a wonderful thing,
not denying their existence" NGO representative

Given the consensus that the school system is poorly equipped to deal with the special needs of HIV-positive learners and the fact that disclosure remains complex, the study recommends that:

a) The MoE review and, most importantly, implement at every level the provisions of its Education Sector HIV and AIDS Policy, as well as its OVC Policy, and address the particular issues of rights violations, stigma, curriculum and training;

b) The MoE review the role and effectiveness of its HIV and AIDS structures at every level to ensure the implementation, monitoring and reporting of its policy;

c) HIV-positive learners be embraced as part of the growing group described as orphans and other vulnerable children (OVCs), all of whose special needs should be subject to confidentiality, negotiation and flexibility at the school level to facilitate ART adherence and access to medical treatment and feeding schemes;

d) Gender and age-appropriate sexual and reproductive health and HIV and AIDS materials should be incorporated without delay into the curriculum and syllabi of examinable subjects to increase access to comprehensive knowledge and understanding. The curriculum should also deal with the sexual and reproductive health needs of HIV-positive learners and young adults, information on which should help reduce peer-group antipathy and misconception.

The pre-service and recurrent in-service training requirements of teachers and school counsellors within the school system should be reviewed, and the commitments of the relevant policies implemented without delay to ensure acceptable levels of capacity in every school.

Greater attention is required to personalizing the disease and its effects. This will serve both to boost the confidence of HIV-positive children in dealing with their condition and to reduce the substantial levels of denial and silence that surround HIV. To this end, the MoE should consider the integration of information on HIV and sexuality into its curriculum and the syllabi of examinable subjects. Aspects of sexuality are relevant because many of the problems of preventing and dealing with the consequences of HIV infection stem from taboos associated with sex.

The functioning of HAMU needs to be revised so that more emphasis is placed on implementation. Several NGO proposals have been offered for its consideration, without any response or action. These include a range of activities that have worked successfully on a small scale under NGO management and that could benefit children on a much larger scale if embraced by the MoE. Best practice in other countries should be explored in an attempt to find more efficient ways of passing on knowledge of HIV & AIDS and reproductive health. The school cluster system could be used as the management vehicle through which such programmes are rolled out across the country. The South African model of Life Orientation being an examinable subject has its merits as it is taken more seriously than voluntary programmes. However, poor teaching of the subject and unstimulating, repetitive content should be avoided. Age- and gender-appropriate approaches are required, together with dynamic materials and presentation. Merely burdening teachers with additional duties which do not interest them, or which may even embarrass them, is not the way to engage young people on the critical issue of HIV and AIDS.

In recognizing the difficulty that parents often have in managing the disclosure of their children’s HIV-status, there is a need to aggregate counselling, guidance and support for families in communities around schools. Principals should be provided with adequate orientation and training, including guidance materials, to assist parents in recognizing and managing these issues.

While multi-sectoral approaches should be strengthened, partners should guard against the assumption that some other partner (ministry or NGO) will "take care of it". That assumption often leads to important tasks falling between stools, the partners involved often disavowing responsibility.

Finally, and recognizing that a comprehensive response to HIV is not the MoE's core business, the Ministry should make every effort to promote a culture of tolerance and understanding in schools, in which HIV-positive learners can be confident and accepted as worthy citizens without discrimination. The present culture of stigma simply needs to be challenged in every way possible.

APPENDIX: LIST OF PARTICIPANTS AND INFORMANTS

1 Catholic Aids Action (CAA), Windhoek: Father Rick, Mary Beth Gallagher, Lucy Steinitz (FHI)
2 Augeikhas Primary School, Katutura, Windhoek: Principal, school counsellor, head of department
3 Augustineum Secondary School: Teacher – Louisa Mulilo, Student – Martha Hamukwaya
4 International Community of Women (ICW), Windhoek: Jenny Mallet, Esther Sheehama
5 Ten members of caregivers' support group, learner focus groups for boys and girls, 5 members of young activist support group.
6 Lironga Eparu, Windhoek: Emma Tuahepa
7 Katutura Hospital – ARV Clinic – paediatric section: Doctors Shalongo and Kasanda. Nurse – Louisa Mulilo. Adherence counsellor – Josephine Michael
8 IBIS, Windhoek: David Lush (HIV manager), Kennedy and Ingrid (facilitators), Tauno Nakasole at Yelula, Oshakati
9 Ministry of Education: Dr Susanchen Fourie (Educational Psychologist)
10 Ministry of Health & Social Services (MoHSS): Dr Angela Mushavi (Technical advisor on PMTCT, working on the CDC Namibia bilateral programme)
11 Learner focus group discussion – Okongo (facilitated by Milau Phillipus and Maria Nambahu)
12 Tonateni New Start Centre, Oshakati: Aino Tobias, counsellor
13 Focus group of caregivers at Tonateni, Oshakati: 10 adults, facilitator Tungeni Ombili Nelumbu plus 10 members
14 Treatment Literacy Campaign, Oshakati: Jeremiah Shitenyinga
15 Consultant working for CBOs and NGOs in Oshakati: Tsitsi Dangarembizi
16 Urban Trust of Nambia: Melago Kondombolo, Magdelena Iipinge, Nestor Florian
17 Nangolo Secondary School, Ondangwa: Teachers – Mr. Natinda, Ms Nakathingo (school counsellor), Mr Hambinga, Mr Chingo.