Strengthening HIV AIDS and Education Research in the Caribbean

Final Project Report

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Abstract

The Caribbean is the region most affected by HIV after sub-Saharan Africa, and the education sector has been active in the response to HIV. HIV-related stigma and discrimination in the Caribbean might have detrimental effects to the school achievement and experiences of children living with or affected by HIV. This study in two Caribbean countries, aimed to describe the nature and extent of HIV-related stigma and discrimination among school-aged children, and to relate this to school experiences and educational outcomes. The study was a cross-sectional survey among children, 10 to 18 years old who were infected with or affected by HIV. A comparison group of students of the same age and gender and from the same schools as the target children were also selected. All children were interviewed using a structured questionnaire which assessed the school experiences and performance, experiences of depression and anxiety, and stigma and discrimination (enacted, perceived, and shame, blame and judgement), HIV knowledge and disclosure issues. School achievement was measured using the WRAT III. Caregivers were interviewed to determine demographic and socioeconomic data for each household and assessed the children's school experiences, school performance, behaviours and issues related to stigma and discrimination from their perspectives, while class teachers and principals of the selected children were interviewed to assess knowledge of national HIV policies, the status of school HIV policies, HIV programme and, and stigmatizing and discriminatory attitudes within the school setting.

In St. Lucia, 10 target children (2 infected and 8 affected) and 10 comparisons were enrolled aged 12-17 years. More target children were not in school, and there was greater reported school absence, but these differences were not statistically significant. Target children reported many cases of perceived and enacted stigma, and stigma significantly predicted school achievement outcomes.

In Guyana, 19 infected and 20 affected children (10 – 18 years old) were enrolled, along with 35 comparison children, 30 caregivers, 35 teachers and 20 principals. All children were attending school, but there was greater absence among target children. School experiences were similar among the groups. Several of the infected and affected children reported they felt that they were stigmatized and discriminated against, while most of the comparison children thought that people living with HIV would be stigmatized. Educators were varied in their responses, most indicating that HIV infected children would be segregated from others. Awareness among educators of national policies and programmes was low on both countries.

The recommendations include confirming (St. Lucia) and implementing (in both countries) the HIV policies related to the education sector, and placing greater emphasis on reducing stigma and discrimination. Strategies to measure and monitor stigma and discrimination should also be designed and implemented.

Literature Review

a. Background

Stigma and discrimination are common responses to disease, and throughout history various diseases have been especially the focus of such responses, including leprosy, tuberculosis, mental illnesses and cancer (Brown, Trujillo, Macintyre, 2001). HIV/AIDS follows in this unfortunate pattern.

Several authors distinguish between felt or perceived stigma and enacted stigma (Brown, Trujillo and Macintyre, 2001). Felt stigma refers to perceived attitudes that there is shame associated with one's HIV status (or that of one's family or associates) and fear that this will be translated into actions such as avoidance, shunning, shaming and so on. Enacted stigma refers to actual experiences of discrimination, such as shunning and avoidance, seeking to harass, punish or vilify the targets, or by failure to act for example to provide certain needs (Brown et al, 2001, de Bruyn, 1998).

The devastation wrought by the HIV epidemic is compounded by the extent and severity of the stigma and discrimination faced by patients and their families and associates. Stigma and discrimination can be extremely detrimental to children, both those living with and otherwise affected by the disease. It may affect their development and behaviour in many ways, and the negative effects on their school experiences and outcomes might have compounded problems since poor academic achievement will lead to tangible long-term issues regardless of morbidity outcomes.

This review focuses on reports from developing countries. We first examine a range of studies which have documented the stigma and discrimination faced by adults and children living with or affected by HIV, and also among affected children who were not HIV positive. As several reviews have already been carried out of this area, both original studies and reviews are presented. The final section focuses on the few studies we found which linked HIV-related stigma with school experiences and academic achievement among children (up to 18 years). Gaps in the knowledge, especially for the Caribbean region are then highlighted.

Studies for the review were initially located through internet searches among a range of databases available through the University of the West Indies, including PubMed, BioMed and ProQuest. The terms searched were HIV, AIDS, stigma, discrimination, school, school achievement, educational outcomes and children. Each relevant paper found was then in turn searched for additional related studies, all published in peer reviewed journals. In addition, a number of technical reports and working papers were accessed through agency websites and personal contacts. A few papers were included which had been presented at conferences only.

b. HIV and Stigma/ Discrimination: Cross-sectional and Intervention Studies

Stigma-related studies among adults. Descriptions of stigma have been published from a number of countries, including the USA, Brazil, eastern and southern Africa, China and Thailand (see Table 1 at Appendix I). However from the Caribbean, only one study from Jamaica was found. One study in the USA which focused on adults examined the psychosocial effects of persons living with HIV and AIDS (PLHA) and found negative self image a serious concern (Berger, Ferrans and Lashley, 2001). Two studies described stigma among uninfected adults. In the US, trends in expression of stigma among uninfected over the period 1991-1999 showed a decline in blatant expression, but continued unease and negative feelings towards PLHA (Herek, Capitanio, Widama, 2002). In Jamaica, a survey among university students indicated that while some sympathy was expressed towards children living with HIV, fewer respondents were sympathetic towards homosexual men or women, or sex workers who were affected (Norman, Carr and Jimenez, 2006), possibly because they were seen as 'deserving' of the disease. This contrasts with another study of Chinese university students (Tan, Pan, Zhou, Xie, Wen and Hong, 2006) which suggested more positive and tolerant attitudes towards PLWHA, especially among males.

A large study across four countries, Thailand, Zimbabwe, Tanzania and South Africa, systematically compared HIV-related stigma among community members as well as factors related to greater or lesser stigma (Genberg, Hlavka, Konda, Maman, Chariyalertsak, Chinogo, Mobida, Rooyen and Celento, 2009). Interesting associations were found with levels of stigma varying significantly with prevalence and knowledge levels of ARV. These included significant associations between never having talked about HIV/AIDS and negative attitudes towards PLHA, an inverse association between ARV coverage and negative attitudes, and greater perceived discrimination against PLHA in sites with the lowest ARV coverage (Tanzania and Zimbabwe).

Studies of children living with or affected by HIV. Sixteen cross-sectional surveys were found which focused on children and adolescents living with HIV and/or orphaned by AIDS (Table 2.2). Most of these reports were however abstracts from conferences for technical reports/ discussion papers/ working papers. Only 5 were published in peer reviewed journals. Most of the papers were studies carried out in one or more countries in sub-Saharan Africa, primarily in southern and eastern Africa, and several were multi-country comparisons with 3, 10, 17 or even 40 African countries included. Other countries reported from were the USA, Jamaica (one), Kenya, Indonesia and Brazil, and a large 28-country study from sub-Saharan Africa as well as Latin America and South East Asia.

Each study is summarized in Appendix I, Table 2. Many of the studies were secondary analyses of large, population based data-sets, which demonstrate the value of mining existing data in this way. Expected findings such as lower school attendance, greater problems at school, additional

responsibilities, and higher absenteeism among orphans were commonly reported. However there were a number of unexpected findings, such as that AIDS orphans in Botswana had better attendance records than non-orphans (Bennel, Hyde and Sainson, 2002), or that there were actually reports from HIV affected children in their treatment at school. (On the other hand, this was with a very small non-random sample (National AIDS Committee, 2002).)

Several reports describe the situation of children living with or affected by HIV in relation to stigma issues, and more so, school outcomes. Mostly these are independent outcome variables, and they are not considered as dependent and outcome variables in analyses. For example, Badcock-Walters, Mallouris and Boler (2008) describe the situation in Tanzania and Namibia among young HIV-positive learners, who cite high levels of stigma and discrimination in the classroom, and separately the many problems in education sector which are compounded for HIV positive learners.

Reviews. A conceptual framework and 2 reviews are shown in Appendix 1, Table 3. Parker and Aggleton (2002) present a framework including a range of sociological variables such as sexuality, gender, race and ethnicity, class, fear of contagion and disease, and discuss these in relation to various contexts: policy and legal, institutions (such as educational, employment, religious, community, family and individual contexts). Exploratory studies and the hypotheses presented here suggest that interventions need to focus on social rather than individual action to address stigma and discrimination which are seen as social processes.

The two reviews describe interventions to reduce stigma (see Appendix 1, Table 3). The first describes some 21 interventions to reduce HIV-related stigma, and conclude that short-term small scale reductions in stigma are reasonably well demonstrated across a range of countries, target audiences, and utilizing different interventions (Brown, Trujillo and Macintyre, 2001). The details of the included studies are also shown. The types of interventions were described as general information provision, making contact with affected groups, coping skills acquisition (among both infected and uninfected groups, uninfected audiences were shown how to manage certain situations), and various counselling approaches. Positive effects were found with all types of interventions. Unfortunately most of the interventions from developing countries were not rigorously evaluated and many were not published in peer reviewed journals (as pointed out by the review authors). However, because of the dearth of reports of any kind from developing countries, these were also included in the review. Our own inspection of the papers and abstracts reviewed here suggests a much narrower view without the reports that were not peer-reviewed, though the general conclusions remain including the need for more careful studies from developing countries, the need for more, larger and longer-term interventions, and a framing of the question as to the predictors of stigma.

The more recent review (1990 – 2006) of stigma reduction interventions concluded that single target and single level group strategies were not sufficient, but patient-centred approaches were more successful (Heijners and Van der Miej, 2006).

c. HIV and Stigma/ Discrimination related to school outcomes

Surprisingly, only two studies were found which were actual interventions focused on addressing HIV/AIDS and school-related outcomes in developing countries (Appendix 1, Table 4). The first involved a one week training workshop among teachers and health workers in Tanzania with an aim for them to educate primary school children in order to reduce the children's risk of HIV infection and to reduce the consequences of HIV infection in their communities (Klepp, Ndeki, Shea et al., 1994). Children were administered a questionnaire on baseline and after a 6 month follow-up period¸ and compared with a comparison group of children from schools without the intervention. There were improved knowledge, information and communication scores and, less negative attitudes towards PLWA, but no significant effects on attitudes towards and intention to engage in sexual intercourse.

This study was carried out fairly early in the development of the explosion of HIV across sub-Saharan Africa, in 1992. However it demonstrated significant benefits of a modest intervention, utilizing a large sample (n=2026 at baseline, 85% of target population) though the follow-up was smaller (n=1785, 88% of original sample), changes were reported knowledge and attitudes only, not of actual behaviour, and the time frame was short¸ so there was no measure of longer-term outcomes.

The second study was in Uganda and the cross-sectional baseline only was reported (Gilborn, Nyonyintono, Kambuli & Jagwe-Wadda, 2001). The sample comprised HIV-positive parents (n=353), children of PLHAs (n=495), orphans (n=233), and current and standby guardians (n=326). Two types of households were: with an HIV positive parent, or with an orphan, and respondents were grouped by parent or not, and children by age groups. The findings included no significant differences in enrolment in school by gender, age group or household type. Older children of PLHA reported a decline in school attendance and performance when parents became ill, and older orphans reported improved school attendance when moved into foster care. Only a quarter of the adults and 17% of older children perceived that the children were differently treated because they had a family member with HIV, and mistreatment of younger children because of their family member having HIV was also reported by younger children of PLHA and orphans, though only among a small proportion of respondents (approximately 6-10%)

This last study is the closest to reporting the issues we highlighted as important in the introduction, namely the relation between HIV related stigma and school-related outcomes. Self

reports of experiences were corroborated by parent and guardian reports, however school achievement was not objectively measured.

Both of these studies were conducted in the region most highly affected by HIV worldwide, sub-Saharan Africa. Neither comprehensively makes a case for serious stigma against affected children, or important differences in attainment as a result of stigma-related issues such as ostracism or non-enrolment. These studies also do not include HIV infected children.

There have now been two assessments of children living with or affected by HIV in Jamaica (National AIDS Committee, and unpublished report). The first rapid assessment (2002) suggests high levels of ignorance fueling stigmatisation among some teachers and others, and describes school absence and poor grades following the illness or death of a parent from HIV. On the other hand, some children described benefits such as helpful teachers. The sample size was very small, and the data were not analyzed statistically, however. The second report (2008) with a larger sample size (n=291) also reported poor school attendance among vulnerable children aged 7-17 y, though other school related issues are not explored. Similar studies were not found for the other English-speaking Caribbean countries.

A Cochrane review by King et al (2009) that sought to assess the effectiveness of interventions that aim to improve the psychosocial well-being of children directly affected by HIV/AIDS including education and school attendance, concluded that the current practice is based on anecdotal knowledge, descriptive studies and situational analyses, thereby lacking the rigour to convincingly assess the effectiveness of these interventions.No studies of interventions were identified which fulfilled the inclusion criteria for the review. The authors argue that this systematic review has identified the need for high quality research studies and an urgent need for rigorous monitoring and evaluation of existing programs and intervention studies to ensure evidence-based practice and policy.

In summary, the extent and nature of HIV related stigma are likely to be highly culturally specific, and the hypothesized negative educational outcomes should be investigated among both HIV infected and affected children in the geographical region of interest. There is no clear understanding of these relationships in developing countries.

Study goal and objectives

The goal of the study was to strengthen HIV and AIDS and Education research in the Caribbean in support of evidence-based policies and practices in education on HIV prevention, treatment, care and support.

The overall objective was to describe the nature and extent of stigma and discrimination related to HIV and AIDS among school-aged children in two Caribbean countries, and relate this to school experiences and educational outcomes.

The specific objectives were:

1. To select or develop instruments to measure the nature and extent of HIV/AIDS-related stigma and discrimination against school-aged children, including piloting and determining reliability.

2. To obtain the sample frame of children living with or affected by HIV eligible for the study.

3. To sample the children and obtain appropriate consent from their caregivers and assent from them.

4. To collect data from the children, their caregivers and their teachers and principals.

5. To analyze and report on the findings, including policy and programme recommendations arising from the study.

Methodology

Study design
The study was a cross-sectional survey, and was conducted in St. Lucia and Guyana.

Sample Targeted
Children, 10 to 18 years old who were infected with or affected by HIV were targeted for the study. To be eligible for the study, children infected with or affected by HIV had to be aware of their own status or that of their caregivers to avoid disclosure of HIV status. 30 children infected or affected by HIV were targeted from each country.

A comparison group of students of the same age and gender, and from the same schools as the HIV infected or affected children were also selected. One comparison student was chosen for each infected or affected child. For HIV infected or affected children who were not attending school, comparison children matched by age and gender were chosen from the last school attended by target child.

The children's caregivers, class teachers and school principals were also targeted.

Questionnaires
Three separate instruments were developed: for the children, the caregivers, and the principals and teachers. Each instrument was developed by adapting questions from previous instruments.

Child questionnaire: The instrument for the children (Appendix II) assessed the children's school experiences and performance, their experiences of depression and anxiety, and stigma and discrimination. Five areas considered central to HIV stigmatization and discrimination were examined: perceived stigma; enacted stigma; shame, blame and judgment; HIV knowledge; and disclosure issues. Parallel forms of statements were used to assess perceived and enacted stigma among the children. Infected or affected children reported how they thought people perceived them and the frequency of stigmatization they may have experienced at school owing to either their or their family member's HIV status. Comparison children reported what they thought other people's perceptions would be towards persons living with HIV and how often they think children with HIV would be stigmatized at school. The children's school achievement was assessed using the Wide Range Achievement Test -3 (Wilkinson, 1993).

Caregiver Questionnaire: The instrument for the caregivers (Appendix II) captured demographic and socioeconomic data for each household and assessed the children's school experiences, school performance, behaviours and issues related to stigma and discrimination from the caregivers' perspectives.

Principal and Teacher Questionnaire: The instrument for principals and teachers (Appendix II) captured background data on principals and teachers, as well as assessed knowledge of national HIV policies, the status of school HIV policies, HIV programmes and activities in their schools, disclosure and safety issues, and stigmatizing and discriminatory attitudes towards children living with or affected by HIV within the school setting.

Piloting
Prior to data collection, all the instruments were piloted in Jamaica and test-retest reliability was established. In addition, they were field tested in each participating country to check understanding and clarity of each item in-country.

Partners
A local multi-agency Project Steering Committee led the study in each country. The committee comprised an HIV Focal Point person from the Ministry of Education who chaired the committee and facilitated access to study participants; an in-country collaborator who monitored the staff working on the project and ensured security of the data; and representatives from the health and education ministries, the National AIDS Programme, UNESCO, HIV and AIDS organizations, and other relevant sectors. A list of the members of the committee for each country can be found at Appendix IV.

Selection and Training of Research Assistants
A Research Assistant was carefully selected from each country by the project steering committee to carry out the field activities. Each country was visited and the Research Assistant trained in the field and interview methods over 3-5 days. The Research Assistants were also instructed on the ethical consideration of the study, particularly as it relates to the confidentiality of information to be collected and non-disclosure of the HIV status of the study participants. Each Research Assistant was also provided with a field instruction sheet and an interview guide to enhance the fieldwork. Inter-rater reliability was also obtained between each Research Assistant and the trainer to establish agreement in conducting the interviews.

Ethics and Data collection procedure
The research study received ethical approval from the review board of the UWI Open Campus. Approval for the study was also received from both countries: the Ministry of Education in St. Lucia, and in Guyana, the Institutional Review Board and University of Guyana. A copy of the ethical approval can be found at Appendix III.

Participants for the study were recruited by the trained Research Assistant located in-country. All participants provided their written informed consent (18 years and older), or written informed assent (10 – 17 years). Parental permission was also obtained for all child participants under 18years. Confidentiality and the voluntary nature of participation in the survey were stressed. The consent and assent forms are attached at Appendix II. All participants were individually interviewed by the Research Assistant. The children and their parents were interviewed at a location of their choice such as their homes. All the children were provided with tokens after their interviews. Prior to being interviewed, the HIV infected/affected children and their caregivers were screened to confirm that they were aware of their status or that of their caregivers' or other family members. The screening forms are shown at Appendix II. The teachers and principals were interviewed individually at their schools.

Data preparation and analysis

All the data were coded, entered, cleaned and analyzed using the Statistical Package for the Social Sciences (SPSS) version 12.0. Descriptive statistics (frequencies, percentages, means, and standard deviations) were used to characterize all the variables. Chi squares (for categorical data), and ANOVAs or t-tests (for continuous data) were used to compare the data across the groups of participants. Composite scores were obtained by summing the infected or affected children's responses to reports of perceived and enacted stigma and regression analyses used to assess whether reports of perceived and enacted stigma predicted school achievement. A p – value of less than 0.05 was used as the threshold for significance.

Sharing findings from the study

Preliminary findings of the analyses were presented in a one-day meeting held in each country (St. Lucia on October 13, 2010 and Guyana on October 15, 2010) with project steering committee members and other key stakeholders. The objectives of the meeting were to present the preliminary findings of the each country's study and discuss its potential for informing policy and programme recommendations for the education sector's response to HIV and AIDS.

Results

St. Lucia

Sample Obtained

In order to obtain a representative sample of HIV infected and affected children, we first planned to obtain a detailed description of all infected and affected children in the country. Initial investigations indicated that there were 5 infected children and approximately 170 affected children. In spite of repeated requests, including to the Project Steering Committee, we were never able to confirm these figures. The children recruited for enrolment to the study were all brought to the attention of the study through the Social Worker in the Ministry of Health responsible for children who were a part of the OVC programme. It was extremely difficult to obtain contact information for the children in this programme, and only those deemed accessible by the Social Worker could be contacted. Since so few children were made available, far fewer than the target 30 children, a decision was taken to include more than one child from a single family, if available.

Only 3 caregivers of infected children were identified to us. Two of them agreed for the children to participate.

Of the 17 caregivers of affected children who were identified to us, children of only 5 caregivers (with 8 children) fit the study criteria. All 5 caregivers and their 8 children agreed to participate. Each of the 10 target children (2 infected and 8 affected) who were enrolled was matched with a child of the same age (± 6 months) and gender, from the same school and these 10 children formed the comparison group.

Each child enrolled in the study and his/her caregiver was individually interviewed by the Research Assistant. The class teacher for each target child and matched comparison (n=10), and the principals of the schools the children attended (n=7) were also interviewed.
Because of the small sample obtained in St. Lucia, many of the planned statistical analyses were no longer appropriate.

Sample description

The characteristics of the children, their caregivers and principals and teachers are presented in Tables 1, 2 & 3 respectively.

The children ranged in age from 12 to 17 years. There were more males than females. For most of them, their mothers were their primary caregivers.

The primary caregivers were female, however, one father responded to the caregiver's questionnaire as the mother was not available for the interview. Most were married or in common-law relationships.. The caregivers of infected and affected children had only primary school education while some of the caregivers of the comparison children had secondary and vocational education as well. Most caregivers were in unskilled or semi-skilled jobs. The socio-

economic status indicators showed similar levels of crowding, and toilet facilities and water sources in the homes. However, the households of comparison caregivers had a greater mean number of possessions.

The principals and the teachers were mostly male. Most worked at public secondary or high schools and all had completed college or university with a bachelor's degree. The range of experiences as a principal or teacher is also shown.

School-related information

School attendance and experiences
All the comparison children were attending school. At the time of the interviews, neither of the 2 infected children was attending school, and 1 of the 8 affected children also was not at school (Table 4). One of the 2 infected children had already graduated from school and was working; the other infected youth refused to go to school and the 1 affected child not at school hoped to migrate to attended school abroad.

For those affected and comparison children attending school, their school attendance in the last school year was similar: most of them reported that they had missed days of school since starting the grades they were in when they did the interviews. The reasons given for missing school are shown in Table 5. The most commonly reported reason was because of illness; however, 2 of the affected children reported that they missed school because there was no money.

Infected and affected children were similar to the comparison children in their experiences at school: most of them reported that they liked school very much, and got along very well or well with both their teachers and their classmates (Table 4).

Caregivers also reported on the children's school attendance and experiences. Their responses are shown in Table 6 & 7. Their reports were similar to those of the children's.

School performance
The infected and affected children were similar to the comparison children in reported school performance; most of them judged themselves to have done very good or good, though they received mostly C's, and most had not repeated a grade (Table 8).

The caregivers also judged how they thought the children performed at school. Their responses are shown in Table 9. The caregivers' reports were similar to the children's, however, a few of them thought that the children were performing worse or better than the children reported.
The children's school performance measured by the Wide Range Achievement Test - 3 is shown in Table 10. The infected children had much lower mean scores than the affected or comparison children on the Reading and Spelling Scales. In addition, the infected and affected children each had lower mean scores than the comparison children on the Math Scale. However, none of the differences achieved statistical significance.

Experiences of Depression and Anxiety

The children reported their experiences of symptoms of depression using the 'Moods and Feelings Questionnaire' and anxiety using the 'What I think and Feel Questionnaire'. Responses to the questions on both scales were summed to generate separate score with higher scores indicating more depressive or anxiety symptoms. The infected children obtained a larger mean score than either the affected or comparison children on both scales, however, the differences were not statistically significant (Table 11).

Behaviours

The children's caregivers reported on their behaviours. A modified version of the Rutter Scale for parents was used. The scale assessed children's prosocial behaviours (10 items) and conduct difficulties (8 items). Prosocial behaviours included deeds such as helping others, and being kind to other children and conduct difficulties included behaviours such as fighting frequently, bullying and hitting other children. The mean scores were similar amongst the groups for prosocial behaviour, although the HIV affected children had much higher scores for conduct difficulties (Table 12).

Stigma and Discrimination

Perceived Stigma
The children's responses to the perceived stigma statements are shown in Tables 13 a & b. Because of the small number of infected children their responses were combined with those of the affected children. 10-30% of the infected and affected children agreed that they had experienced at least one of the perceived stigma issues asked. The comparison children mostly agreed that people living with HIV would experience the issues asked.

Enacted Stigma
The children's responses to the enacted stigma statements are shown in Tables 14 a & b. The responses of the infected children were combined with the affected children because of the small number. 10-30% of the infected and affected children indicated that they had experienced at least one of the enacted stigma issues asked about most of the time or sometimes. Most of the comparison children thought that someone with HIV at their schools would experience the issues asked about most of the time or sometimes.

Prediction of school achievement
A series of hierarchical regressions were carried out to determine how the children's experiences of perceived and enacted stigma related to their school achievement. Due to the small size of the sample, infected and affected children were combined to form one group called "exposed" and the contribution of perceived and enacted stigma experiences to school achievement for this

combined group was examined. Composite scores for perceived and enacted stigma were entered into independent regression models as independent variables along with child's age, gender (female = 1, male =0) and HIV status (infected = 1, affected = 0) as covariates to determine contributions to the children's scores on the Maths, Spelling and Reading Scales (dependent variables).

The results of the regressions for whether experiences of perceived stigma, controlling for age, gender and HIV status, predicted scores on Maths, Spelling and Reading Scales indicated that only gender was significant in predicting spelling ($\beta = 0.754$, $p < 0.05$) and reading scores($\beta = 0.828$, $p < 0.05$).

The results of the regressions for whether experiences of enacted stigma, controlling for age, gender and HIV status, predicted scores on Maths, Spelling and Reading Scales indicated that enacted stigma experiences predicted Math scores ($\beta = -1.155$, se = 5.44, $p < 0.05$); gender was also significant in the regression ($\beta = 0.970$, se = 2.62, $p < 0.05$). The adjusted R^2 for the model was 0.507. Gender was significant in the regression predicting Spelling scores ($\beta = 1.033$, se = 0.096, $p < 0.05$), and gender ($\beta = 1.091$, se = 5.92, $p < 0.01$) and age ($\beta = 0.616$, se = 1.79, $p < 0.05$) were significant in regression predicting Reading scores.

Shame, Blame and Judgment

All the children were asked whether they agreed or disagreed with a series of statements on whether people with HIV should be blamed for their HIV and feel ashamed. Their scores for the statements are shown in Table 16. The infected and affected children, in general, had lower mean scores than the comparison group for all the statements indicating lower blame and judgment. However, the difference was significant for only one of the statements, 'People with HIV deserving what they get.' The composite blame and judgment score was not significantly different for any of the groups of children, though.

The principals and teachers also reported whether they agreed or disagreed with a series of statements on whether people with HIV should be blamed and feel ashamed. Their responses to the statements are shown in Table 17. Most of them disagreed with the statements.

Knowledge about how HIV is transmitted

The responses to the questions inquiring about the children's knowledge of how HIV is transmitted are shown in Table 18. There were no significant differences among the groups for any of the individual questions as most of them selected the correct answers, although more of the infected and affected children selected the correct answers which indicated that they had somewhat greater knowledge. The composite HIV knowledge score was also not significantly different among the groups.

Knowing children with HIV

The children and their principals and teachers were asked whether they knew of any children with HIV at school. The children's responses are shown in Table 19, and the principals' and teachers' reports are shown in Table 20.

The children were asked whether they knew about any children at school living with HIV. The infected and affected children did not differ significantly from comparison group in their responses: most of them said it was not easy to know if someone had HIV and that they did not suspect anyone from their schools to have HIV. All the children reported that they did not have a friend at school living with HIV.

The principals and teachers were asked whether they were aware of students with HIV at their schools. Most reported that they were not.

Opinions on HIV Disclosure

The responses to questions on attitudes towards HIV disclosure as reported by the children, their caregivers, and principals and teachers are shown in Tables 21, 22, 23a & b respectively.

The children were asked whether they thought someone with HIV should keep it a secret, tell only family or tell everybody. Most of them felt that such a person should tell only family. They gave multiple reasons for their choices including, it is a personal or family problem; people would act differently towards, keep away from, tease or talk about the person.

The caregivers were asked whether they thought the principal, teachers, students and other parents should be told if a child living with HIV started attending school. More caregivers of comparison children than those of infected and affected children felt that the principal, teachers, and other parents should be told with the difference being significant for principals and teachers being told.

The principals and teachers were also asked whether they thought information on a student's HIV infection should be told to the school community. Most thought that principals and teachers should be told, and that other students and parents should not be told.

The principals alone were asked as well whether they would disclose information about an HIV infected or affected child to the school community. Most or all of them indicated that they would disclose to teachers and the school nurse but not to the students or parents.

Disclosure of HIV status

The infected and affected children reported on knowledge of theirs or their family members HIV status and whether they had told anyone at school about it (Table 24). The average age of disclosure for the infected children was 13 years and 12 years for the affected children. Disclosure was done by a doctor for the infected children, and mostly by the mothers of the affected children.

All the children reported that they had not informed anyone at their school about of theirs or their family members HIV status.. Their reasons for not telling were that they were afraid that whoever they told would tell others, it was nothing to talk about, they were afraid they would be talked about, laughed at or treated badly.
The caregivers also reported on the children's knowledge of their or their family members' HIV status and whether anyone at the children's school had been told about it (Table 25). The caregivers mostly confirmed the children's reports about who had informed them. Also, they all reported that they have had talks with the children about their or their family members' HIV status, and some reported that this has affected the children's daily life and behaviour. Only one caregiver reported that a teacher had been told

Attitudes towards children with HIV

All the children were asked about whether they would be afraid if a friend told them they had HIV. There was no significant difference among them in their responses to the question as most of them said that they would not be afraid (Table 26). Their reasons included: it is nothing to be afraid of, because the person is still a friend, cannot get HIV by being friends, and cannot get HIV by touching, playing or talking to the person. One child said he did not want to be touched by the persons, however, and others said that they would be cautious with cuts.

The principals and teachers were asked a series of questions on their opinions about children infected or affected by HIV being in school. Their responses to the questions are shown in Table 27. Most of them disagreed that children infected or affected by HIV should not be allowed to attend school, and should be segregated from others. Also, most of them agreed that they would not treat children infected or affected by HIV differently from other students, and they would be willing to teach a class for these students.

HIV Policies, Programmes and Activities

The principals and teachers were asked whether they were aware of HIV education policies and programmes in their country. More principals than teachers indicated that they were aware of HIV policies and programmes in-country (Table 28).

The principals and teachers were also asked whether their schools had an HIV policy, and HIV programmes and activities for students. Many of them reported that their schools did not have a specific HIV policy, however, they had an HIV education programmes for students which was a part of the curriculum and applied to all the grades. Many of them also reported that they had programmes in their school to reduce stigma and discrimination, however only some reported specific HIV activities for students (Table 29).

Some children also reported that their schools had no HIV activities (Table 30). When asked whether they thought that the activities were helpful and enough, they reported they were helpful; however, they were not enough.

HIV Education and Safety in schools

Table 31 refers to the principals and teachers opinions about HIV education in schools. They all agreed that teaching about HIV should be done at different grade levels in schools beginning from basic or primary school.

The principals were asked about measures in their schools to handle an accident or injury with bleed from a child. They reported multiple measures, the most common of which was the use of universal safety precautions (e.g. use of gloves and chlorine). Other measures included having a special teacher assigned to assist and taking the injured child to the hospital or health centre.

Dissemination of findings

The findings were presented in a one-day meeting held with the project steering committee members and other key stakeholders on October 13, 2010 in St. Lucia. There were over 20 people in attendance, of which 3 were caregivers who participated in the study (see list of attendees in the report, Appendix V). The meeting provided stakeholders an opportunity to highlight the potential policy and programme recommendations for the education sector's response to HIV and AIDS based on the study findings.

The participants at the meeting were generally in agreement with the results. However, surprise was expressed that the children, principals and teachers did not know about HIV programmes and activities in their schools, although HFLE, including HIV education, is taught in schools and representatives (principals and teachers) from all the schools were trained in this. This stimulated a discussion about weaknesses in the existing system and potential strategies for improvement. See the report for further details.

Findings from St. Lucia were also presented at Caribbean Child Research Conference, held October 20-21, 2010. The abstract can be found at Appendix VII. An academic paper has been drafted.

Guyana

Sample Obtained

Numbers and a description of all infected and affected children under 18 years were not available from Guyana. Initially information given indicated that approximately 290 children under 16 years were living with HIV and registered with the national AIDS Programme, of which approximately 170 were receiving anti-retroviral drugs. Estimates of children aged 16-18 years infected or affected were not obtained.

Eventually, considering the number of children that were targeted, participants for the study were recruited from the Dorothy Bailey Municipal Centre OVC Programme. 28 of 29 caregivers with children fitting the study criteria who were in the programme agreed to participate; the other caregiver refused. The 28 caregivers had 17 infected and 20 affected children among them. All 28 caregivers and their 37 children were screened and enrolled into the study.

35 students of the same age (± 6 months) and gender as infected and affected children, and in the same class at school were recruited as comparisons. 37 comparison students were initially targeted to match the infected/affected group, however during their interviews with the Research Assistant, 2 of them revealed that they were HIV positive. These 2 children and their 2 caregivers were added to the infected or affected group bringing that numbers to 39 infected or affected children and 30 caregivers. One teacher for each target child and matched comparison (n=35), and the principals of the schools the children attended (n=20) were also recruited.

Missing information

The child questionnaire was not completed at different points during the interviews of a few children (6 infected, 1 affected and 1 comparison) because the children either became emotional or stopped talking. The sizes of the groups were preserved by inputting means for missing cases for the relevant variables during the data analyses. There were a few other instances of missing information when the Research Assistant failed to collect information for some questions.

Sample description

The characteristics of the children, their caregivers and principals and teachers are presented in Tables 32, 33 & 34 respectively.

The children ranged in age from 10 to 18 years and their mean age was 13 years. There were more females than males. Mothers were the primary caregivers for most. A few of the infected or affected children had a brother or sister as caregiver.

Most of the caregivers for infected and affected children were single, while more of those for the comparison children were married or in common-law relationships. Most caregivers had completed secondary school education, and some had further training, whether college, vocational, technical or tertiary level training. Most caregivers of comparisons were in highly

skilled or professional jobs while caregivers of infected or affected were in semi-skilled jobs. Some caregivers of infected (27%) or affected (7%) children were sex workers.

The socio-economic status indicators showed similar levels of crowding, and water sources in the homes. However, the households of comparison caregivers had a greater mean number of possessions. Also more of them had their own toilet facilities.

The principals and teachers were mostly female. Also, most of them worked at public secondary or high schools, had completed college or university and obtained a bachelors degree. Their range of experiences as principal or teacher is also shown.

School-related information

School attendance and experience
All of the children were attending school (Table 35). More infected and affected children than comparisons reported that they had missed days of school since starting the grades they were in when they did the interviews. The most common reasons for missing school were because of being ill for the infected children, and caregiver being ill for the affected children (Table 36).

The children differed in their reported experiences at school. Significantly fewer affected children than infected and comparison children reported that they liked school. However, the children reported that they got along with their teachers and classmates similarly (Table 35).

The caregivers' reports on the children's school attendance and experiences are shown in Table 37 & 38. Their reports were similar to the children's, however, more caregivers of affected children reported that the children liked school more than the children had reported..

School Performance
The infected and affected children did not differ significantly from their comparisons in reported school performance; most of them children reported that they had done 'very good' or 'good', received mostly A's, and had not repeated a grade (Table 39).

The caregivers' reports on how they thought the children performed at school are shown in Table 40. Their reports were similar to the children, however some caregiver reported that the children received lower or higher grades than the children had reported..

The children's school performance measured by the Wide Range Achievement Test - 3 is shown in Table 41. The infected children had lower mean score than affected or comparison children on Math Scale and comparison children had lower mean scores than infected or affected children on Reading and Spelling Scales; however, none of these differences achieved significance.

Experiences of Depression and Anxiety

The children reported experiences of symptoms of depression using the 'Moods and Feelings Questionnaire,' and anxiety using the 'What I think and Feel Questionnaire' are shown in Table 42. The mean scores among the infected and affected groups were higher, indicating more depressive and anxiety symptoms; however, these differences did not achieve statistical significance.

Behaviours

The caregivers' reports on the children's behaviours using the Rutter Scale for parents are shown in Table 43. The mean scores were similar amongst the groups for prosocial behaviours, however, for conduct difficulties, the HIV infected group had a much lower mean score than the other groups. However, this difference did not achieve statistical significance.

Stigma and Discrimination

Perceived Stigma
The children's responses to the perceived stigma statements are shown in Tables 44 a, b & c. Several of the infected children (30-57 %) agreed that they had experienced the perceived stigma issues asked about. Even more of the affected children (50-60 %) agreed with these statements.

The comparison children largely agreed that people living with HIV would experience the issues asked about.

Enacted Stigma
The children's responses to the enacted stigma statements are shown in Tables 45 a, b & c. Many of the infected children (30-57 %) reported that they had experienced most of the enacted stigma issues asked about most of the time or sometime. In the same way, the affected children reported that they had experienced most of the issues.

Most of the comparison children thought that someone with HIV at their schools would experience the issues most of the time or sometime.

Prediction of school achievement
The relation of the children's experiences of perceived and enacted stigma related to their school achievement as for the St. Lucia sample was assessed using a series of hierarchical regressions. Regression analyses were performed separately for the infected and affected children.

The results of the regressions for whether experiences of perceived stigma, controlling for age, and gender predicted scores on Maths, Spelling and Reading Scales indicated that gender (β = -0.475, se = 3.47, $p < 0.05$) was significant in predicting spelling scores for infected children.

Gender was also significant in the regression for whether experiences of enacted stigma, predicted spelling scores for the infected children (β = - 0.505, se = 3.48, $p < 0.05$).

Shame, Blame and Judgment

The children's scores for whether they agree or disagree with statements that people with HIV should be blamed for their HIV and feel ashamed are shown in Table 47. The scores generally indicated lower blame and judgment for the comparison children when contrasted with the infected and affected children. However, this difference was not significant for any of the statements. The composite blame and judgment score was also not significantly different among the children.

The principals' and teachers' responses to statements whether they agree or disagree with statements that people with HIV should be blamed for their HIV and feel ashamed are shown in Table 48. Most of them disagree with the statements.

Knowledge about how HIV is transmitted

The responses to the questions inquiring about the children's knowledge of how HIV is transmitted are shown in Table 49. The results indicated that more of infected and affected children than the comparison children selected the correct answer for the individual questions, indicating greater knowledge; however, these differences did not achieve significance. The composite HIV knowledge score was not significantly different among the children either.

Knowing children with HIV

The children and their principals and teachers responses to whether they knew children with HIV at school are shown in Table 50 & 51. More of the infected children than affected or comparison children reported that it was easy to know if someone had HIV, they suspected someone from their schools to have HIV and they had a friend at school living with HIV. These differences, however, did not achieve significance.

Some principals and teachers reported that they were aware of students with HIV at their school.

Opinions on HIV Disclosure

The responses to questions on attitudes towards HIV disclosure as reported by the children, their caregivers, and principals and teachers are shown in Tables 52a, 53 & 54a & b respectively.

Most of the children thought that someone with HIV should keep it a secret or tell only family. The reasons they gave for their choices included: it is a personal or family problem; told not to tell or it is the best way to go; people would act differently towards, keep away from, tease or talk about the person.

Most caregivers of comparison children thought that the principals and teachers should be told if a child living with HIV started attending school but not the students and other parents. Whereas most caregivers of infected or affected children thought that neither principals, teachers, students nor parents should be told.

Most of the principals and teachers agreed that they should be told about a student's HIV infection and not the student's classmates or their parents.

The principals also reported whether they would share information about an HIV infected or affected students with teachers, the school nurse, other students and parents. Most or all of them indicated that they would disclose to teachers and the school nurse but not to the students or parents.

Disclosure of HIV status

The infected and affected children's reports on their knowledge of their or their family members' HIV status and whether they had told anyone at school about it is shown in Table 55. Data were only available for 68 % of infected (13 out of 19) and 90% of affected (18 out of 20) children. The average age of disclosure was approximately 8 years. Disclosure was done by multiple persons with the mothers being the one to primarily inform the children.

Only 1 infected (8%) and 1 affected (6%) children said that they told someone while the others said that they had told no one. Reasons for not telling included: told not to tell, afraid that whoever is told would tell others, afraid that I would be talked about, laughed at or treated badly, it was nothing to talk about, it was not a good topic, and felt uncomfortable talking about it.

The caregivers' reports on the children's knowledge of their or their family members' HIV status and whether anyone at the children's school had been told about it are shown in (Table 56). Of those for whom data were available, most confirmed the children's reports that they were informed by multiple persons about their HIV status and that the mothers were the primary informants.

Also, most reported that they have had talks with the children about their or their family members' HIV status, however only some reported that this has affected the children's daily life and behaviour. A few of the caregivers reported that the children's principals, teachers and classmates had been told.

Attitudes towards children with HIV

The children's responses whether they would be afraid if a friend told them they had HIV are shown in Table 57. More infected and affected children than comparison children said that they would not be afraid although the difference was not significant. Their reasons for not being afraid included: it is nothing to be afraid of, the person is an individual or still a friend, there is no difference between HIV and cancer, the person is still alive, and they were told to treat everyone equal. Some children said they were not sure why they were not afraid.

The principals and teachers opinions about children infected or affected by HIV being in school are shown in Table 58. Most of them disagreed that children infected or affected by HIV should not be allowed to attend school, and should be segregated from others. Also, most of them agreed that they would not treat children infected or affected by HIV differently from other students, and they would be willing to teach a class for these students.

HIV Policies, Programmes and Activities

The principals' and teachers' reports on whether they were aware of HIV policies and programmes in their country are shown in Table 59. Most the reported that they were unaware of these, although a few teachers indicated being aware of policies or laws addressing HIV issues.

The principals' and teachers' reports on whether their schools had an HIV policy, and HIV programmes and activities for students are shown in Table 60. Only one teacher reported that they had an HIV education programmes for students which was a part of the curriculum and applied to all the grades. On the other hand, a few principals and teachers reported that they had programmes in their schools to reduce stigma and discrimination, and activities to support children living with HIV.

A few of the children also reported that their schools had HIV activities for students (Table 61). When asked whether they thought that the activities were helpful and enough, only one of them thought not.

HIV Education and Safety in schools

Table 62 summarizes the principals and teachers responses regarding HIV education in school. Most teachers agreed that teaching about HIV should be done at different grade levels in schools beginning from basic or primary school, while most principals were neutral in their opinion.

The principals also reported on measures in their schools to handle an accident or injury with bleed from a child. They reported multiple measures. The most common measure was taking the child to the hospital or health centre. Other measures included having a first aid or health kit, a special teacher assigned to assist (teacher has nursing skills), and using home remedy.

Dissemination of findings

These findings were presented in a one-day meeting held with the project steering committee members and other key stakeholders on October 15, 2010 in Guyana. There were over 40 people in attendance. As in St. Lucia, the meeting provided stakeholders an opportunity to highlight the potential policy and programme recommendations for the education sector's response to HIV and AIDS based on the study findings.

The participants at the meeting were generally in agreement with the results, although concerns were raised about the small size of the sample and its representativeness of the population of children infected or affected by HIV in the country. It was suggested that the study be replicated using a larger sample. Also, the revelation that principals and teachers, and children had little or no knowledge of HIV programs, policies and activities in the schools encouraged the Ministry of Education to select the schools from this study to participate in a forthcoming project. That project seeks to sensitize 30 schools about the School Health, Nutrition and HIV& AIDS Policy which was shared at the stakeholders' meeting. The selected schools will also be sensitized about the National HIV Strategic Plan. The full report on the meeting including recommendations can be found at Appendix VI.

Discussion

This study comprised the first we are aware of which focused on stigma and discrimination related to HIV and AIDS among school children in St. Lucia and Guyana. The results from both countries suggested that there is some level of stigma and discrimination experienced by school children who are either living with or affected by the disease, while school attendance, experiences and performance might all be impacted by the disease, whether directly or indirectly. The findings are discussed in greater detail below.

Although there have been assessments of children living with or affected by HIV from Jamaica describing experiences of stigma and discrimination , this report is an important contribution to the understanding of education-related outcomes among such children in other English-speaking Caribbean countries. While the English-speaking Caribbean is often treated as a homogeneous region, there are in fact a host of cultural differences throughout and even within countries which are likely to affect social issues such as HIV-related stigma and discrimination. This would be especially important when considering appropriate interventions, since measures which work in one place might not be effective elsewhere.

This report also adds to the findings from developing countries on HIV-related stigma and associated school outcomes, presently dominated by studies in sub-Saharan Africa.

Study Strengths and Weaknesses

The strengths of the study include the focus on these populations which had previously not been investigated with respect to HIV-stigma and school related issues. There was triangulation through the respondents, whereby for each target and comparison child enrolled and interviewed, their respective caregivers, teachers and principals were also interviewed in order to compare responses and expand the information related to each child and situation. (Teachers and principals were the same for each matched pair, since classroom was one of the matching criteria.) Children of the same age and sex and attending the same schools were matched so they could be compared with those target children who were either living with or affected by HIV. However, 'overmatching' was avoided so that differences between the groups could be observed. For example socio-economic status was not matched for, and this allowed us to observe that poorer backgrounds among the infected and affected groups compared with the comparison children. The training of interviewers was intensive, detailed and consistent across the two countries, which will allow for comparison of the data. On the other hand, there were some challenges related to implementing and monitoring the study in the two countries from Jamaica, in particular issues related to timely reporting and feedback. However, it will be possible to expand and replicate this study in other Caribbean countries since the instruments and protocols are all well defined and tested.

A number of weaknesses should also be noted. The study team was never able to satisfy Objective 2 for either country: "To obtain the sample frame of children living with or affected by HIV eligible for the study." In spite of repeated requests including to the Project Implementation Teams this information was not made available to us. This will preclude a discussion of how

representative the sample was of the population of children living with and affected by HIV in both countries, and therefore to what extent the findings may be generalized.

The sample in St. Lucia was very small, with only 2 infected children and 8 affected children enrolled. This represented almost all the children who were made available to us (10 out of 11 children) with only one parent refusing to allow participation. Based on our preliminary information, the original study design targeted sufficient children to allow for statistical analyses among the variables, in particular to determine the relation between school experiences including stigma and discrimination, and school outcomes. In contrast, information subsequently obtained in the Rapid Situation Analysis of the Education Sector's Response to HIV & AIDS in St. Lucia (2008) suggests that in 2008 estimates were "that 78 children were affected by HIV and AIDS while 3 were infected." It is not clear what age defined "children" in this statement. However, if this is close to the case, we would have sampled almost 100% of the infected children in the country.

The small sample size did not allow for appropriate analyses, and genuine differences among groups are not likely to have been statistically significant. (Some striking differences were shown to be statistically significant however.) The results have therefore been treated more qualitatively, almost as case studies, contrary to the original plan.
All questions were completely answered by the respondents in St. Lucia. However there were some instances of missing data from Guyana, which were handled with the appropriate statistics where possible.

The numbers of target children enrolled were higher in Guyana. Because of logistic constraints, all were recruited from a single centre however, and it is possible that the samples might not be especially representative of children living with or affected by HIV. It was encouraging that these 39 children were drawn from 20 schools, suggesting a wide range of school experiences.

Findings

We had good cooperation from most caregivers, with almost all from both countries agreeing to participate, and only one parent from each country refusing to allow participation of their child/ward. We had full cooperation among the comparison children and their caregivers, and all teachers and parents gave generously of their own time, and allowed children to be interviewed. The children ranged in age across the entire target age group in both countries, though those in St. Lucia were somewhat older than those in Guyana, especially the two infected children whose were about 17 years old. Both genders were represented almost evenly. The groups were mostly looked after by their mothers, though in Guyana the father was the primary caregiver for 4-5 children in each of the three groups, living with HIV, affected by HIV and comparison group. It is not clear why other adults are the primary caregivers, whether the mother had died or just did not live in the household. The numbers of caregiver respondents does not match the number of children in the HIV infected and affected groups since some caregivers had more than one child in the study.

The caregivers described their education, marital status and employment situation. It was interesting that 5 caregivers (of children living with and affected by HIV) in Guyana indicated to us that they were sex workers. This suggests that they were most likely open and honest in their responses in general. There were differences among the groups in various measures of socio-economic status, which achieved significance in Guyana where job category, number of specified possessions in the home and toilet type indicated better living circumstances among the comparison group compared with the HIV infected and affected groups. There were also significantly more married caregivers among the Guyanese comparison children compared with the other groups. Similarly, in St. Lucia there appeared to be higher educational levels, and more highly skilled jobs, better toilet and water facilities and more possessions among the comparison group caregivers. HIV may have affected poorer children to a greater extent than better off children, or it is possible that infected and affected children attending the health centre in Guyana where our children were recruited represented those poorer children, or those children in St. Lucia who were registered with the government social worker, while better-off children who were also living with or affected by HIV received treatment and counselling from other sources. There is a large body of work describing the links between HIV and poverty in both the developed and developing world (e.g. Adaora et al., 2006; Gillespie, Kadiyala & Greener, 2007; Mbirimtengerenji, 2006) which suggest that the former inference, that greater poverty was related to HIV in this sample, is a genuine one.

While all children from all groups in Guyana were attending school, neither of the 2 infected children (though one had graduated), and one of the affected children in St. Lucia were attending school. There was significantly greater absence from school among affected children in both countries. This is not surprising among children living with HIV who fall ill or must attend clinic, and among affected children elsewhere (e.g. Jamaica). We explored the reasons for this absence, and indeed illness was the main reason for school absence among infected children. We note the mention of caregiver illness (in St. Lucia) and financial difficulties (in Guyana) as well.

We explored issues of liking school and getting along with teachers and classmates, both from the children's and their parents' perspectives. Reports were that almost all children liked school very much, and got on well with teachers and classmates. There was no pattern suggesting that the few disliking school or having difficulties with teachers or classmates were more likely to come from the infected or affected groups.

There were few indications of differences among reported school performance, except that caregivers of comparison children in Guyana reported significantly better grades than the other two groups. School achievement was independently assessed and showed little variation among the groups in Guyana. However in St. Lucia, the infected group had lower scores than other groups in both reading and spelling on the WRAT III test, while both the infected and affected groups scored much lower than the comparison group on the math subscale. Interpretation is difficult because of the very small sample sizes in St. Lucia, however.

A very interesting finding from St. Lucia was that controlling for age, gender and status (HIV infected or affected), experiences of perceived stigma predicted each of math, spelling and reading scores, while experiences of enacted stigma predicted math scores among the exposed

group of 10 children. This suggests a powerful link between exposure to stigma and discrimination and poor school performance. However with the very small sample size, this finding must be treated with caution. On the other hand, small sample sizes are more likely to fail to detect significant findings rather than producing spurious results. The prediction was not found among the Guyanese children.

The screening for depression and anxiety was suggestive of somewhat greater depression symptoms among children living with HIV and affected children in both countries, and greater anxiety symptoms as well, though the differences did not achieve statistical significance. There were no noticeable trends regarding parent reports of prosocial or conduct disordered behaviours. Reports by children living with HIV or affected by HIV clearly indicated incidents of both perceived and enacted stigma. On the other hand, it was encouraging that several infected and affected children reported not having experienced some of the statements, especially among the St. Lucia cohort. These findings point to some direct areas for possible interventions. In particular the issues of feeling ashamed or guilty, dirty or unclean, or 'disgusting' can be tackled through education programmes both in schools and targeting the public. There were also a few reports of fear towards children with HIV among all groups of children, surprisingly.

The blame and judgement scale indicated typically scores between 1 (strongly disagree) and 2 (disagree) to the statements describing HIV as a judgement and blameworthy. This is the case across all groups in both countries, and is encouraging. Some respondents however must have indicated that they agreed with these statements so there remains scope for improving this among youngsters. In contrast, although most teachers and principals disagreed with similar statements, there were a few who agreed (or at least did not disagree) that "People with HIV should be ashamed of themselves." This suggests another target area for schools. Interestingly, a few also agreed that they would leave the teaching profession should they contract the disease.
Among all groups of children there was also a reasonably high level of knowledge about transmission, though there was evidence of slightly greater knowledge among children living with HIV and those affected compared with the controls as demonstrated by their mean knowledge scores. There was an interesting set of responses regarding knowledge of children with HIV. A few children across all groups in Guyana, and among the comparisons in St. Lucia thought it would be easy to determine if someone has HIV. It was interesting too that a few children knew of friends at school with HIV, who therefore had the confidence of the children living with HIV. Teachers and principals in St. Lucia generally reported that there were no students with HIV at their school indicating that they were unaware of these children's status. Most principals and teachers in both countries generally felt that both should be told if a student with HIV was attending the school. However they generally did not agree that other students or their parents should be told about an HIV positive student in their child's class. Conflictingly, in Guyana, most principals and several teachers felt that they had a responsibility to alert other parents about an HIV positive student. It is possible to interpret this to mean that the respondents felt that parents should not be told, but if anyone were to tell the parents, it should be them.
The issue of disclosure was fraught with concern across all groups interviewed. Children in both countries mostly reported that the disease should be kept secret, except to family, to avoid expected untoward responses. This was also their lived experience, in that only 2 children (both from Guyana) had shared with anyone at their school that they or a family member had HIV.

Again the silence was to avoid being treated badly or being uncomfortable highlighting the ongoing stigma of the disease. Caregivers were similarly cautious in revealing HIV status at school. A few had told the school principal or teacher (only one in St. Lucia).

Principal and teacher reports further indicated some instances of unfounded attitudes towards hypothetical children with HIV, such as agreeing they should be segregated for certain activities or should have separate classes. Most teachers and principals reported more tolerant attitudes, but where more than a third of teachers and a quarter of principals (in Guyana) feel that a child who merely lives with an HIV positive person should not be allowed to attend school there is clearly great room for increasing knowledge, tolerance and understanding.

Although Guyana has had a National HIV policy and strategic plan for 2007-2011, as well as a draft HIV policy for the education sector since 2008, the educators in our study were not aware of these. Similarly, a draft policy for St. Lucia for the education sector has been in place since late 2008, but most of the educators there were also not familiar with this. More strikingly, although HFLE has been taught in schools in both countries for many years, neither group clearly identified HFLE as an HIV-related school-based activity. The School Health, Nutrition and HIV&AIDS Policy in Guyana was shared with schools after the survey was completed (in fact during the project dissemination meeting, see report in the Appendices.) Greater efforts to share the policies and plans among educators are required in both countries.

In summary, the study has produced rich findings from both St. Lucia and Guyana from children living with HIV, children affected by HIV, and matched comparison children, their caregivers, teachers and principals. Children reported on experiencing stigma and discrimination, and both positive and negative school experiences, while parents of infected/affected children described poorer home backgrounds and confirmed their children's missing more school than comparison children. Some school personnel had good knowledge and tolerance, but many showed a high level of intolerance.

Recommendations

National policy level recommendations

St. Lucia

St. Lucia has had a draft HIV and AIDS policy for the education sector since 2008, but this has not yet been confirmed. The first recommendation is that this policy be confirmed quickly to provide a strong framework for national plans and strategies. The draft policy is a sound one, based on international and national law and designed with guidelines and technical assistance through the Caribbean Education Sector HIV and AIDS Capacity Building Programme. Up to the time of its formulation and the Rapid Situation Analysis of the Education Sector's Response to HIV and AIDS in ST. Lucia (also 2008), a national policy on HIV and AIDS was in draft only, and a workplace policy had also been drafted by the St. Lucia Teachers' Union.

Recommendations are:

- As with the case of Guyana, implementation of the policy is required.
- Strategies and plans to make the policy actionable are required.
- These include mechanisms to reduce stigma and discrimination through greater education and information regarding transmission, inherent rights and protection issues, and the capacity development to address stigma and discrimination at the community, school and teacher levels.

The following areas, highlighted for attention in the draft policy, also addresses areas of concern arising from the results of the present study:

- Greater attention needs to be paid to the teaching about HIV and AIDS in the current HFLE curriculum.
- Practical measures need to be identified to prevent stigmatization and discrimination against children affected or thought to be affected.
- A better understanding of the need to protect non-disclosure was required.

Guyana:

In Guyana a national School Health, Nutrition and HIV&AIDS policy is now in place, and was distributed to education sector and other personnel in November 2010. The stated aim of the policy is "to promote and facilitate the implementation of health and nutrition programming and **HIV Prevention** throughout the education sector in Guyana" (emphasis added). That the focus of activities should be on HIV prevention is reasonable, and is in keeping with the Mexico Ministerial Declaration, "Educating to Prevent" which focuses on strengthening HIV prevention activities. However there are clearly HIV-related issues outside of prevention which need to be addressed, including reducing the level of stigma and discrimination, and increasing the care and support of children living with HIV and those affected by the disease. In fact, stigma and discrimination is briefly addressed in the policy. For example:

4.2.4 HIV Education (of Students)

This section lists the proposed outcomes of the education programme for students which include:

"Develop supportive attitudes towards those infected with and/or affected by HIV and work against stigma and discrimination."

4.4 Workplace Education

This indicates that all employees of the Ministry of Education should have the opportunity to participate in a planned education programme which will cover *inter alia* "promotion of non-discrimination, supportive and sensitive attitudes towards PLHIV and those affected by HIV and AIDS [and] Assists staff to maintain productive, non-discriminatory and stigma-free staff, student, parent and community relations."

5.1.1 Preventing Stigma and Discrimination

This section mentions a "code of conduct" which all education institutions are meant to adhere to, which will contain clear guidelines for employees and students.

7.2 Employment, care, treatment and support of people affected by HIV&AIDS
This concerns ensuring the rights and dignity of those infected or affected by HIV& AIDS, and, "(i)n particular, heads of education institutions shall be responsible for creating an enabling environment that is free from stigma and discrimination."

7.4 Care and Support of Orphans and Vulnerable Children (OVC)
This section indicates that educational institutions have "a responsibility to identify and support any student who is ill, orphaned, vulnerable or with special needs so that he/she is able to continue and complete their education..."

The establishment of this policy and these specific guidelines are an important step towards reducing the identified problems related to stigma and discrimination which were identified in the study. The recommendations arising are therefore:

- The policy be widely shared and discussed with all employees of the Ministry of Education, all teachers and teacher trainees, as well as with students and parents.
- An implementation plan should be devised (if it is not already) so that the policy is translated to action.
- Social dialogue is undertaken as proposed in the policy to discuss the policy and its implementation.
- The education plans described above for teachers, teacher trainees, Ministry of Education personnel, students should undertaken as soon as is feasible.
- Education plans should also address issues of confidentiality which are addressed in the policy.
- Presently the policy discusses the potential for sanctions (e.g. 5.1.1 "...stigmatisation and discrimination...shall not be tolerated under any circumstances and shall result in the application of the maximum sanctions available."). These should also be made clear and discussed both with teachers and with students.
- Ongoing review of the policy and monitoring of its implementation is also required.

School level recommendations

In keeping with recent policy in Guyana, and with the proposed policy in St. Lucia, schools should:

- Seek to take advantage of all opportunities to undertake ongoing training related to HIV&AIDS for teachers and other staff especially as relates to issues of stigma and discrimination; the rights, care and protection of vulnerable children; confidentiality and non-disclosure of medical conditions.
- Maintain dialogue with parents and guardians, especially through Parent-Teacher associations, and seek to provide information regarding HIV including transmission, and stigma and discrimination issues.
- Openly discuss issues related to HIV among staff, students and parents and in this way seek to expose unfounded fears, while promoting safety.
- Seek to support individual children who are ill, orphaned, otherwise vulnerable or with special needs to maximize their education and provide a positive school experience. Avenues for support through governmental and NGO means should be determined and lists maintained of agencies which might be approached for assistance.
- Not to await ministerial directive, but to be proactive in supporting the elimination of stigma and discrimination, and attention to school achievement and interpersonal relationships, among students, staff and parents.
- Note the demonstrated links between experiences and perception of stigma and discrimination and poor school achievement outcomes, and seek to support students who are performing poorly.

General recommendations

With the high level of stigma and discrimination against children living with HIV and AIDS and those affected by HIV in both countries, as described by this study and previously (e.g. Rapid Situation Analyses of the Education Sector's Response to HIV & AIDS in St. Lucia (2008) and in Guyana (2007), the following are suggested:

- Systematic measurement of levels of stigma and discrimination should be included in regular national surveys (e.g. MICS, surveys of living conditions, census surveys) in order to monitor changes in response to policy and other measures.
- Interventions and social programmes to reduce HIV-related stigma and discrimination should be carried out on a pilot basis to determine effectiveness, and scaled up where appropriate.
- Similar studies in additional Caribbean countries should be carried out, which would illuminate the situation with regards to HIV-related stigma and discrimination especially in countries with more mature HIV policies for the education sector.

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Tables: St Lucia study

Table 1: Background of the children in St. Lucia

Variables (n, %)	**HIV Infected (n=2)**	**HIV Affected (n=8)**	**Comparisons (n=10)**
Age in years (mean, s.d.)	17.0, 1.4	15.1, 1.5	15.0, 1.6
Gender			
Male	1, 50	5, 62	6, 60
Female	1, 50	3, 38	4, 40
Primary caregiver			
Mother	1, 50	6, 75	9, 90
Grandmother	1, 50	2, 25	--
Foster mother	--	--	1, 10

Table 2: Background of the caregivers and their socio-economic status in St. Lucia

Variables (n, %)	HIV Infected (n=2)	HIV Affected (n=5)	Comparisons (n=10)
Age (mean, s.d)*	57.5, 10.6	44.8, 8.4	41.8, 7.1
Gender			
Male	--	--	1, 10
Female	2, 100	5, 100	9, 90
Relation to Child			
Mother	1, 50	4, 80	8, 80
Foster mother	--	--	1, 10
Grandmother	1, 50	1, 20	--
Father	--	--	1, 10
Marital Status			
Single	1, 50	1, 20	5, 50
Married	1, 50	2, 40	3, 30
Common Law	--	1, 20	2, 20
Separated	--	1, 20	--
Education Completed			
Primary/Elementary	2, 100	5, 100	4, 40
High School/Secondary School	--	--	4, 40
College/Technical/Vocational	--	--	2, 20
Current/last job			
Unskilled	--	3, 60	4, 40
Semi-skilled	1, 50	2, 40	2, 20
Skilled	1, 50	--	4, 40
Crowding score (mean, s.d.)[a]	1.7, 0.5	1.8, 1.1	1.5, 0.6
Possessions score (mean, s.d.)[b]	4.5, 0.7	4.6, 2.5	6.5, 1.7
Toilet facilities			
No toilet	--	1, 20	--
Pit toilet	1, 50	--	2, 20
Shared outside flush	--	--	1, 10
Own inside flush	1, 50	4, 80	7, 70
Water source			
Own pipe inside	2, 100	4, 80	7, 70
Own pipe in yard	--	--	1, 10
Shared pipe in yard	--	--	2, 20
River, Spring	--	1, 20	--

* Anova $p<0.05$

[a] Number of people per room

[b] Sum of presence of car/bus/truck, bike/bicycle, television, refrigerator, radio, cable television, computer, DVD, stove (range 0 – 9)

Table 3: Background of principals and teachers in St. Lucia

Variables (n, %)	Principals (n=7)	Teachers (n=10)
Gender		
Female	3, 43	--
Male	4, 57	10, 100
Age		
Less than 29	--	3, 30
30-39	--	1, 10
40-49	5, 71	3, 30
50-59	2, 29	3, 30
Type of School		
Public	6, 86	9, 90
Private	1, 14	1, 10
Highest Education Completed		
College	1, 14	1, 10
University	6, 85	9, 90
Highest Degree		
Certificate	--	1, 10
Diploma	1, 14	2, 20
Bachelors	4, 57	6, 60
Masters	2, 29	1, 10
How long a principal/teacher		
Less than 1 year	--	1, 10
1 – 5 years	2, 29	2, 20
5 – 10 years	3, 43	1, 10
More than 10 years	2, 29	6, 60

Table 4: School attendance and experiences of children in St. Lucia – Children's Reports

Variables (n, %)	HIV Infected (n=2)	HIV Affected (n=8)	COMPARISON (n=10)
Attends School ††			
Yes	--	7, 88	10, 100
No	2, 100	1, 12	--
Current/Last School			
Secondary/High	--	6, 75	6, 60
College/Vocational/Technical	2, 100	2, 25	4, 40
How often attended school			
Every day	2, 100	5, 62	7, 70
Most of the time	--	3, 38	3, 30
Some of the time	--	--	--
Missed school since start of current grade ††			
Yes	--	6, 75	7, 70
No	--	1, 13	3, 30
Not Applicable	2, 100	1, 12	--
Liked school			
Very Much	2, 100	4, 50	6, 60
Somewhat	--	1, 12	2, 20
Liked/Disliked Equally	--	3, 38	2, 20
Got along with teacher			
Very Well	2, 100	5, 63	5, 50
Well	--	2, 25	4, 40
Fairly Well	--	1, 12	1, 10
Got along with classmates			
Very Well	1, 50	3, 37	6, 60
Well	--	3, 38	2, 20
Fairly Well	1, 50	2, 25	2, 20

†† Chi square $p<0.01$

Table 5: Reasons for missing school – Children's reports in St. Lucia*

VARIABLES (n)	HIV Affected (n=6)	Comparisons (n=7)
Reasons for missing school		
No school fess/No money	2	--
Was ill	2	5
Did not want to go to school or tired	1	--
To do school work (work on SBA)	1	1
Sporting activities	1	1
Attend event for school	--	1
How spends day when miss school		
Doing housework	1	--
Playing alone	2	--
Stays home sick	--	1
Watches television	1	2
Sleeps	1	4
Studying or working on SBA	2	2
At the doctor/In hospital	1	1

*Multiple options possible

Table 6: School attendance and experiences of children in St. Lucia – Caregivers' Reports

Variables (n, %)	HIV Infected (n=2)	HIV Affected (n=8)	Comparisons (n=10)
Child goes to school††			
Yes	--	7, 88	10, 100
No	2, 100	1, 12	--
Kind of school child attended			
Secondary/High School	--	6, 75	6, 60
College/Vocational School	2, 100	2, 25	4, 40
How often did child go to school			
Everyday	1, 50	5, 62	6, 60
Most of the time	1, 50	3, 38	3, 30
Some of the time	--	--	1, 10
Missed School††			
Yes	--	6, 75	5, 50
No	--	1, 13	5, 50
Not applicable	2, 100	1, 12	--
Child liked school			
Liked it Very Much	2, 100	5, 63	7, 70
Liked it Somewhat	--	1, 12	1, 10
Liked/Disliked it Equally	--	--	1, 10
Disliked it Somewhat	--	1, 12	--
Disliked it Very Much	--	1, 12	1, 10
Child got along with teacher			
Very Well	2, 100	6, 75	7, 70
Well	--	1, 12	2, 20
Fairly Well	--	1, 12	--
Badly	--	--	1, 10
Child got along with classmates			
Very Well	1, 50	6, 75	7, 70
Well	--	2, 25	2, 20
Fairly Well	1, 50	--	--
Badly	--	--	1, 10

†† Chi square $p<0.01$

Table 7: Reasons for missing school – Caregivers' Reports in St. Lucia*

VARIABLES	HIV Affected (n=6)	Comparisons (n=5)
Reasons for missing school		
No school fees/No money	1	0
Child was ill	5	3
Child refused to go to school	1	2
How spends day when miss school		
Doing homework or studying	2	2
Playing alone or with other children	4	2
Stays home sick	5	2
Watches television	1	0
Sleeps	4	2
At the doctor/In hospital	1	1

*Multiple options are possible

Table 8: School performance of children in St. Lucia – Children's Reports

Variables (n, %)	HIV Infected (n=2)	HIV Affected (n=8)	Comparisons (n=10)
How did in school			
Very Good	2, 100	1, 12	1, 10
Good	--	2, 25	5, 50
Fair	--	4, 50	2, 20
Poor	--	1, 13	2, 20
What grades were like			
Mostly A's	1, 50	--	2, 20
Mostly B's	--	3, 38	1, 10
Mostly C's	1, 50	5, 62	5, 50
Failed or Mostly D's	--	--	2, 20
Repeated a Grade			
Yes	--	2, 25	--
No	2, 100	6, 75	10, 100

Table 9: School performance of children in St. Lucia – Caregivers' Reports

Variables (n, %)	HIV Infected (n=2)	HIV Affected (n=8)	Comparisons (n=10)
How child did in School			
Very Good	2, 100	2, 25	4, 40
Good	--	2, 25	--
Fair	--	3, 38	4, 40
Poor	--	--	1, 10
Very Poor	--	1, 12	1, 10
What child's grades were like			
Mostly A's	1, 50	1, 12	2, 20
Mostly B's	1, 50	4, 50	2, 20
Mostly C's	--	2, 25	4, 40
Failed or Mostly D's	--	1, 12	2, 20
Child Repeated a Grade			
Yes	--	1, 12	--
No	2, 100	7, 88	10, 100

Table 10: Performance scores of children in St. Lucia

Variables	**HIV Infected (n=2)**	**HIV Affected (n=8)**	**Comparisons (n=10)**
Math **(mean, s.d.)**	29.0 (7.1)	30.5,3.9	39.9, 4.1
Reading **(mean, s.d.)**	24.5 (2.1)	35.0,12.7	31.0,10.0
Spelling **(mean, s.d.)**	19.0 (2.8)	29.4,10.4	27.4,8.6

Table 11: Depression & Anxiety scores for the children in St. Lucia

Variables (n, %)	**HIV Infected (n=2)**	**HIV Affected (n=8)**	**Comparisons (n=10)**
Depression score **(mean, s.d.)**	10.5 (14.8)	5.4, 4.7	4.8, 2.9
Anxiety score **(mean, s.d.)**	12.0 (12.7)	9.1, 7.5	7.5, 6.5

Table 12: Children's behaviours as rated by caregivers in St. Lucia (Rutter Scale)

Children's Behaviours	**HIV Infected (n=2)**	**HIV Affected (n=8)**	**Comparisons (n=10)**
Prosocial Behaviours (mean, s.d)	17.0, 2.8	18.1, 1.6	17.8, 2.3
Conduct Difficulties (mean, s.d)	1.5, 2.1	3.1, 3.0	1.8, 2.4

Table 13a: Perceived stigma reported by HIV infected and affected children in St. Lucia

Variables	**HIV infected and affected children (n=10)**			
	Strongly agree	Agree	Disagree	Strongly disagree
People are uncomfortable around me	1	2	0	7
People stay away from me	1	0	2	7
People will stop being friends with me	1	0	2	7
People think I am disgusting	1	0	1	8
[My (insert family member)] having HIV makes me a bad person	0	1	1	8
I feel ashamed or guilty	1	0	3	6
I feel dirty or unclean	1	0	2	7
People will judge me	0	1	3	6
People who know will tell others	4	1	1	4
People will not drink water from same pipe if know	0	2	2	6
People are afraid of me	1	0	1	8

Table 13b: Perceived stigma reported by comparison children in St. Lucia

Variables	**Comparison children (n=10)**			
	Strongly agree	Agree	Disagree	Strongly disagree
People are uncomfortable around someone with HIV	2	6	2	0
People stay away from someone with HIV	3	4	2	1
People will stop being friends with someone with HIV	2	3	4	1
People think someone with HIV is disgusting	2	5	1	2
People with HIV are bad	0	5	3	2
Someone with HIV feel ashamed or guilty	2	4	3	1
People with HIV are dirty or unclean	1	3	5	1
People judge someone living with HIV	2	6	2	0
People who know someone has HIV will tell others	2	4	3	1
People will not drink water from same pipe if someone with HIV drank from it	3	4	2	1
People are afraid of someone with HIV	3	5	2	0

Table 14a: Enacted stigma reported by HIV infected and affected children in St. Lucia

Variables *How often.....*	**HIV infected and affected children (n=10)**			
	Most of the time	Sometimes	Once or twice	Never
Others did not want to sit beside me	0	2	0	8
Others refused to eat beside me	0	1	0	9
Friends refused to hug me	1	1	0	8
Told to use my own fork or spoon to eat	1	1	0	8
Others made fun of me	1	1	0	8
Others stopped being my friend	0	2	0	8
Friends would not play with me	1	0	0	9
Friends would not talk to me	1	1	0	8
Others shouted at me	1	1	1	7
Parents refused to let me play with their children	0	1	0	9
Others insulted or teased me	3	0	0	7
Told I cannot touch other children	1	0	0	9
Told I could not go to class parties or trips	0	1	0	9
Hit, kicked or punched by others	1	1	1	7
Teachers did not want to help me with my school work	1	0	0	9
Teachers ignored me in class	1	1	0	8
Teachers did not want to touch me	1	0	0	9
Others gossiped about me	2	1	1	6

Table 14b: Enacted stigma reported by comparison children in St. Lucia

Variables *How often you think.....*	**Comparison children (n=10)**			
	Most of the time	Sometimes	Once or twice	Never
Others did not want to sit beside them	5	2	2	1
Others refused to eat beside them	5	4	0	1
Friends refused to hug them	8	2	0	0
Told to use their own fork or spoon to eat	7	3	0	0
Others made fun of them	8	1	1	0
Others stopped being their friend	6	4	0	0
Friends would not play with them	5	5	0	0
Friends would not talk to them	4	5	1	0
Others shouted at them	6	2	1	1
Parents refused to let them play with their children	5	4	1	0
Others insulted or teased them	6	3	1	0
Told they cannot touch other children	7	2	1	0
Told they could not go to class parties or trips	2	2	2	4
Hit, kicked or punched by others	3	3	1	3
Teachers did not want to help them with my school work	0	2	1	7
Teachers ignored them in class	2	1	1	6
Teachers did not want to touch them	2	2	0	6
Others gossiped about them	6	2	2	0

Table 16: Blame stigma - Children's reports in St. Lucia

VARIABLES (mean, s.d.)	HIV Infected (n=2)	HIV Affected (n=8)	Comparisons (n=10)
HIV is a punishment for bad behaviour	2.0, 1.4	1.5, 0.8	2.0, 0.9
HIV is a punishment from God	2.0,1.4	1.9, 1.0	1.9, 1.0
People with HIV deserve what they get*	1.0, 0.0	1.3, 0.5	1.9, 0.6
People with HIV should be ashamed of themselves	1.5, 0.7	1.4, 0.5	1.9, 0.7
Children with HIV should stay away from school	1.5, 0.7	1.3, 0.5	1.7, 0.7
People with HIV should be blamed for their infection	1.5, 0.7	1.3, 0.5	1.9, 0.7
I would be ashamed if someone in my family had HIV	2.0, 1.4	1.6,1.1	2.0, 0.8
Shame/Blame/Judgment score	**11.5, 6.4**	**10.1, 3.4**	**11.9, 4.4**

*Anova $p<0.05$

[c] Item scored on a scale from 1 (strongly disagree) to 4 (strongly agree)
[d] Sum of 7 blame and judgment items in Table, higher is more blame and judgement; range 7 – 28

Table 17: Blame stigma – Principals' and teachers' reports in St. Lucia

Variables (n, %)	**Principals (n=7)**	**Teachers (n=10)**
People with HIV deserve what they get:		
Agree/Strongly agree	--	--
Neutral	--	1, 10
Disagree/Strongly disagree	7, 100	9, 90
People with HIV should be ashamed of themselves:		
Agree/Strongly agree	--	--
Neutral	--	--
Disagree/Strongly disagree	7, 100	10, 100
People with HIV should be ashamed of their infection:		
Agree/Strongly agree	1, 14	1, 10
Neutral	--	1, 10
Disagree/Strongly disagree	6, 86	8, 80
If I contracted HIV, I would leave the teaching profession:		
Agree/Strongly agree	--	1, 10
Neutral	1, 14	1, 10
Disagree/Strongly disagree	6, 86	8, 80
All persons with HIV should be quarantined:		
Agree/Strongly agree	--	--
Neutral	--	--
Disagree/Strongly disagree	7, 100	10, 100

Table 18: HIV Knowledge for children in St. Lucia

VARIABLES	HIV Infected (n=2)	HIV Affected (n=8)	Comparisons (n=10)
Someone may get HIV by sharing food with someone who has HIV **(n, %)**			
No	2, 100	6,75	6,60
Yes/Don't know	--	2,25	4,40
Someone may get HIV by playing with someone with HIV **(n, %)**			
No	2, 100	8, 100	9,90
Yes/Don't know	--	--	1,10
Someone may get HIV by sitting beside someone with HIV **(n, %)**			
No	2, 100	8,100	10,100
Yes/Don't know	--	--	--
Someone may get HIV by touching someone who has HIV **(n, %)**			
No	2, 100	8,100	9,90
Yes/Don't know	--	--	1,10
Someone may get HIV by using same toilet seat as someone with HIV **(n, %)**			
No	2, 100	7, 88	8,80
Yes/Don't know	--	1,12	2,20
HIV Knowledge score (mean, s.d.)[e]	5.0,0.0	4.6,0.7	4.2,1.3

[e] Sum of 5 HIV knowledge questions in Table coded as no = 1, yes/don't know = 0; range 0 – 5, higher score is more knowledge

Table 19: Knowing children with HIV - Children's reports in St. Lucia

Variables (n, %)	HIV Infected (n=2)	HIV Affected (n=8)	Comparisons (n=10)
Easy to know if someone has HIV			
Yes	--	--	2, 20
No	2, 100	8, 100	8, 80
Anyone from school suspect has HIV			
Yes	--	--	1, 10
No	2, 100	8, 100	9, 90
Friend at school living with HIV			
Yes	--	--	--
No/Don't know	2, 100	8, 100	10, 100

Table 20: Knowing children with HIV - Principals' and Teachers' reports in St. Lucia

Variables (n, %)	**Principals (n=7)**	**Teachers (n=10)**
Students with HIV in your school		
Yes	1, 14	--
No	6, 86	10, 100
Students with HIV in your class		
Yes	--	--
No	1, 14	--
Not Applicable	6, 86	10, 100

Table 21: Opinions on HIV Disclosure – Children's reports in St. Lucia

VARIABLES	HIV Infected (n=2)	HIV Affected (n=8)	Comparisons (n=10)
Would you tell a person who has HIV to tell (n, %):			
No one/ Keep secret	--	1, 10	--
Family only	2, 100	9, 90	10, 100
Everybody	--	--	--
Reasons would tell person with HIV to tell no one/keep secret or tell only family (n)*:			
Personal/Family problem	2	2	5
People act differently towards person	--	2	2
People would keep away from person	1	2	1
People would tease person	--	3	1
People would talk about person	--	2	4

*Multiple reasons possible

Table 22: Opinions on HIV Disclosure – Caregivers' reports in St. Lucia

VARIABLES (n, %)	HIV Infected (n=2)	HIV Affected (n=5)	Comparisons (n=10)
Principal should know if child with HIV at school†			
Yes	1, 50	2, 40	10, 100
No	1, 50	3, 60	--
Teacher should know if child with HIV at school††			
Yes	--	1, 20	10, 100
No	2, 00	4, 80	--
Students should know if child with HIV at school			
Yes	--	1, 20	4, 40
No	2, 100	4, 80	6, 60
Parents should know if child with HIV at school			
Yes	--	1, 20	6, 60
No	2, 100	4, 80	4, 40

† Chi square $p<0.05$**,** †† Chi square $p<0.01$

Table 23a: Opinions on HIV Disclosure – Principals' and Teachers' reports in St. Lucia

Variables (n, %)	**Principals (n=7)**	**Teachers (n=10)**
Principals should be told if student with HIV at school		
Agree/Strongly agree	6, 86	9, 90
Neutral	--	1, 10
Disagree/Strongly disagree	1, 14	--
Teachers should be told if student with HIV in their class:		
Agree/Strongly agree	4, 57	7, 70
Neutral	1, 14	1, 10
Disagree/Strongly disagree	2, 29	2, 20
Other students should be told if a classmate is HIV positive:		
Agree/Strongly agree	1, 14	--
Neutral	3, 43	3, 30
Disagree/Strongly disagree	3, 43	7, 70
Other parents should be told if HIV positive student in their child's class:		
Agree/Strongly agree	1, 14	--
Neutral	--	2, 20
Disagree/Strongly disagree	6, 86	8, 80
It is my responsibility to alert other parents about HIV positive student:		
Agree/Strongly agree	1, 14	--
Neutral	--	2, 20
Disagree/Strongly disagree	6, 86	8, 80

Table 23b: Disclosure of students' HIV status – Principals' reports in St. Lucia

If knew child living HIV attending your school, would you share information with…….	**Principals (n=7)**
Teachers	
Yes	5, 71
No	2, 29
School nurse	
Yes	7, 100
No	--
Other students	
Yes	--
No	7, 100
Parents	
Yes	--
No	7, 100
If knew child affected by HIV attending your school, would you share information with…….	
Teachers	
Yes	2, 29
No	5, 71
School nurse	
Yes	6, 86
No	1, 14
Other students	
Yes	1, 14
No	6, 86
Parents	
Yes	1, 14
No	6, 86

Table 24: Disclosure of HIV Status – Reports of infected and affected children in St. Lucia

Variables	HIV Infected (n=2)	HIV Affected (n=8)
Age learnt of yours/your family member HIV status (mean, s.d.)	13.5, 0.7	12.2, 2.2
Who told you about yours/ your family member HIV status (n, %):		
Mother	--	6, 75
Grandmother	--	1, 13
Doctor	2, 100	1, 13
Told anyone at school (n, %):		
Yes	--	--
No	2,100	8,100
Why have you told no one (n):		
Afraid whoever was told would tell others	1	3
It is nothing to talk about/no special reason/decide not to talk	-	3
Afraid I would be talked about or laughed at	-	1
Afraid I would be treated badly	-	1

Table 25: Disclosure of HIV Status – Reports of infected and affected children's caregivers in St. Lucia

Variables (n, %)	HIV Infected (n=2)	HIV Affected (n=8)
How long child knows about his/her/your HIV status		
1 – 5 years	2, 100	6, 75
6 – 10 years	--	2, 25
Who told child about your/ their status (n, %):		
Mother	--	6, 75
Grandmother	--	2, 25
Doctor	2, 100	--
Spoke to child about his/her/family member's HIV status	2, 100	8, 100
Yes	--	--
No		
Talk with child about his/her/family member's HIV status affect his/her daily life:		
Not at all	1, 50	7, 88
Just a little	--	--
Quite a bit	1, 50	1, 12
Talk with child about his/hers/family member's HIV status affect his/her behaviour:		
Not at all	1, 50	7, 88
Just a little	--	1, 12
Quite a bit	1, 50	--
School principal told child/family member has HIV		
Yes	--	--
No	2, 100	8, 100
Child's teacher told child/family member has HIV		
Yes	--	1, 12
No	2, 100	7, 88
Child's classmates told family member has HIV		
Yes	--	--
No	2, 100	8, 100
Other Parents Told child/family member has HIV		
Yes	--	--
No	2, 100	8, 100

Table 26: Attitudes towards children with HIV – Children's reports in St. Lucia

VARIABLES	HIV Infected (n=2)	HIV Affected (n=8)	Comparisons (n=10)
How would feel if a friend told you he/she has HIV			
Afraid of them	--	--	1, 10
Not Afraid of Them	2, 100	8, 100	9, 90
Reasons would not be afraid if friend told me he/she has HIV:			
It's nothing to be afraid of / I am just not afraid	-	1	1
Because the person is still a friend to me	2	2	4
Can't get HIV by touching them/don't touch me though	-	-	2
Can't get HIV by just playing with them	-	2	-
Can't get HIV by talking to the person, sharing things etc	-	1	1
Would be cautious with cut	-	1	2

Table 27: Attitudes towards children with HIV – Principals' and Teachers' Reports in St. Lucia

Variables (n, %)	**Principals (n=7)**	**Teachers (n=10)**
Children who live with an HIV positive person should not be allowed to attend school:		
Agree/Strongly agree	1, 14	--
Neutral	--	--
Disagree/Strongly disagree	6, 86	10, 100
A child who is HIV positive should not be allowed to attend school:		
Agree/Strongly agree	1, 14	--
Neutral	--	1, 10
Disagree/Strongly disagree	6, 86	9, 90
If it were up to me, I would allow a child with HIV to remain in my school:		
Agree/Strongly agree	7, 100	9, 90
Neutral	--	--
Disagree/Strongly disagree	--	1, 10
If I had a student who had HIV in my school I would not treat him differently from other students:		
Agree/Strongly agree	7, 100	9, 90
Neutral	--	--
Disagree/Strongly disagree	--	1, 10
If there was a separate class for students with HIV I would be willing to teach it:		
Agree/Strongly agree	7, 100	10, 100
Neutral	--	--
Disagree/Strongly disagree	--	--
HIV positive students should be segregated for certain activities:		
Agree/Strongly agree	1, 14	1, 10
Neutral	--	--
Disagree/Strongly disagree	6, 86	9, 90

Table 28: National HIV Policies and Programmes in St. Lucia

Variables (n, %)	Principal (n=7)	Teachers (n=10)
Aware of policies/laws addressing HIV issues:		
Yes	5, 71	4, 40
No	2, 29	2, 20
Don't Know	--	4, 40
Country has HIV policy for school		
Yes	5, 71	3, 30
No	2, 29	4, 40
Don't Know	--	3, 30
Country has HIV Education Programme for students at school		
Yes	4, 57	4, 40
No	3, 43	3, 30
Don't Know	--	3, 30
Aware of organizations where parents/children affected by HIV can get support		
Yes	5, 71	4, 40
No	2, 29	6, 60

Table 29: Schools' HIV Policies, Programmes and Activities – Reports of principals and teachers in St. Lucia

Variables (n, %)	**Principals (n=7)**	**Teachers (n=10)**
Your school has HIV policy		
Yes	1, 14	1, 10
No	6, 86	6, 60
Don't Know	--	3, 30
HIV Education Programme for student at your school		
Yes	4, 57	5, 50
No	3, 43	5, 50
One time class or incorporated into curriculum		
One time class	1, 14	1, 10
Part of Curriculum	3, 43	4, 40
Not Applicable	3, 43	5, 50
Grades Apply to:		
All Grades	4, 57	4, 40
Certain grades/levels	--	1, 10
Not Applicable	3, 43	5, 50
Programs in your school to reduce HIV stigma and discrimination		
Yes	5, 71	6, 60
No	2, 29	4, 40
Activities carried out in your school to support children living with HIV		
Yes	2, 29	2, 20
No	5, 71	7, 70
Don't Know	--	1, 10
Activities implemented in your school to help children living with HIV		
Yes	2, 29	2, 20
No	5, 71	8, 80

Table 30: Schools' HIV Activities – Reports of children in St. Lucia

VARIABLES	HIV INFECTED (n=2)	HIV AFFECTED (n=8)	COMPARISON (n=10)
School has activities on HIV for children			
Yes	1, 50	--	4, 40
No/Don't know	1, 50	8, 100	6, 60
HIV Activities helpful			
Yes		--	4, 40
Not applicable		8, 100	6, 60
HIV Activities enough			
Yes	1, 50	--	--
No	--	--	4, 40
Not applicable	1, 50	8, 100	6, 60

Table 31: Opinions on HIV Education in schools - Reports of principals and teachers in St. Lucia

Variables (n, %)	**Principals (n=7)**	**Teachers (n=10)**
Schools should HIV education programme in different grade levels from basic/primary through high school:		
Agree/Strongly agree	7, 100	10, 100
Neutral	--	--
Disagree/Strongly disagree	--	--
HIV education should begin at basic/primary school:		
Agree/Strongly agree	7, 100	10, 100
Neutral	--	--
Disagree/Strongly disagree	--	--

Tables: Guyana study

Table 32: Background of the children in Guyana

Variables	HIV Infected (n=19)	HIV Affected (n= 20)	Comparisons (n = 35)
Age (mean, s.d.)	13.5, 2.1	13.7, 2.4	13.7, 2.2
Gender (n, %)			
Male	7, 37	11, 55	18, 51
Female	12, 63	9, 45	17, 49
Primary Caregiver (n, %)			
Mother	12, 63	9, 45	29, 83
Father	4, 21	5, 25	5, 14
Grandmother	1, 5	2, 10	-
Aunt	-	2, 10	1, 3
Brother/Sister	2, 10	1, 5	-
Adoptive Mother	-	1, 5	-

Table 33: Background of the children's caregivers and their socio-economic status in Guyana

VARIABLES	HIV Infected (n=15)	HIV Affected (n=15)	Comparisons (n=35)
Age (mean, s.d)	33.5, 7.5	34.1, 4.8	37.3, 4.4
Gender (n, %)			
Male	5, 33	4, 27	5, 14
Female	10, 67	11, 73	30, 85
Relation to Child			
Mother	10, 67	8, 53	28, 80
Adoptive mother	--	--	1, 3
Father	3, 20	4, 27	5, 14
Grandmother	--	1, 7	--
Aunt	--	2, 13	1, 3
Brother	1, 7	--	--
Sister	1, 7	--	--
Marital Status†			
Single	9, 60	7, 47	12, 34
Married	2, 13	1, 7	15, 43
Common Law	--	--	4, 11
Divorced	2, 13	4, 27	1, 3
Separated	2, 13	1, 7	2, 6
Widow/widower	--	2, 13	1, 3
Education Completed†			
In School	2, 13	--	--
Primary/Elementary	--	4, 27	2, 6
High School/Secondary School	8, 53	5, 33	15, 43
College/Technical/Vocational	2, 13	4, 27	11, 31
University	3, 20	2, 13	7, 20
Current/last job††			
In School	2, 13	--	--
Unskilled	1, 7	1, 7	6, 17
Semi-skilled	4, 27	7, 47	6, 17
Skilled	4, 27	5, 33	10, 29
Highly skilled	--	1, 7	10, 29
Professional	--	--	3, 9
Other –Sex worker	4, 27	1, 7	--
Crowding score (mean, s.d.)[a]	0.8, 0.4	0.9, 0.6	0.7, 0.2
Possessions score (mean, s.d.)[b]**	4.2, 1.3	4.5, 1.6	5.6, 1.4
Toilet facilities††			
Pit toilet	5, 33	8, 53	3, 9
Own inside flush	10, 67	7, 47	32, 91
Water source			
River, Spring	--	1, 7	--

Pipe outside yard	1, 7	2, 13	1, 3
Shared pipe in yard	2, 13	1, 7	--
Own pipe in yard	2, 13	2, 13	2, 6
Own pipe inside	10, 67	9, 60	32, 91

* Anova $p<0.05$

†† Chi square $p<0.01$

[a] Number of people per room

[b] Sum of presence of car/bus/truck, bike/bicycle, television, refrigerator, radio, cable television, computer, DVD, stove (range 0 – 9)

Table 34: Background of principals and teachers in Guyana

Variables (n, %)	Principals (n=20)	Teachers (n=35)
Gender		
Female	16, 80	28, 83
Male	4, 20	6, 17
Age		
Less than 29	--	18, 51
30-39	5, 25	14, 40
40-49	12, 60	3, 9
50-59	3, 15	--
Type of School		
Public	16, 80	26, 74
Private	4, 20	9, 26
Highest Education Completed		
High/secondary School	--	4, 11
College/Vocational/Technical School	1, 5	19, 54
University	19, 95	11, 34
Highest Degree		
Teacher Certificate	1, 5	7, 20
Bachelors	2, 10	27, 77
Masters	15, 75	1, 3
Doctor	2, 10	--
How long a principal/teacher		
Less than 1 year	--	1, 3
1 – 5 years	--	22, 63
5 – 10 years	10, 50	10, 29
More than 10 years	10, 50	2, 6

Table 35: School Attendance and Experiences of children in Guyana – Children's Reports

VARIABLES (n, %)	HIV Infected (n=19)	HIV Affected (n=20)	Comparisons (n=35)
Attends School			
Yes	19, 100	20, 100	35, 100
No	--	--	--
Current /Last School			
Secondary/High	18, 95	18, 90	32, 91
College	--	2, 10	2, 6
University	1, 5	--	1, 3
How often attended school			
Every day	17, 90	18, 90	34, 97
Most of the time	1, 5	2, 10	1, 2.9
Some of the time	1, 5	--	--
Missed school since start of current grade†			
Yes	6, 32	3, 15	1, 3
No	13, 68	17, 85	34, 97
Liked School†			
Very Much	16, 84	13, 65	31, 89
Somewhat	--	7, 35	2, 6
Like/dislike it equally	2, 11	--	1, 3
Dislike it somewhat	1,5	--	1, 3
Got along with teacher			
Very well	8, 42	11, 55	19, 54
Well	7, 37	6, 30	12, 34
Fairly well	3, 16	2, 10	2, 6
Badly	1, 5	1, 5	1, 3
Very badly	--	--	1, 3
Got along with classmates			
Very well	8, 42	11, 55	20, 57
Well	8, 42	6, 30	10, 29
Fairly well	2, 11	2, 10	4, 11
Badly	1, 5	1, 5	1, 3

† Chi square $p<0.05$

Table 36: Reasons for missing school – Children's reports in Guyana*

VARIABLES	HIV Infected (n=6)	HIV Affected (n=3)	Comparisons (n=1)
Reasons for missing school			
Was ill	5	1	1
Caregiver ill	1	2	--
Attend clinic	--	1	--
Travelled	--	1	--
How spends day when miss school			
Doing housework	1	--	--
Playing	1	--	1
Caring for sick caregiver	1	2	--
Stay home sick	4	2	1
At the doctor/clinic	--	1	--
Travelled	--	1	--

*Multiple options possible

Table 37: School attendance and experiences of children in Guyana – Caregivers' Reports

VARIABLES (n, %)	HIV Infected (n=19)	HIV Affected (n=20)	Comparisons (n=35)
Child goes to school			
Yes	19, 100	20, 100	35, 100
No	--	--	--
Kind of school child attended			
Secondary/High School	18, 95	18, 90	32, 91
College/Vocational School	--	2, 10	2, 6
University	1, 5	--	1, 3
How often did child go to school			
Every day	16, 84	18, 90	33, 94
Most of the time	2, 11	2, 10	2, 6
Some of the time	1, 5	--	--
Missed School††			
Yes	5, 26	4, 20	--
No	14, 74	16, 80	35, 100
Child liked School			
Liked it Very Much	16, 84	16, 80	28, 80
Liked it Somewhat	1, 5	3, 15	7, 20
Liked/Dislike(d) it Equally	1, 5	1, 5	--
Disliked it Somewhat	1, 5	--	--
Child got along with teacher			
Very Well	9, 47	10, 50	23, 66
Well	8, 42	8, 40	11, 31
Fairly Well	1, 5	1, 5	1, 3
Badly	1, 5	1, 5	--
Child got along with classmates			
Very Well	9, 47	9, 45	22, 63
Well	8, 42	8, 40	12, 34
Fairly Well	2, 11	1, 5	1, 3
Badly	--	2, 10	--

†† Chi square $p<0.01$

Table 38: Reasons for missing school – Caregivers' Reports in Guyana*

VARIABLES	HIV Infected (n=5)	HIV Affected (n=4)
Reasons for missing school		
Death of child's parent	1	--
No school fees/No money	--	1
Child was ill	3	1
Child refused to go to school	1	--
Child had to go to clinic	1	--
Child had to look after sick parent	--	1
Child was out of country	--	1
How spends day when miss school		
Doing homework or studying	--	1
Playing alone or with other children	2	3
Caring for sick caregiver	1	1
Child stayed home sick	3	1
At the doctor/In hospital	--	1

*Multiple options are possible

Table 39: School Performance of children in Guyana – Children's Reports

VARIABLES	HIV Infected (n=19)	HIV Affected (n= 20)	Comparisons (n = 35)
How did in school			
Very Good	9, 47	11, 55	24, 69
Good	8, 43	7, 35	6, 17
Fair	2, 11	2, 10	4, 11
Poor	--	--	1, 3
What grades were like			
Mostly A's	9, 47	9, 45	16, 46
Mostly B's	8, 42	9, 45	13, 37
Mostly C's	2, 11	2, 10	6, 17
Repeated a Grade			
Yes	--	--	--
No	19, 100	20, 100	35, 100

Table 40: School Performance of children in Guyana – Caregivers' Reports

VARIABLES	HIV Infected (n=19)	HIV Affected (n= 20)	Comparisons (n = 35)
How child did in School			
Very Good	9, 47	10, 50	27, 77
Good	7, 37	8, 40	7, 20
Fair	2, 11	1, 5	1, 3
Poor	1, 5	1, 5	--
What child's grades were like†			
Mostly A's	6, 32	9, 45	22, 63
Mostly B's	11, 58	7, 35	13, 37
Mostly C's	1, 5	4, 20	--
Failed or Mostly D's	1, 5	--	--
Child Repeated a Grade			
Yes	--	--	--
No	19, 100	20, 100	35, 100

† Chi square $p<0.05$

Table 41: Performance scores of children in Guyana

VARIABLES	**HIV INFECTED (n=19)**	**HIV AFFECTED (n=20)**	**COMPARISONS (n=35)**
Math **(mean, s.d.)**	31.6, 4.1	32.6, 4.8	32.1, 4.4
Reading **(mean, s.d.)**	35.0, 6.4	34.0, 8.7	32.8, 5.8
Spelling **(mean, s.d.)**	35.7, 8.4	34.5, 7.7	33.6, 7.5

Table 42: Depression & Anxiety scores for the children in Guyana

VARIABLES	**HIV Infected (n= 19)**	**HIV Affected (n = 20)**	**Comparisons (n =35)**
Depression score **(mean, s.d.)**	14.1, 7.8	15.2, 7.3	11.0, 5.5
Anxiety score **(mean, s.d.)**	14.1, 5.5	13.9, 6.4	12.7, 5.8

Table 43: Children's behaviour as rated by caregivers in Guyana (Rutter scale)

Children's Behaviours	**HIV Infected (n= 19)**	**HIV Affected (n = 20)**	**Comparisons (n =35)**
Prosocial Behaviours (mean, s.d)	11.1, 3.1	11.6, 4.4	11.1, 4.0
Conduct Difficulties (mean, s.d)	6.0, 2.9	6.6, 3.5	6.6, 3.9

Table 44a: Perceived stigma reported by HIV infected children in Guyana

Variables	**HIV infected children (n=19)**			
	Strongly agree	Agree	Disagree	Strongly disagree
People are uncomfortable around me	0	9	8	2
People stay away from me	0	6	10	3
People will stop being friends with me	0	7	9	3
People think I am disgusting	0	9	8	2
[My (insert family member)] having HIV makes me a bad person	0	8	8	3
I feel ashamed or guilty	0	9	8	2
I feel dirty or unclean	0	8	9	2
People will judge me	0	11	7	1
People who know will tell others	0	10	8	1
People will not drink water from same pipe if know	0	8	8	3
People are afraid of me	1	7	9	2

Table 44b: Perceived stigma reported by HIV affected children in Guyana

Variables	**HIV affected children (n=20)**			
	Strongly agree	Agree	Disagree	Strongly disagree
People are uncomfortable around me	1	11	7	1
People stay away from me	1	11	8	0
People will stop being friends with me	1	10	8	1
People think I am disgusting	1	9	10	0
[My (insert family member)] having HIV makes me a bad person	1	9	10	0
I feel ashamed or guilty	1	10	9	0
I feel dirty or unclean	1	9	10	0
People will judge me	1	10	9	0
People who know will tell others	1	10	9	0
People will not drink water from same pipe if know	1	9	10	0
People are afraid of me	1	9	10	0

Table 44c: Perceived stigma reported by comparison children in Guyana

Variables	**Comparison children (n=35)**			
	Strongly agree	Agree	Disagree	Strongly disagree
People are uncomfortable around someone with HIV	0	19	15	1
People stay away from someone with HIV	0	17	16	1
People will stop being friends with someone with HIV	0	18	15	1
People think someone with HIV is disgusting	0	16	18	0
People with HIV are bad	0	13	21	0
Someone with HIV feel ashamed or guilty	0	13	21	0
Persons with HIV are dirty or unclean	0	15	19	0
People judge someone living with HIV	1	20	13	0
People who know someone has HIV will tell others	3	18	13	0
People will not drink water from same pipe if someone with HIV drank from it	1	17	15	1
People are afraid of someone with HIV	1	21	12	0

Table 45a: Enacted stigma reported by HIV infected children in Guyana

Variables *How often.....*	**HIV infected children (n=18)**			
	Most of the time	Sometimes	Once or twice	Never
Others did not want to sit beside me	2	6	3	8
Others refused to eat beside me	2	7	3	7
Friends refused to hug me	2	6	3	8
Told to use my own fork or spoon to eat	3	7	3	6
Others made fun of me	2	8	2	7
Others stopped being my friend	2	6	1	10
Friends would not play with me	2	6	2	9
Friends would not talk to me	2	6	5	6
Others shouted at me	2	7	4	6
Parents refused to let me play with their children	2	5	3	9
Others insulted or teased me	3	5	3	8
Told I cannot touch other children	2	6	3	8
Told I could not go to class parties or trips	4	2	1	11
Hit, kicked or punched by others	3	3	1	11
Teachers did not want to help me with my school work	4	2	3	9
Teachers ignored me in class	4	4	0	10
Teachers did not want to touch me	3	4	0	1
Others gossiped about me	8	2	2	6

Table 45b: Enacted stigma reported by HIV affected children in Guyana

Variables *How often.....*	**HIV affected children (n=20)**			
	Most of the time	Sometimes	Once or twice	Never
Others did not want to sit beside me	2	7	3	8
Others refused to eat beside me	2	8	1	9
Friends refused to hug me	2	7	0	11
Told to use my own fork or spoon to eat	3	8	0	9
Others made fun of me	2	8	0	10
Others stopped being my friend	2	7	2	9
Friends would not play with me	3	7	1	9
Friends would not talk to me	3	6	2	9
Others shouted at me	3	7	1	9
Parents refused to let me play with their children	2	7	0	11
Others insulted or teased me	2	6	1	11
Told I cannot touch other children	2	8	0	10
Told I could not go to class parties or trips	3	6	1	10
Hit, kicked or punched by others	3	7	1	9
Teachers did not want to help me with my school work	3	8	2	7
Teachers ignored me in class	3	6	3	8
Teachers did not want to touch me	3	7	3	7
Others gossiped about me	5	5	2	8

Table 45c: Enacted stigma reported by comparison children in Guyana

Variables *How often do you think.....*	**Comparison children (n=35)**			
	Most of the time	Sometimes	Once or twice	Never
Others did not want to sit beside them	1	11	4	18
Others refused to eat beside them	1	13	3	17
Friends refused to hug them	1	10	10	13
Told to use their own fork or spoon to eat	1	13	7	13
Others made fun of them	1	15	5	13
Others stopped being their friend	2	12	4	16
Friends would not play with them	2	11	8	13
Friends would not talk to them	1	11	9	13
Others shouted at them	0	11	8	15
Parents refused to let them play with their children	1	10	8	15
Others insulted or teased them	1	10	8	15
Told they cannot touch other children	1	13	6	14
Told they could not go to class parties or trips	0	12	7	15
Hit, kicked or punched by others	0	12	7	15
Teachers did not want to help them with my school work	0	10	7	17
Teachers ignored them in class	0	14	6	14
Teachers did not want to touch them	0	12	7	15
Others gossiped about them	5	11	7	11

Table 47: Blame stigma - Children's reports in Guyana

VARIABLES	HIV Infected (n=19)	HIV Affected (n=20)	Comparisons (n=34)
HIV is a punishment for bad behaviour[c]	2.2, 0.7	2.4, 0.5	2.2, 0.4
HIV is a punishment from God	2.6, 0.8	2.4, 0.6	2.3, 0.5
People with HIV deserve what they get	2.3, 0.8	2.3, 0.6	2.2, 0.3
People with HIV should be ashamed of themselves	2.3, 0.7	2.2, 0.7	2.2, 0.4
Children with HIV should stay away from school	2.3, 0.7	2.1, 0.8	2.2, 0.4
People with HIV should be blamed for their infection	2.3, 0.7	2.1, 0.8	2.1, 0.5
I would be ashamed if someone in my family had HIV	2.3, 0.8	2.1, 0.8	2.2, 0.6
Shame/Blame/Judgment score (mean, s.d.) [d]	**16.3, 4.6**	**15.5, 4.3**	**15.2, 2.5**

[c] Item scored on a scale from 1 (strongly disagree) to 4 (strongly agree)

[d] Sum of 7 blame and judgment items in Table, higher is more blame and judgement; range 7 – 28

Table 48: Blame stigma - Principals' and teachers' reports in Guyana

Variables (n, %)	**Principals (n=20)**	**Teachers (n=35)**
People with HIV deserve what they get:		
Agree/Strongly agree	1, 5	--
Neutral	--	--
Disagree/Strongly disagree	19, 95	35, 100
People with HIV should be ashamed of themselves:		
Agree/Strongly agree	1, 5	--
Neutral	--	--
Disagree/Strongly disagree	19, 95	35, 100
People with HIV should be ashamed of their infection:		
Agree/Strongly agree	2, 10	2, 6
Neutral	--	1, 3
Disagree/Strongly disagree	18, 90	32, 91
If I contracted HIV, I would leave the teaching profession:		
Agree/Strongly agree	7, 35	13, 37
Neutral	1, 5	6, 17
Disagree/Strongly disagree	12, 60	16, 46
All persons with HIV should be quarantined:		
Agree/Strongly agree	5, 25	19, 54
Neutral	13, 65	13, 37
Disagree/Strongly disagree	2, 10	3, 9

Table 49: HIV Knowledge for children in Guyana

VARIABLES	HIV Infected (n=19)	HIV Affected (n=20)	Comparisons (n=35)
Someone may get HIV by sharing food with someone who has HIV **(n, %)**			
No	19, 100	19, 95	31, 89
Yes/Don't know	--	1, 5	4, 11
Someone may get HIV by playing with someone with HIV **(n, %)**			
No	19, 100	19, 95	30, 86
Yes/Don't know	--	1, 5	5, 14
Someone may get HIV by sitting beside someone with HIV **(n, %)**			
No	18, 95	19, 95	30, 86
Yes/Don't know	1, 5	1, 5	5, 14
Someone may get HIV by touching someone who has HIV **(n, %)**			
No	18, 95	19, 95	30, 86
Yes/Don't know	1, 5	1, 5	5, 14
Someone may get HIV by using same toilet seat as someone with HIV **(n, %)**			
No	17, 90	17, 85	24, 69
Yes/Don't know	2, 10	3, 15	11, 31
HIV Knowledge score (mean, s.d.)[e]	**4.8, 0.5**	**4.6, 1.2**	**4.1, 1.4**

[e] Sum of 5 HIV knowledge questions in Table coded as no = 1, yes/don't know = 0; range 0 – 5, higher score is more knowledge

Table 50: Knowing children with HIV - Children's reports in Guyana

VARIABLES (n, %)	HIV Infected (n=19)	HIV Affected (n=20)	Comparisons (n=35)
Easy to know if someone has HIV			
Yes	3, 16	2, 10	1, 3
No	14, 74	18, 90	33, 94
Don't know	2, 10	--	1, 3
Anyone from school suspect has HIV			
Yes	4, 21	1, 5	1, 3
No	13, 68	18, 90	33, 94
Don't know	2, 11	1, 5	1, 3
Friend at school living with HIV			
Yes	2, 10	1, 5	3, 9
No	14, 74	14, 70	29, 83
Don't know	3, 16	5, 25	3, 9

Table 51: Knowing children with HIV - Principals' and Teachers' reports in Guyana

Variables (n, %)	**Principals (n=20)**	**Teachers (n=35)**
Student with HIV in your school		
Yes	10, 50	12, 34
No	10, 50	22, 63
Don't know	--	1, 3
Students with HIV in your class		
Yes	1, 5	11, 31
No	--	1, 3
Don't know	--	1, 3
Not Applicable	19, 95	22, 63

Table 52: Opinions on HIV Disclosure - Children's reports in Guyana

VARIABLES	HIV Infected (n=19)	HIV Affected (n=20)	Comparisons (n=35)
Would you tell a person who has HIV to tell (n, %):			
No one/ Keep secret	8, 42	12, 60	18, 51
Family only	9, 47	5, 25	13, 37
Don't know	2, 11	3, 15	4, 11
Reasons would tell person with HIV to tell keep it a secret or tell only family **(n):**			
Personal/Family problem	6	5	14
People act differently towards person	3	4	5
People would keep away from person	--	--	2
People would tease person	1	--	2
People would talk about person	2	5	4
Told to do so/this is the best way to go	2	3	1

Table 53: Opinions on HIV Disclosure - Caregivers' reports in Guyana

VARIABLES (n, %)	HIV Infected (n=15)	HIV Affected (n=15)	Comparisons (n=35)
Principals should know if child with HIV at school††			
Yes	3, 20	2, 13	22, 63
No	12, 80	13, 87	13, 37
Teachers should know if child with HIV at school†			
Yes	4, 27	4, 27	22, 63
No	11, 73	11, 73	13, 37
Students should know if child with HIV at school			
Yes	1, 7	--	2, 6
No	14, 93	15, 100	32, 91
Don't know	--	--	1, 3
Parents should know if child with HIV at school			
Yes	1, 7	--	6, 17
No	14, 93	15, 100	29, 83

† Chi square $p<0.05$**,** †† Chi square $p<0.01$

Table 54a: Opinions on HIV Disclosure - Principals' and Teachers' reports in Guyana

Variables (n, %)	**Principals (n=20)**	**Teachers (n=35)**
Principals should be told if student with HIV at school		
Agree/Strongly agree	19, 95	27, 77
Neutral	--	1, 3
Disagree/Strongly disagree	1, 5	7, 20
Teachers should be told if student with HIV in their class:		
Agree/Strongly agree	19, 100	25, 71
Neutral	--	1, 3
Disagree/Strongly disagree	--	9, 26
Other students should be told if a classmate is HIV positive:		
Agree/Strongly agree	1, 5	5, 14
Neutral	--	2, 6
Disagree/Strongly disagree	19, 95	27, 80
Other parents should be told if HIV positive student in their child's class:		
Agree/Strongly agree	3, 15	7, 20
Neutral	--	2, 6
Disagree/Strongly disagree	17, 85	26, 74
It is my responsibility to alert other parents about HIV positive student:		
Agree/Strongly agree	11, 55	13, 37
Neutral	4, 20	13, 37
Disagree/Strongly disagree	5, 25	9, 26

Table 54b: Disclosure of students' HIV status - Reports of principals in Guyana

If knew child living HIV attending your school, would you share information with…….	**Principals (n=20)**
Teachers	
Yes	19, 95
No	1, 5
School nurse	
Yes	20,100
No	--
Other students	
Yes	--
No	20, 100
Parents	
Yes	--
No	20, 100
If knew child affected by HIV attending your school, would you share information with…….	
Teachers	
Yes	13, 65
No	7, 35
School nurse	
Yes	13, 65
No	7, 35
Other students	
Yes	--
No	20, 100
Parents	
Yes	--
No	20, 100

Table 55: Disclosure of HIV Status - Reports of infected and affected children in Guyana

VARIABLES	HIV Infected (n=13)	HIV Affected (n=18)
Age learnt of yours/your family member HIV status (mean, s.d.)	8.6, 2.4	8.1, 2.1
Who told you about yours/ your family member HIV status (n, %)*:		
Mother	7, 54	13, 68
Dad	1, 8	1, 5
Grandmother	1, 8	1, 5
Doctor	2, 15	1, 5
Counsellor	4, 31	6, 32
Told anyone at school:		
Yes	1, 8	1, 6
No	12, 92	17, 94
Why have you told no one (n)		
Told not to tell anyone	3	3
Afraid I would be talked about or laughed at	3	2
Afraid whoever was told would tell others	2	--
Afraid I would be treated badly	1	--
It is nothing to talk about/no special reason/decide not to talk	1	4
Feel uncomfortable talking about status /I would never tell anyone/that not a good topic	--	3

*Multiple options possible

Table 56: Disclosure of HIV Status - Reports of infected and affected children's caregivers in Guyana

Variables (n, %)	HIV Infected (n=18)	HIV Affected (n=19)
How long child knows about his/her/your HIV status		
Less than 1 year	2, 11	3, 16
1 – 5 years	11, 61	14, 74
6 – 10 years	5, 28	2, 11
Who told child about your/ their status (n, %)*:		
Mother	9, 50	13, 72
Grandmother	1, 6	1, 6
Brother	1, 6	--
Doctor	1, 6	1, 6
Nurse	2, 11	1, 6
Counsellor	6, 33	3, 17
Spoke to child about his/her/family member's HIV status		
Yes	14, 82	12, 75
No	3, 18	4, 25
Talk with child about his/her/ family member's HIV status affect his/her daily life:		
Not at all	3, 19	10, 53
Just a little	8, 50	1, 5
Quite a bit	1, 6	2, 11
All the time	1, 6	1, 5
Don't know	--	1, 5
Not applicable	3, 19	4, 21
Talk with child about his/her/family member's HIV status affect his/her behaviour:		
Not at all	4, 22	13, 68
Just a little	6, 33	--
Quite a bit	2, 11	--
All the time	3, 17	1, 5
Don't know	--	1, 5
Not applicable	3, 17	4, 21
School principal told child/family member has HIV		
Yes	4, 22	--
No	12, 67	18, 95
Don't know	2, 11	1, 5
Child's teacher told child/family member has HIV		
Yes	4, 22	1, 5
No	12, 67	17, 90
Don't know	2, 11	1, 5

Child's classmates told child/family member has HIV		
Yes	1, 6	--
No	16, 89	18, 95
Don't know	1, 6	1, 5
Other Parents Told child/family member has HIV		
Yes	--	--
No	16, 89	18, 95
Don't know	2, 11	1, 5

*Multiple options possible

Table 57: Attitude towards children with HIV - Children's Reports in Guyana

VARIABLES	HIV Infected (n=19)	HIV Affected (n=20)	Comparisons (n=35)
How would feel if a friend told you he/she has HIV (n, %)			
Afraid of them	1, 5	2, 10	8, 23
Not Afraid of Them	16, 84	16, 80	25, 71
Don't know	--	1, 5	--
Not applicable	2, 11	1, 5	2, 6
Reasons would not be afraid if friend told me he/she has HIV **(n)**			
It's nothing to be afraid of / I am just not afraid	3	5	4
They are individuals/no difference between HIV & cancer	3	1	6
Because they are / he/she is still a friend to me	-	-	7
Told treat everyone equal	-	-	1
They are still alive	1	2	2
Not sure/Don't know	1	2	4

Table 58: Attitudes towards children with HIV - Principals' and Teachers' Reports in Guyana

Variables (n, %)	**Principals (n=20)**	**Teachers (n=35)**
Children who live with an HIV positive person should not be allowed to attend school:		
Agree/Strongly agree	5, 25	13, 37
Neutral	--	--
Disagree/Strongly disagree	15, 75	22, 63
A child who is HIV positive should not be allowed to attend school:		
Agree/Strongly agree	5, 25	11, 32
Neutral	--	--
Disagree/Strongly disagree	15, 75	24, 69
If it were up to me, I would allow a child with HIV to remain in my school:		
Agree/Strongly agree	17, 85	31, 89
Neutral	1, 5	1, 3
Disagree/Strongly disagree	2, 10	3, 9
I would be comfortable having a student with HIV in the school I work:		
Agree/Strongly agree	8, 40	21, 60
Neutral	5, 25	8, 23
Disagree/Strongly disagree	7, 35	6, 17
If I had a student who had HIV in my school I would not treat him differently from other students:		
Agree/Strongly agree	11, 55	20, 57
Neutral	6, 30	8, 23
Disagree/Strongly disagree	3, 15	7, 20
If there was a separate class for students with HIV I would be willing to teach it:		
Agree/Strongly agree	12, 60	19, 54
Neutral	6, 30	12, 34
Disagree/Strongly disagree	2, 10	4, 11
HIV positive students should be segregated for certain activities:		
Agree/Strongly agree	3, 15	7, 20
Neutral	1, 5	3, 9
Disagree/Strongly disagree	16, 80	25, 71

Table 59: National HIV Policies and Programmes in Guyana

Variables (n, %)	Principals (n=20)	Teachers (n=35)
Aware of policies/laws addressing HIV issues:		
Yes	--	2, 6
No	20, 100	27, 77
Don't Know	--	6, 17
Country has HIV policy for school		
Yes	--	--
No	20, 100	33, 94
Don't know	--	2, 6
Country has HIV Education Programme for students at school		
Yes	--	--
No	19, 95	34, 97
Don't Know	1, 5	1, 3
Aware of organizations where parents/children affected by HIV can get support		
Yes	9, 45	14, 40
No	11, 55	21, 60

Table 60: Schools' HIV Policies, Programmes and Activities – Reports of principals and teachers in Guyana

Variables (n, %)	Principals (n=20)	Teachers (n=35)
Your school has HIV policy		
Yes	--	--
No	20, 100	35, 100
HIV Education Programme for students at your school		
Yes	--	1, 3
No	20, 100	34, 97
One time class or incorporated into curriculum		
One time class	--	--
Part of Curriculum	--	1, 3
Not Applicable	20, 100	34, 97
Grades Apply to:		
All Grades	--	1, 3
Certain grades/levels	--	--
Not Applicable	20, 100	34, 97
Programs in your school to reduce HIV stigma and discrimination		
Yes	1, 5	2, 6
No	19, 95	33, 94
Activities carried out in your school to support children living with HIV		
Yes	2, 10	6, 17
No	18, 90	29, 83
Activities implemented in your school to help children living with HIV		
Yes	2, 10	3, 9
No	18, 90	32, 91

Table 61: Schools' HIV Activities – Reports of children in Guyana

VARIABLES (n, %)	HIV Infected (n=16)	HIV Affected (n=20)	Comparisons (n=34)
School has activities on HIV for children			
Yes	1, 6	1, 5	2, 6
No	13, 81	16, 80	29, 85
Don't know	2, 13	3, 15	3, 9
HIV Activities helpful			
Yes	1, 6	1, 5	1, 3
No	--	--	1, 3
Not applicable	15, 94	19, 95	34, 94
HIV Activities enough			
Yes	1, 6	1, 5	1, 3
No	--	--	1, 3
Not applicable	15, 94	19, 95	34, 94

Table 62: Opinions on HIV Education in schools - Reports of principals and teachers in Guyana

Variables (n, %)	**Principals (n=20)**	**Teachers (n=35)**
Schools should HIV education programme in different grade levels from basic/primary through high school:		
Agree/Strongly agree	5, 25	21, 60
Neutral	12, 60	11, 31
Disagree/Strongly disagree	3, 15	3, 9
HIV education should begin at basic/primary school:		
Agree/Strongly agree	5, 25	22, 63
Neutral	12, 60	10, 29
Disagree/Strongly disagree	3, 15	3, 9

Appendix I:

Table 1 HIV- related Stigma: Cross-sectional studies among adults

REFERENCE	SAMPLE/STUDY DESIGN	METHODOLOGY	OUTCOME MEASURES	RESULTS	REMARKS
1. Berger, B.E.; Ferrans, C.E. and Lashley, F.R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. Research in Nursing & Health Vol.24 (6): 518 – 529. *(Abstract only)*	U.S. – Persons living with HIV (19% women, 21% African American and 8% Hispanic; *n = 318*)	40-itemed instrument developed measuring the perception of stigma based on stigma-related literature and the psychosocial aspects of having HIV. Instrument distributed throughout HIV-related organizations across the Unites States. Psychometric analysis performed on returned questionnaires.	Personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes toward people with HIV.	Coefficient alphas between 0.90 and 0.93 for the subscales. Coefficient alpha (0.96) for 40-itemed instrument provided evidence of internal consistency reliability.	HIV stigma scale was reliable and valid with a large diverse sample of people living with HIV.
2. Herek, G.M.; Capitanio, J.P. and Widaman, K.F. (2002). HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991 – 1999. American Journal of Public Health Vol. 92 (3): 371 – 377.	English speaking adults (≥ 18 yrs.) were contacted between the period September 1996 – March 1997 (*n = 1309*) and approximately 2 years later between the period September 1998 – May 1999 (*n = 669*) to assess the prevalence of AIDS stigma and misinformation with respect to HIV transmission in the United States. Findings were compared with results from a similar 1991 survey.	Surveys conducted using a computer-assisted telephone interviewing system. Samples were generated with a list-assisted random-digit-dialing procedure. Re-contact attempts for each randomly dialed number was unlimited. Interviewer ascertained the names of all members of the household (≥ 18yrs.) and a tally created of their names. The respondent to be interviewed was randomly selected from that list. Comparison of data from the 1997 and 1999 surveys with those from the 1990-	9-item stigma index computed which centered around: support for coercive AIDS-related policies, negative feelings towards people with AIDS (PWAs), responsibility and blame, beliefs about HIV transmission, discomfort and avoidance.	Blatant expression of stigma declined throughout the 1990-1999 survey period (statistically significant odds ratio, $P<0.05$), attaining very low levels in 1999. Stigma index scores showed a significant decrease throughout the 1991 – 1999 study periods. The mean number of stigma-related responses was 2.6 in 1991 (S.E. = 0.11), 1.7 in 1997 (S.E. = 0.06) and 1.5 in 1999 (S.E. = 0.08). Misleading beliefs about the possibility of contracting the disease by random public contact however increased as did the view that PWAs warranted	Despite the support for harsh policies towards PWAs has declined, AIDS related stigma still persists in the United States.

		1991 survey.		their illness. The 1999 survey demonstrated that an estimated ⅓ of the respondents interviewed communicated uneasiness and negative feelings towards PWAs.	
3. Badcock-Walters, P.; Desmond, C.; Heard, W. and Wilson, D. (2003). Educator mortality in KwaZulu Natal: a consolidated study of impact and trends. Pa-per presented at the scientific meeting on empirical evidence for the demographic and socio-economic impact of AIDS, hosted by the Health Economics and HIV/AIDS Research Division (HEARD), University of Natal, Durban, South Africa, 26-28 March 2003.	South Africa – KwaZulu Natal Province 100 schools, sampled randomly, in addition to provincial data on schools and pensions.	Analysis of annual school survey data; a random sample survey of 100 schools to investigate reporting of educator mortality; analysis of educator mortality records, including pension and medical records.	Mortality rates of educators over a five-year period; cause of death of educators.	Mortality among educators of both genders rose significantly over the five years between 1997 and 2001, from 406 in 1997 to 681 in 2000 and 609 in 2001. A by-product of the 100-school random sample survey was an analysis of the quality and dependability of school record-keeping. Data were not available for many educators who took early retirement.	Data analysis confirmed that mortality among educators of both genders rose significantly from 1995 to 2001, especially among those aged 25 to 40. The overwhelming cause of death among both sexes under 45 was illness/natural causes.
4. Norman, L.R.; Carr, R. and Jiménez, J. (2006). Sexual stigma and sympathy: Attitudes towards persons living with HIV in Jamaica. Culture, Health and Sexuality 8 (5):423 – 433.	Non-probability sampling frame used. Data collected from 1252 students throughout the U.W.I. faculties (11% of total student population enrolled) from June 2001 – February 2002.	Survey conducted using a 193-item questionnaire related to HIV/AIDS education, prevention, attitudes and behaviour. Test instrument was self-administered with no identifiers (due to the nature of the questionnaire).	Sympathy (5 point Lickert scale), HIV awareness, HIV education, knowledge of HIV transmission, spirituality, church attendance, age and sex.	Most students (97.5%) reported sympathy toward children living with HIV. Minority reported sympathy toward homosexual men or women workers living with HIV (40.1% and 44.4%, respectively). Males were less likely to express sympathy than females towards homosexual men living with HIV (OR = 0.55%, 95% C.I. = 0.41 – 0.73). Students who reported being very spiritual were more likely to express sympathy towards homosexual men living with HIV than less	Jamaican students had less than sympathetic attitudes towards various groups of persons living with HIV (attitudes vary depending on target factors). Majority of respondents reported sympathy for children whilst less sympathy was expressed for adults from certain categories. Findings suggest

				spiritual students (OR = 1.35, 95% C.I. = 1.01 – 1.80). Students (who had inaccurate knowledge concerning HIV transmission) were less likely to express sympathy towards women sex workers with HIV when compared to those students with accurate knowledge (OR = 0.57, 95% C.I. = 0.35 – 0.95). Significantly higher levels of sympathy were expressed toward heterosexual men and women who were not sex workers (67.2% and 81.3%,).	high levels of negative attitudes in Jamaica that warrant both individual and societal level actions and interventions.
5. Tan, X.; Pan, J.; Zhou, D.; Xie, C.; Wen, X. and Hong, Y. (2006). HIV/AIDS knowledge, attitudes and behaviours among undergraduate students in China. Journal of US-China Medical Science Vol. 3 (5): 39 - 46	29 university students across various faculties of Wuhan University, were surveyed to assess their attitudes, practices and knowledge regarding HIV/AIDS	Students were selected randomly through stratified cluster sampling. A self-administered questionnaire, with no identifiers, was used in the investigation.	Sample characteristics, sources of HIV/AIDS information, knowledge of HIV/AIDS, attitudes and beliefs about HIV/AIDS, practices about HIV/AIDS, gender differences, faculty differences, monthly expenditure differences.	Most undergraduate students (*n = 212*, 82.2%) had a moderate level of HIV/AIDS knowledge (score range 19 – 35, mean score = 28.06; SD = 2.93), and tolerant attitudes towards people with HIV/AIDS. 153 students (59.8%) were willing to live in the same community with persons living with HIV/AIDS. Males were more tolerant and had positive attitudes towards people with HIV/AIDS than girls (Z = -2.153, P = 0.031). Students in the medical faculty were more tolerant and knowledgeable, than non-medical students (X^2 = 12.912, p = 0.024) than non-medical students (X^2 = 11.300, p = 0.046). Students whose monthly consumption was	Results from the investigation revealed that the majority of undergraduate students had moderate knowledge of HIV/AIDS, positive and tolerant attitudes towards people living with HIV/AIDS. It is important that students maintain up-to-date HIV/AIDS knowledge and attitudes. Condom use and the cultivation of moral responsibility

				between 300 – 599 Yuan were more knowledgeable about HIV/AIDS, held more positive attitudes towards HIV/AIDS infected persons and practiced safer sexual behaviour (knowledge: Z = -5.545, p = 0.000; attitudes: Z = -3.101, p = 0.002; practices: Z = -7.448, p = 0.000).	towards HIV/AIDS infected persons are important steps in AIDS prevention.
6. Genberg, B.L.; Hlavka, Z.; Konda, K.A.; Maman, S.; Chariyalertsak, S.; Chingono, A.; Modiba, P.; Rooyen, H.V. and Celentano, D.D. (2009). A comparison of HIV/AIDS-related stigma in four countries: Negative attitudes and perceived acts of discrimination towards people living with HIV/AIDS. Social Science & Medicine Vol. 68 (12): 2279 – 2287.	48 communities in 5 sites: Chiang Mai Province, Thailand (14 communities), Mutoko District, Mashonaland East Province, Zimbabwe (8 communities); Kisarawe District in the Pwani region of Tanzania (10 communities); Vulindlela, KwaZulu Natal Province (8 communities); and Soweto, Gauteng Province, South Africa (8 communities) – (*n = 14,203*) Data collected during 2005 – 2006. Random household probability samples were drawn from household enumeration. Eligible individuals (aged 18 – 32 yrs.) were randomly selected from each household to participate.	Interviewer administered questionnaire. Respondents were asked to respond to 22 statements about PLHAs (5 point Likert scale). Instrument measured three constructs of HIV-related stigma and discrimination: 1. Negative attitudes and beliefs associated with PLHA. 2. Perception of acts of discrimination faced by PLHAs within their community. 3. Personal attitudes and beliefs related to fair treatment of PLHAs in society.	Demographic characteristics, sexual behaviour, communication regarding HIV/AIDS, attitudes and perceptions about HIV stigma and discrimination, HIV testing history and ARV knowledge.	In all sites, never having had an HIV test was associated with negative attitudes towards PLHA when compared to those who had never been tested (statistically significant in Thailand only; OR = 1.68, 95% CI: 1.37 – 2.04). No knowledge of ARVs was associated with negative attitudes towards PLHA when compared with those who had knowledge across all sites, with the exception of Soweto (statistically significant OR = 1.38, 95% CI: 0.92 – 2.06). Never having talked about HIV/AIDS was also associated with negative attitudes towards PLHA. More negative attitudes were found in sites with the lowest HIV prevalence (Tanzania and Thailand) and more perceived discrimination against PLHA was found in sites with the	Negative attitudes and perceived discrimination towards PLHA were related to lacking knowledge of ARVs, a lack of prior history of HIV testing, and not having discussed HIV/AIDS with anyone. Universal access to treatment for HIV and widespread educational and prevention efforts that promote understanding of ARVs, adoption of HIV testing, and discussion of HIV/AIDS, may reduce HIV/AIDS-related stigma and discrimination.

				lowest ARV coverage (Tanzania and Zimbabwe). The mean negative attitudes score was 1.20 (SD = 0.65) across sites, ranging from 0.79 in Soweto to 1.66 in Tanzania. Negative attitudes towards PLHA were negatively correlated with HIV prevalence (rho = -0.60, p<0.28). A weaker negative correlation was observed between ARV coverage and negative attitudes towards PLHA (rho = -0.36, p<0.55). The mean perceived discrimination score overall was 1.90 (SD = 0.75) across the five study sites, with Thailand having the lowest mean score (1.32) with the highest score found in Zimbabwe (2.32). A weak positive correlation between HIV prevalence and perceived discrimination scores (rho = 0.30, p<0.62). There was a strong statistically significant negative correlation between perceived discrimination towards PLHA and Arv (rho = -0.87, p<0.05).	

Table 2. HIV- related stigma: Cross-sectional studies among children

REFERENCE	SAMPLE/STUDY DESIGN	METHODOLOGY	OUTCOME MEASURES	RESULTS	REMARKS
1. Rossi, M.M. and Reijer, P. (1995). Prevalence of orphans and their education status in Nkwazi compound – Ndola. Paper presented to the fifth National AIDS Conference, Lusaka, 1995.	Zambia - Nkwazi compound, in Ndola district – 250 households.	Retrospective survey of 250 households selected among 10 sections in the community.	School attendance, living arrangements	Out of the 250 households surveyed, 81 (32 per cent) had orphans, and out of a population of 909 children, 192 (21 per cent) were orphans, of which 22 per cent were double orphans. Of the 149 single orphans, 24 per cent were maternal orphans and 76 per cent were paternal orphans. Out of 140 orphans of school-going age, only 46 per cent were attending school as compared with 56 per cent of non-orphans. Fifty-three (65 per cent) of the guardians of the orphans said that they had added responsibilities owing to the presence of an orphan in the family, with 27 per cent mentioning a lack of money as the problem, 22 per cent as having problems with school fees, 35 per cent mentioning food and 37 per cent mentioning clothes as their main problem. Only 5 per cent of the 81 households with an orphan	The study showed that orphaned children had lower school attendance than non-orphans. The extended family system was also the only system that cared for orphans, and the majority of the carers found difficulties with the added responsibility; the major problems being lack of clothes, money for school fees and food.

				said that they received support from others in the community. Support came mostly from other relatives and the church.	
2. Malaney, P. (2000). The impact of HIV/AIDS on the education sector in Southern Africa. CAER II Discussion Paper No. 81. Cambridge, Massachusetts: Harvard University Center for International Development, Consulting Assistance on Economic Reform II.	Southern Africa	Construction of input-output model, focus group discussions.	None reported	According to the author, "Attendance is affected both directly and indirectly as a result of AIDS-related morbidity and mortality. Children orphaned by the disease will in many cases simply drop out, as they can no longer afford to attend school. In cases where caretaking responsibilities fall on students, absenteeism is likely to increase, and studies have shown that children who are excessively absent from school tend to perform poorly and drop out prematurely. Studies have also shown that the quality of education influences attendance". Using modeling with a lower enrolment for orphans (assumed at 76 per cent), the study projected that the total enrolment rate would decline to 86.7 per cent in 2005 and 85 per cent in 2010. In the study, the gross enrolment rate in Namibia was estimated at 87 per cent in 1999.	
3. Ainsworth, M. and Filmer, D. (2002). Poverty, AIDS and children's schooling: a targeting dilemma. Working Paper No.	28 countries in sub-Saharan Africa, Latin America, the Caribbean and Southeast Asia - **Western Africa**:	Nationally representative samples from 34 Demographic and Health Surveys and five Living	Prevalence of orphans in 28 countries; wealth status of households with orphans;	In all countries, there were more paternal than maternal orphans, and some countries had two or three times as	Large differentials in enrolment by orphan status, but in most cases the

2885. Washington, D.C.: World Bank.	Benin, Burkina Faso, Cameroon, Central African Republic, Chad, Côte d'Ivoire, Ghana, Guinea, Mali, Niger, Nigeria, Senegal and Togo; **Eastern Africa**: Kenya, Madagascar, Tanzania and Uganda; **Southern Africa**: Malawi, Mozambique, South Africa, Zambia and Zimbabwe; **Latin America**: Brazil, Guatemala and Nicaragua; **Caribbean**: Domini-can Republic and Haiti; **Southeast Asia**: Cambodia. *Sample size*: Total sample sizes for children 7-14 ranged from 5,000 to 24,500, but most were about 5,000 to 10,000. *Control group*: Orphans compared with other children in the general population.	Standards Surveys. For asset ownership and housing characteristics: principal components analysis; for wealth status, orphan hood and enrolment status: regressions.	relationship between orphan hood and school enrolment; school gender gap.	many paternal orphans. Only a small percentage of children aged 7-14 were two-parent orphans, ranging from 0.2 per cent in the Dominican Republic to 4.5 per cent in Uganda. In all countries, most single-parent orphans lived with the surviving parent, but in Eastern and Southern Africa, maternal orphans were less likely to live with their fathers than in other countries. Orphans aged 7-14 were less likely to be enrolled in school than non-orphans in 22 of 28 countries, regardless of the overall enrolment level in the country. In Chad, Mali, Niger and Southern Africa, enrolment rates were similar for orphans and non-orphans, but in Nigeria and the United Republic of Tanzania, enrolment rates for orphans were higher than those for children with parents. Twenty-five of 28 countries had large differences in enrolment rates according to the wealth status of the household, but this did not always translate into a disadvantage for orphans. The relationship between orphan status, wealth status and the enrolment gender gap showed no clear pattern across countries of discrimination against female orphans.	gap between children from richer and poorer households was more dominant. The gender enrolment gap was not substantially different from the gap between girls and boys whose parents were living. The enormous diversity across countries underscores the need to assess the specific country situation before considering mitigation measures.

4. Bennel, P.; Hyde, K. and Swainson, N. (2002). The Impact of the HIV/AIDS Epidemic on the Education Sector in Sub-Saharan Africa: A Synthesis of the Findings and Recommendations of Three Country Studies. Brighton, United Kingdom: University of Sussex, Centre for International Education.	Botswana, Malawi and Uganda – total of 41 schools in r countries surveyed.	A range of qualitative and quantitative methods was employed. Extensive interviews of education managers and teachers were conducted. Representatives of ministries, non-governmental organizations and donor organizations were also interviewed.	None reported	The study found that in Botswana, absenteeism rates were relatively low and, in primary schools, that orphans had better attendance records than non-orphans. Strong school culture may explain the very low dropout rates in both primary and secondary schools. The Government has also introduced a comprehensive programme of material support for disadvantaged orphans. On the other hand, in Malawi and Uganda, absentee-ism was very high among all primary school children. The principal causes were mainly poverty-related. While student absenteeism tended to be higher among orphans than non-orphans, the differences were much lower than expected. Illness in the family was not a major reason for absence, except for maternal and double orphans in Uganda. Generally the poorest orphans had the most problems at school.	
5. Murphy, D.A.; Roberts, J.K. and Hoffman, D. (2002). Stigma and ostracism associated with HIV/AIDS: Children carrying the secret of their mothers' HIV+ serostatus. Journal of Child and Family Studies Vol. 11 (2): 191 – 202.	Respondents enlisted from a cohort of 135 mother/child pairs partaking in a PACT (Parents and Children Coping Together) longitudinal study. Mothers were either HIV symptomatic or diagnosed	In-depth qualitative interviews were conducted with mothers and children separately at their home. Interviews were semi-structured which comprised lead questions and probes. Interviews were taped in	Mothers' request for confidentiality, limited disclosure to 'safe' people, rationale for secrecy (privacy, protection of the child, protection of the mother, protection of	77% of mothers warned their child not to disclose their (mother) HIV+ serostatus to others. Of this 95% warned their child in an explicit manner due largely to fear of stigmatization and ostracism for themselves and their	Stigmatization and ostracism from friends and family were the primary reasons given by the mother-child pairs for non-disclosure of the

	with AIDS and had a child between 7 – 14 yrs. of age. Criteria for eligibility: 1) participation in PACT, 2) disclosure of mother's HIV status to child, 3) reconfirmation of disclosure of mother's HIV status, 4) parental consent and child assent. Children were screened to confirm awareness of their mother's HIV status. 47 mothers (mean age 36 yrs., S.D = 5.26; range 24 – 52) with a racial ethnic composition of 50% African American, 21% mixed race; 13% Latina; 8% White; 4% Alaskan/Native American and 4% Asian American participated. 41 children (mean age = 10.47 yrs., S.D. = 1.97) participated, 53% male. During the investigation period all children resided with their mother.	order to be transcribed and analyzed.	others), children's responses to mother's request for confidentiality (maintenance of family privacy, protection of self and mother, compliance with mothers' request for secrecy), child disclosure.	children. 23% of mothers did not warn their children. ¼ of the mothers interviewed identified 'safe' people (close friends, teachers, doctors and therapists) with whom the children could discuss the serostatus of their mother. 87% of children did not disclose their mother's HIV+ status. 5 children disclosed their mother's serostatus. Four of the five children disclosed their mother's status despite explicit warnings.	mothers' HIV+ serostatus.
6. National AIDS Committee (2002). A rapid assessment of the situation of orphans and other children living in households affected by HIV/AIDS in Jamaica. National AIDS Committee.	Jamaica – children, aged 7 – 17 yrs. (*n = 34*, 19 girls and 15 boys; median age 12) and caregivers (*n = 26*)	• Rapid assessment survey of children orphaned by AIDS, children at risk of being orphaned by AIDS, adult caregivers/guardians of children orphaned by AIDS over a 10-day period (May 2002).	Care and support, HIV/AIDS and psycho-social impact.	10 of the children interviewed reported positive changes, 13 reported no change and 8 reported negative changes in their treatment at school or in the community, when asked whether other persons treated them differently since their parents' illness or death. When specifically asked if their experience at school	7 recommendations were made: 1. Drug therapies – universal access to anti-retroviral therapies and drugs. 2. Access to public services

		• Literature review • Inventory of organizational and individual role payers		changed, 6 of the 34 replied 'no'. Several children reported enforced school absence and/or deterioration in their grades. One respondent stated a fall in grades as a result of sexual abuse by their step-father following their mother's death. 5 respondents accounted ill treatment by teachers as well as other students. 5 children broached the subject of HIV/AIDS within their families. 3 of the 34 children, who acknowledged their parents' serostatus, were further questioned to find out if other persons knew and whether or not they were treated differently. Two respondents reported indifferent treatment and one respondent stated their family was more protective and generous towards them. Four of the 26 caregivers interviewed revealed that stigma was the greatest barrier to getting their needs met, 18 caregivers referred to material items or money, a few spoke of friendship, love and assistance with schoolwork, whereas one caregiver mentioned anti-retroviral therapy. Most of the respondents reported that they	3. Stigmatization - HIV/AIDS awareness and behaviour training should be employed. 4. Economic empowerment of caregivers – income-generating activities 5. Psycho-social support/ counseling – training programme should be developed and implemented for adults who work with children. 6. Networking – sharing and documenting of experience and ideas in relation to OVC; referral network should be established to assist in the collaboration and addressing the needs of individual and groups of children.

				were not treated differently because of their association with HIV/AIDS. However most did not reveal their status or the cause of death of the child's parent to anyone.	7. Planning for OVC – establishment of a steering committee to prepare a National Plan of Action for OVC.
7. Bicego, G.; Rutstein, S. and Johnson, K. (2003). Dimensions of the emerging orphan crisis in sub-Saharan Africa. Social Science and Medicine, Vol. 56 (6): 1235 - 1247	17 countries in sub-Saharan Africa Nationally and regionally representative samples. *For the prevalence study*: Benin, Cameroon, Chad, Ghana, Guinea, Kenya, Madagascar, Malawi, Mali, Mozambique, Niger, Nigeria, United Republic of Tanzania, Togo, Uganda, Zambia and Zimbabwe *For the in-depth study*: Ghana, Kenya, Niger, United Republic of Tanzania and Zimbabwe. *Sample size*: Average sample size was from 5,000 to 8,000 households per country. *Control group*: Orphans compared with other children in the general population.	The investigation used recent data from the Demographic and Health Surveys. Univariate and multivariate analysis, logistic regressions.	Level and trend of orphan hood compared with national HIV/AIDS prevalence rate; likelihood of living in female-headed or grandparent-headed household; economic situation of households with orphans; schooling opportunities for orphans.	Maternal orphan prevalence ranged from less than 2.5 per cent in Mali and Niger to more than 4.5 per cent in Malawi, Mozambique, Uganda and Zimbabwe. Paternal orphan hood was higher in every country and ranged from about 4 per cent to more than 8 per cent. The percentage of orphans who had lost both parents was higher in severely impacted countries in East and Southern Africa (10-17 per cent of all orphans) than in West and Central Africa (4-8 per cent). Earlier onset of the disease was associated with higher orphan prevalence. Orphans were much more likely than non-orphans to live in households headed by grandparents—one fourth to one half of orphans compared with 10-20 per cent of non-orphans. In Zimbabwe, 50-55 per cent of orphans lived in households headed by grandparents. Orphans were also more likely than non-	Findings showed a strong correlation between orphan hood prevalence and national adult HIV prevalence estimates, although the relation-ship was affected by the timing of the onset of the disease. Orphans were more likely to live in households headed by females or grandparents than were non-orphans. In general, orphans did not live in poorer households than non-orphans, although this varied across countries. Losing one or both parents was significantly associated with lower educational attainment.

				orphans to live in female-headed households, but the differential varied across countries. Orphans were less likely than non-orphans to be at the proper educational level for age. East African double orphans 6-10 years old were only half as likely as non-orphans to be in the appropriate grade, and double orphans 11 to 14 were two thirds as likely to be in the proper grade	
8. Case, A.; Paxson, C. and Ableidinger, J. (2003). Orphans in Africa. Working paper: Manuscript. Princeton University.	The study used data from 19 Demo-graphic and Health Surveys conducted in 10 countries (Ghana, Kenya, Malawi, Mozambique, Namibia, Niger, Uganda, United Republic of Tanzania, Zambia and Zimbabwe) between 1992 and 2000 to study the living arrangements and school enrolment of orphans and non-orphans in sub-Saharan Africa. The 10 countries accounted for about 50 per cent of the AIDS orphans living in sub-Saharan Africa. *Sample size*: Country samples ranged from 8,339 to 28,888. *Control group*: No; surveys of the general population.	Data from Demo-graphic and Health Surveys Multiple regression analysis	Orphan rates by age of children; living arrangements of orphans (three mutually exclusive groups: maternal orphans, paternal orphans and double orphans) compared with those of non-orphans; household wealth of orphans and non-orphans; school enrolment of orphans.	Roughly 10 per cent of the children in the surveys had lost one or both parents. On average, 2.4 per cent of children were maternal orphans, 5.7 per cent were paternal orphans and 2 per cent were double orphans. In most countries, more children had lost a father than a mother. Children who had lost one parent were less likely than non-orphans to live with the surviving parent in all countries examined, and this disparity was more pronounced in later surveys. In Zambia, for example, only 40 per cent of maternal orphans lived with their fathers, as compared with 74 per cent of non-orphans. Orphans on average lived in poorer households than non-orphans, and paternal orphans were the	Orphans who lived in poorer households than non-orphans and were significantly less likely than non-orphans to be enrolled in school. Poverty did not explain the lower school enrolment, however: orphans were equally less likely to be enrolled in school relative both to non-orphans as a group and to the non-orphans with whom they lived. Outcomes for orphans de-pended largely on how closely related they were to the

				most disadvantaged. In all countries, orphans were more likely to live in house-holds with a higher fraction of elderly persons, with less well-educated heads and with female heads. Orphans of any type were less likely to be in school than non-orphans with whom they lived, and in most countries double orphans were 10 to 30 percentage points less likely to be in school. Lower enrolment was not due solely to orphans' poverty but was explained in part by the relation-ship of the orphan to the head of household. The probability of school enrolment was inversely related to the closeness of the relationship.	household head. Orphans who lived with distant relatives or with non-relatives were less likely than non-orphans to be enrolled in school. There was no evidence that female orphans were systematically disadvantaged.
9. Gertler, P.; Levine, D. and Martinez, S. (2003). The presence and presents of parents: do parents matter for more than their money? Paper presented at the scientific meeting on empirical evidence for the demographic and socio-economic impact of AIDS, hosted by HEARD, Durban, South Africa, 26-28 March 2003.	Indonesia – 312 communities in 13 provinces *Sample size*: 6,185 children in 3,378 households. *Control group*: Survey of the general population; comparisons between orphaned children and others.	Data from the 1993 and 1997 rounds of the Indonesia Family Life Survey (IFLS) were used	Changes in household consumption; school enrolments and dropouts; changes in child health and nutritional status (mortality, height for age, weight for age, weight for height, body mass index, stunting and wasting).	Among children who lost a parent, those with deceased fathers were more likely to drop out of school, whereas those whose mothers had died were less likely to start school. Children in households with higher consumption and children with educated and healthy mothers were more likely to start school than others. Children whose mothers had died were more likely to die than those who had not lost a parent. Paternal death had no effect on children's health, but the	Children who had lost a parent were less likely to be in school and were less healthy than children whose parents had lived. However, the reduction in economic resources measured by the change in household consumption explained only a small portion of the effect of parental

				effect of maternal death was large and statistically significant, especially for measurements related to weight. Bereaved children were generally less healthy than children whose parents had lived.	death. Parental presence in the household is thought to play an important role in investments in child human capital
10. Monasch, R. and Snoad, N. (2003). The situation of orphans in a region affected by HIV/AIDS. Paper presented at the scientific meeting on Empirical Evidence for the Demographic and Socio-economic Impact of AIDS, hosted by the Health Economics and HIV/AIDS Research Division (HEARD), Durban, 26-28 March.	40 countries in sub-Saharan Africa *Sample size:* Samples ranged from 6,200 children in Sao Tome and Principe to 66,345 children in northern Sudan. Average sample size was 18,474 children. *Control group*: Surveys of the general population; comparisons between orphans and other children.	Cross-national comparison of data from nationally representative population-based surveys conducted between 1997 and 2001. Surveys included Multiple Indicator Cluster Surveys (MICS), organized by UNICEF, and Demographic and Health Surveys.	Living arrangements of AIDS orphans and characteristics of households where they live; school attendance, nutritional status and child labour status of AIDS orphans.	The death of parents had significant implications for orphans in terms of households and living arrangements and well-being. Orphans were less likely to attend school than non-orphans, especially in countries with lower overall school attendance. Orphan hood did not seem to be associated with being malnourished in most countries.	
11. Nyamukapa, C.; Gregson, S. and Wambe, M. (2003). Extended family childcare arrangements and orphan education in Eastern Zimbabwe. Paper presented at the scientific meeting on empirical evidence for the demographic and socio-economic impact of AIDS, hosted by HEARD, Durban, South Africa, 26-28 March 2003.	Zimbabwe – Manicaland (Eastern Zimbabwe) *Sample size*: Statistical analysis done for population census of 14,372 children under the age of 15; in-depth interviews conducted with 48 pairs of children and caregivers stratified by gender and current orphan status. *Control group*: Non-orphans were compared with three types of orphans (paternal, maternal and double	Statistical analysis of data on parental survival, household circum-stances and school education from a socio-economic, location-stratified population census; systematic analysis of qualitative data on extended family-care arrangements and children's education from in-depth interviews with a purposive sample of children and caregivers, government and non-governmental organization representatives and community leaders.	Family-care arrangements for orphans and non-orphans; primary-school completion rates for orphans and non-orphans.	The average age of all types of orphans was two to three years higher than non-orphans, and orphans were found disproportionately (relative to adult HIV prevalence) in rural business centers and subsistence farming areas. Children who had lost their mothers were less likely to have completed primary school than were non-orphans and children who had lost their fathers. Orphan-care arrangements vary considerably in Zimbabwe but still take as a common model	Despite their being overrepresented in poor households, paternal orphans were no less likely to have completed primary school than non-orphans of the same age. However, fewer maternal orphans had completed primary school. The evidence suggested that extended family and external

	orphans).			an extended-family childcare system. However, this system is being eroded by socio-economic change and high HIV-related adult mortality.	support was greater for widow-headed households than for widower-headed households, and that widowed mothers gave higher priority to their children's education than did widowed fathers. Extended-family care for orphans was found to be under stress as the number of orphans continued to increase, and the results suggested that programmes to support extended-family care should be strengthened, especially in the rural communities where families typically bring up orphans.
12. Suliman, E.D. (2003). HIV/AIDS effects on AIDS orphans in Tanzania. Working paper. Baltimore, Maryland: Johns Hopkins University.	United Republic of Tanzania *Sample size*: A total of 5,184 households in the United Republic of Tanzania (Mainland Tanzania and Zanzibar) from the Tanzania Human Re-source Development Survey (HRDS); 8,327	Modified life-table approach for estimates of AIDS orphans; logistic regression models on the effects of orphan hood on schooling participation.	Validation of estimates of the number of AIDS orphans in the United Republic of Tanzania; orphan versus non-orphan differences in child labour (work for pay, unpaid family work and help with household chores) and child schooling	Single-parent orphans were twice as likely as non-orphans to have ever worked for pay, and dual orphans were more than ten times as likely to have worked for pay. Orphans were significantly less likely to attend school (orphan hood lowered the odds of attending school by 45 to 64 per cent) and were more likely to drop	Orphans were found to have school participation rates an average of 4 percentage points lower than those of non-orphans and rates of participation in paid labour an average of 9

	households from the 1992 Tanzania Demographic and Health Survey; and 3,615 households from the 1999 Tanzania DHS. *Control group*: Surveys of the general population; comparisons between orphans and other children.		(enrolment rates and drop-out rates); and projections of the effect of orphan hood on future labour markets in the United Republic of Tanzania.	out as compared with non-orphans. Orphans were also more likely to work while attending school than non-orphans. The 1999 DHS data showed school attendance rates 5-10 percentage points lower for orphans than non-orphans and participation rates in paid work 5-10 percentage points higher for orphans.	percent-age points higher. As orphans enter the labour force, they will be less well educated than non-orphans and are likely to be less productive. The large number of orphans will reduce the pool of qualified candidates for jobs in the Government and in the private sector.
13. Abadía – Barrero, C.E. and Castro, A. (2006). Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil. Social Science and Medicine (62): 1219 – 1228.	Life trajectories of 50 children and adolescents (aged 1 – 15 yrs.) living with HIV and/or orphaned by AIDS residing in support housing were studied during a 20 month period (1999 – 2001).	Standard ethnographic methodologies consisting of participant observation and semi-structured informal interviews.	Ethnographic data of personal accounts and social interaction. Interplay between individual experiences, social inequality and power differentials in relation to stigma.	AIDS-related stigma occurred within complex discrimination processes – cultural practices, structural inequality and power differentials which act in synchronicity rather than isolation – that changed when children become adolescents. Structural violence (racism, poverty, inequality in gender and age) fuels stigma related experiences in children. In contrast, access to HAART reduced stigma in Brazil by: 1) reverting the logic of interpretation of the disease by transforming AIDS from fatal and incurable to chronic and manageable, 2) the accessibility to HAART in conjunction with Brazil's AIDS public health policy guarantees the rights of those	Structural violence proposed as the framework for stigma – related studies. Interventions to reduce stigma which target only the attitudes and discrimination towards persons living with HIV are limited.

				persons living with AIDS, and 3) the redressing of structural forces that impede health care in poor communities.	
14. Gray, G.E.; Van Niekerk, R.V.; Struthers, H.; Violari, A.; Martinson, N.; McIntyre, J. and Naidu, V. (2006). The effects of adult morbidity and mortality on household welfare and the well-being of children in Soweto. Vulnerable Children and Youth Studies 1 (1): 15 – 28.	Africa (Soweto) – A total of 4,912 households: 4,501 households with children and 411 households with no children (<16 yrs. of age). Total number of individuals surveyed 22, 724. Study conducted May – June 2002. Respondents were caregivers or heads of the household.	Prospective cross-sectional household survey. Sample design was a stratified, two-stage cluster sample from 226 enumerator areas (EA). The sample was stratified non-proportionally into five strata (council houses, private-sector houses, backyard dwellings, informal settlement houses, hostels) according to accommodation type and reflected economic status.	Living conditions, adult and child health, effect of adult illness on child welfare, impact of adult illness on children, sick children in households, impact of deceased parent(s) on children, child-headed households.	44% of all households were classified as 'sick' households (at least one sick adult present). 22% of all adults were categorized as sick, 12% had HIV/AIDS-related illness or tuberculosis in the past month. . 11% of children lost a parent. In sick households, child health was adversely affected (increased vulnerability to disease, $p<0.0001$; incomplete immunizations, $p = 0.02$). Children from sick households were less likely to have their school fees paid ($p = 0.0001$) because there was no money to pay school fees; were more likely to be absent from school ($p<0.0001$); be unsupervised while doing homework ($p = 0.01$) and go hungry ($p<0.0001$). Abuse occurred more frequently in sick households ($p<0.0001$). Children with deceased parents were more likely to have had HIV/AIDS related symptoms or be HIV infected ($p = 0.002$), go hungry ($p<0.0001$) and face abuse ($p = 0.03$). Children with deceased parent(s) were less likely to be enrolled at school	The frequency of adult sickness in the household has an impact on the health, education and welfare of the household and the well-being of children. HIV testing, access to antiretroviral therapy, comprehensive care and support for people living is required to help alleviate these effects.

				because of lack of money to pay school fees (t = -3.3). Once enrolled and at school, there was no difference noted in absenteeism or being behind in the payment of school fees. Over 90% of children were enrolled at school whether or not their parents were alive. The main reasons for children not being enrolled were either they were too young or had no money for school fees.	
15. Hamra, M.; Ross, M.W.; Orrs, M. and D'Agostino, A. (2006). Relationship between expressed HIV/AIDS-related stigma and HIV-beliefs/knowledge and behaviour in families of HIV infected children in Kenya. Tropical Medicine and International Health, Vol.11 (4):513-527.	Representative sample of households served by the Lea Toto Kangemi Outreach Program, Nairobi Kenya was selected, from all six program areas (Ruthimitu, Riruta, Kawangware, Waithaka, Mutuini and Kangemi). Target groups of the program were HIV+ children and their caretakers. Some of the children were double orphans (25%). The number of individual respondents was 873 from 180 households.	Household survey – A stigma index and indices (6-point stigma scale) was created for social and knowledge domains that influence HIV related healthcare. X^2 (chi-squared), ANOVA and correlations were used to identify association between domains.	Practicing risk reduction, attitudes or behaviour towards HIV testing, attitudes or behaviour towards PLWAs, general AIDS knowledge and overestimation of risk.	Mean (±S.D.) expressed stigma score was 3.65±1.64. Adolescents (12-20 y) had significantly lower expressed stigma than any other age group; No significant gender differences were found. Composite AIDS knowledge scores were skewed toward more knowledge. Mean (±S.D.) general knowledge scores (n = *303*) were 15.38±2.65. Respondents with more general AIDS knowledge had significantly less expressed stigma. Personal acquaintance with PLWAs was associated with less expressed stigma (P = 0.003).	Associations between stigma and other domains can inform interventions that improve HIV care and mitigate the spread of HIV.
16. Badock-Walters, P.; Mallouris, C. and Boler, T. (2008). Supporting the educational needs of HIV	Respondents from Tanzania (n = *80*) and Namibia (n = *76*), residing in urban and rural areas. Respondents	• Desk Review • Semi-structured interviews and focus	None reported	Similar findings discovered from both Namibia and Tanzania. The negative consequences of disclosure of	Increase in the provision of school counselors to support at risk

positive learners: lessons from Tanzania and Namibia. http://www.unesco.org/aids (ED/UNP/HIV/IAC2008/POSTER/10) - July 9, 2009	include children, young people, teachers, ministry officials and NGO representatives.	group discussions		a HIV+ serostatus were viewed to be far greater than the positive benefits by young persons. The responses by teachers' to disclosure are individual, with some providing extra support whilst others isolate the student. Children in rural areas appeared to suffer more than those residing in urban areas due to less available services, increased poverty and more difficulty in hiding their HIV status. Children with a HIV+ serostatus do not see the benefit of status disclosure and mention high levels of stigma and discrimination in the classroom. Ministries of Education do not address the issue because it is secreted. HIV and AIDS worsen existing problems in education. It proves difficult to meet the needs of learners in general and in particular HIV+ learners within the education sector.	children. A zero tolerance approach should be exercised towards HIV-related stigma and discrimination in schools whilst tolerance and inclusion should be promoted. The introduction of a compulsory module on HIV and AIDS into pre- and in-service teacher training courses.

Table 3. HIV-related stigma: Reviews

REFERENCE	SAMPLE/STUDY DESIGN	METHODOLOGY	OUTCOME MEASURES	RESULTS	REMARKS
1. Shaeffer, S. (1994). The impact of HIV/AIDS on education: a review of literature and experience. UNESCO Programme of Education for the prevention of AIDS. (http://portal.unesco.org/en/file_download.php/88b0375c67aaa2c21fcd60cbd62190c0impactoneducation.pdf) – July 9, 2009	None reported	Literature review	Impact on the effectiveness of education: the delivery of messages about AIDS; Impact of HIV/AIDS on demand, supply and process; Impact on the education system: how it responds to HIV/AIDS; Implications of the impact of HIV/AIDS for training, research and donor programming	Owing to HIV/AIDS there will be relatively less children needing education. Fewer children will be born because of the early death of one or both parents Additionally children affected perinatally will die before the age of admission into school. The decrease is already evident in some areas such as the Rakai district of Uganda, with a drop in enrolment from 1,534 children in 1989 to 950 in 1993. There may also be relatively fewer children wanting an education or fewer parents wanting their children to be educated due to an unwillingness of parents investing in their children's education. The higher probability of the death of an educated child leads to a lower return on educational investment. Fewer children and their families are able to afford an education owing to the household's budget constraints resulting from either:	Appropriate and effective preventive AIDS education programs should be developed by Ministries of Education. Training of educational managers and planners must be changed. More research investigated on the impact of HIV and AIDS at the micro and macro level on the developmental process and education sector. The establishment of policies in relation to AIDS in the donor work-place and in regard to issues such as the examination of candidates for donor-funded scholarships in the donor country

				1. The illness or death of productive members of the family. 2. The loss of income due to expenditures on treatments, care and funeral costs. 3. The expansion of extended families. 4. The loss of the traditional economic safety net. Disinterest in school may arise from the increased randomness of education provided resulting from increased absenteeism of teachers and pupils as a result of HIV and AIDS which will make the education provided irregular and random. Fewer children are able to complete their school education either due to financial constraints or other factors which include: 1. Illness in school – Due to the debilitating episodes of HIV-related illness, school completion will prove difficult in HIV-infected children. Additionally illness may affect enrollment at higher levels of the school system. 2. Need for children to	

				work and care for ill adults – Regular or cyclic absenteeism may result from children substituting their labour for other family members that have died or are ill. 3. Trauma related to the illness or death of family members – difficulty concentrating in class 4. Stigma, discrimination and ostracism – from fellow school mates. 5. Low school motivation from extended family. 6. Uprooting from family and community through forced migration or orphan hood. 7. Early marriage of girls who then drop out of school Studies also show that, in the United Republic of Tanzania, some 14,460 teachers will die by 2010 and 27,000 teachers by 2020. The study estimates that the approximate cost of training re-placement teachers will be $37.8 million. In Uganda, between 1993 and 1996, it was estimated that 2,200 teachers were suffering or dying from AIDS, with a replacement cost of 1.1 billion Uganda shillings or $1 million.	

				The net result of the various kinds of impacts on the demand, supply and process of education may be a loss of both financial and human re-sources (and thus the quantity of education) and of efficiency and effectiveness (and thus the quality of education).	
2. Foster, G. and Williamson, J. (2000). A review of literature of the impact of HIV/AIDS on children in sub-Saharan Africa. AIDS, 14 (suppl. 3): S275 – S284.	Children in sub-Saharan Africa	Literature Review	Epidemiological characteristics of children affected by HIV/AIDS, coping mechanisms, current knowledge of the impact of HIV on children.	The impact of HIV/AIDS on children and families is compounded by the fact that many families live in disadvantaged communities and there is limited access to basic services. Coping strategies have negative impacts on children in households indirectly affected by HIV/AIDS. When a parent develops symptoms related to HIV, children oftentimes take on new responsibilities. When a parent becomes ill, children's school attendance drops because labour is needed to pay medical expenses or because families cannot afford to pay school fees. Adults make decisions that children should drop out of school to provide care for sick relatives or siblings. The amount of work	Long term solutions will need to be crafted for these children because the impact of HIV/AIDS will linger for decades even after the epidemic diminishes. Research is needed that assess the impacts that caring has on children, the needs of children as caregivers and the ways in which school interruptions can be reduced. Further research is needed to determine whether maintaining or re-establishing orphans' education has social, economic or psychological

				performed by children affected by HIV/AIDS begins when a parent becomes sick and increases when children become orphaned. The workload of orphans may be greater than non-orphans residing in the same household. Increased domestic workload is disproportionately greater on girls than boys. Studies have shown that in Uganda, there is evidence of the impact of orphanhood on children's school attendance. Strain on finances had led to households with orphans being unable to send their children to school. Older girl children usually take over household and care giving chores thereby disrupting their education when parents become sick. Among children aged 15 – 19 yrs, in Uganda, whose parents had died, 29% continued school, 25% missed out on school whilst 45% dropped out of school. Those children with the greatest probability of continuing their education were those who lived with a surviving parent; those who were taken care of by grandparents had the least chance. Studies from other countries showed significantly less enrolment rates in orphans	benefits to children and their households. Long-term studies should be set up to observe the mental health of children who have experienced multiple bereavement.

				than non-orphans and several risk factors were identified namely girl orphans, children orphaned by AIDS, rural or poor households in addition to orphans residing in households headed by men. Dropping out of school, stigmatization, increased workload, discrimination and social isolation of orphans increase the stress and trauma of parental death. Stigmatization may be associated with adverse mental health. In Zimbabwe, orphan stigmatization was a common occurrence and was primarily based on orphan status or poverty rather than HIV/AIDS association. A study in Zambia showed that 82% of caregivers noted behavioural changes in children during a parent's illness. Children became sad, worried and stopped playing. Changes in self-esteem were observed but not in sociability. Internalized behavioural changes were exhibited by orphans rather then sociopathic behaviour.	
3. Kelly, M.J. (2000). The encounter between HIV/AIDS and education. Lusaka: University of Zambia.	Zambia - National	Estimation and projection of the school-age population, Literature review	None reported	The study found that HIV/AIDS is affecting pupils, teachers and the curriculum con-tent in Zambia. It is also affecting the organization, management and planning of	In the face of the epidemic, education can generate hope owing to its potential to work at

				education and resources for education. It is slowly leading to questions about the very nature, purpose and provision of education. Many of the potential impacts that are outlined are already destroying the system. It is only when civil and public society comes to grip with the potential and actual extent of those HIV/AIDS impacts that appropriate actions will be taken to respond to, and possibly even control, the situation. A study conducted in two high-density areas in Lusaka found that of 1,359 children aged 18 and below, two thirds (67 per cent) had lost one or both parents. Seven per cent of them dropped out of school in the twelve months prior to the study as compared with an overall drop-out rate of 1.4 per cent in Lusaka the same year.	different levels where AIDS-related interventions are needed.
4. Parker, R. and Aggleton, P. (2002). HIV/AIDS related stigma and discrimination: A conceptual framework and an agenda for action. Horizons Program. (http://gametlibrary.worldbank.org/FILES/300_What%20have%20we%20learned%20about%20reducing%20stigma.pdf – July	Analysis of stigma and discrimination (S&D) sources, the manifestation of HIV/AIDS related S&D, contexts wherein HIV/AIDS related S&D takes place. Research and intervention agenda identification. Limitations of current	Develop a conceptual framework that defines stigma and discrimination as social processes used to create and maintain social control as well as to produce and reproduce structural inequalities.	Sexuality, gender, race & ethnicity, class, fear of contagion and disease. Policy and legal contexts, institutional contexts (education and schools; employment and the workplace; health care systems; HIV/AIDS programs; religious	The interaction between HIV/AIDS related S&D and the re-enforcement of pre-existing S&D notions associated with sexuality, gender, race and poverty must be acknowledged. The development of such a framework suggests new approaches to research which includes exploratory studies	If S&D are the consequences of social rather than individual processes, challenging S&D requires social rather than individual action I order to change the context within

02,2009)	thinking in relation to S&D highlighted.		institutions), community contexts, family contexts, individual contexts. Exploratory and hypothesis-generating research, investigative research, strategy and policy oriented research. Environmental and structural change.	aimed at identifying and assessing concepts that take into consideration the social, cultural, political and economic determinants of S&D; investigative studies which explore these processes in a range of contexts; and strategic and policy-oriented studies to inform implementation of effective responses. Additionally the development of such a framework indicate new approaches to program development and intervention that engage communities, societies and those who experience S&D.	which individuals and communities react to HIV/AIDS.
5. Burkina Faso. National Committee to Combat HIV/AIDS and Sexually Transmitted Infections (2003). The impact of HIV/AIDS on the social sectors: the case of health care and education. Paper presented at the scientific meeting on empirical evidence for the demographic and socio-economic impact of AIDS, hosted by HEARD, Durban, South Africa, 26-28 March 2003.	Burkina Faso – education and sectors	Literature review. Analyses were carried out using data available from the health and education sectors and assuming different scenarios about HIV/AIDS prevalence rates. Results of qualitative studies were also considered.	Impact of HIV/AIDS on demand for and cost of health care; impact on quality of health care; impact on children who lost parents to HIV/AIDS; impact on quantity and quality of educational services and on demand for education.	HIV/AIDS has already had major impacts on social sectors. In the health sector, 30 to 50 per cent of the hospital beds in Burkina Faso are monopolized by patients living with HIV/AIDS, and the increase in the demand for care was projected at 30 per cent by UNDP in 2000. The increase in resources allocated to HIV/AIDS treatment has resulted in fewer re-sources available to combat other scourges, such as malaria, malnutrition and tuberculosis. Fear of contracting the HIV virus on the part of health workers has led to a decline in the quality of care. In the	

				education sector, the national goal of universal primary education has stagnated at about 30 per cent of eligible children. Girls constitute only about one third of the student population. Orphans are 50 per cent less likely to receive an education if a parent has died of AIDS and 90 per cent less likely if both parents died of the disease.	
6. Okafor, C.B. and Holder, B. (2005). HIV/AIDS related stigma in Sub-Saharan Africa: context and consequences. Journal of Development Alternatives and Area Studies. Vol. 24 (3 - 4): 131 – 152.	None reported	Review of Literature	HIV-related stigma, background and significance, conceptual framework, individual factors, community factors, interpersonal, policy factors, family factors, intervention.	The effects of stigma and discrimination against persons with HIV/AIDS play a key role in emotional stress. Stigma and discrimination is an important part of the HIV/AIDS pandemic, and is referred to as a second epidemic. The stigma of HIV/AIDS has a wider scope and a greater impact than the virus because it affects the victim's lives and the lives of their family. Stigma related to HIV is a major hindrance in all aspects of the management of the disease. The intense fear of stigmatization undermines the ability of families and communities into provide support and care of infected persons. Additionally, it undermines preventative and treatment efforts, as persons are reluctant to be screened or to reveal their positive serostatus to a family member.	A pre-requisite for effective participation in HIV/AIDS prevention and care require a mobilized, community equipped with sufficient information and other vital skills needed for action. Stigma is influenced by individual, interpersonal, institutional, family, community and public policy factors. Capacity building is needed at all these levels of influence in the community. Stigma and

				Three types of stigma are distinguished: 1. Body hatred. 2. Flaw of individual's character 3. Association with a reviled social group. The common reactions in the aforementioned conditions are concealment, denial, irony or defiance. Placement of blame on specific groups or individuals, allow society to validate a non-challenge attitude, and denial of care and responsibility to those affected. Stigma among African Americans in the United States focused on AIDS as a disease that threatened the black community, whereas stigma among whites reflected attitudes toward the social groups primarily affected by the epidemic. Stigma is viewed as a disgraceful and influential societal label that changes how individuals view themselves and are viewed. Stigmatized persons are thought of as deviants who brought themselves shame and as a consequence are shunned, rejected, penalized or discredited. Stigmatization creates differences and	discrimination help to sustain a high incidence rate in the society. Fear of stigma attached to the infection makes it difficult for individuals to be honest about their serostatus. Because the stigma attached to individuals living with HIV/AIDS is derived in the community, this contributes to the suffering of infected persons in a variety of ways, and it may impede appropriate help-seeking efforts, or may make persons terminate treatment.

				contributes in transforming and sustaining these differences. Several community factors aid in HIV/AIDS stigma creation. The created stigma subsequently sustains the community factors that created stigma initially. Community intervention focuses on several key factors at the individual, family and community level which include cultural, governmental, environmental, and organizational policies that influence community behaviour. In a phenomenological study conducted in Eastern Nigeria of PLWHA, a respondent described her experience being worst than leprosy along with feelings of guilt, shame and disgrace. Concern was expressed towards the respondent's sisters stating that they may never marry and the community on a whole would feel betrayed and disgraced by the respondent's illness. Beliefs that contribute to stigma at the community level include AIDS being contagion, 'witch craft', sexual deviance, sin and promiscuity. Self-perceived stigma may be	

				responsible for diminished self esteem that arise from actual interaction and occurs whether or not the perceived stigma accurately reflects the views of others or not. Self-perceived stigma occurs when beliefs, attitudes and behaviour patterns are adopted that isolate them (PLWHA) from society. Individual factors that influence self-perceived stigma include gender, social class, knowledge, self-esteem and behaviour. Expression of HIV/AIDS – related stigma at the individual level depends on family ties, family strength and social support available to the family. Fear of stigma may cause an individual to play into it where strong stigmatizing behaviour and attitude exists within a family. Fear of stigmatization and discrimination by members of the community has as its consequences refusal of serostatus disclosure in addition to failure to participate in life saving treatments. HIV/AIDs related stigma oftentimes groups the family, friends and affected persons together. The phenomena of secondary stigmatization	

				contributes immensely to public isolation of those related to or are friends with infected persons, including children who may be kept out of school because a family member's illness. Studies have shown negative consequences associated with HIV+ serostatus disclosure. PLWHA and those individuals suspected of having HIV/AIDS have been removed from their home by family members, divorced by spouses and have experienced physical violence and in some cases death. Individuals infected with HIV/AIDS may oftentimes experience stigma in the home and women are more frequently targeted than men or children. Discriminatory and negative attitudes that target women living with HIV/AIDS include blame, rejection, loss of children and home. Discriminatory and stigmatizing policy measures observed in several African countries included, required screening and testing, enforced case notification, isolation, restriction of the right to anonymity, segregation from public events including schools and	

				prohibition from certain occupations. Children with HIV/AIDS or whose family member is infected have been stigmatized and discriminated against in several countries. An investigation conducted in Nigeria revealed that 76% of the teachers interviewed at an elementary school reported that they would not admit a HIV+ child into the class with other children. Stigma and discrimination is derived across different elements of the society and therefore any proposed intervention has to take a multi-level approach and has to be mainstreamed into all community organizations. Health promotion models are effective in influencing behavioural change at the individual level. Skill development in 5 key areas are essential for community intervention: 1. Community organization skills. 2. Data collection skills. 3. Establishment of priorities and objectives. 4. Intervention planning. 5. Evaluation of project outcome.	

7. Heijnders, M. and Van Der Miej, S. (2006). The fight against stigma: An overview of stigma reduction strategies and interventions. Psychology, Health and Medicine 11 (3): 353 – 363.	References identified using Pubmed, PsychInfo and ScienceDirect (online databases). Main keywords used were 'interventions', 'stigma' and one of the five listed specific health related fields (leprosy, HIV/AIDS, mental illness, TB and epilepsy). References were reviewed from significant/important papers and searches conducted using similar keywords. Articles were included in the investigation if a detailed description of an intervention was given. The investigation was limited to English and Dutch documents published in peer-reviewed journals after 1990.	Literature review conducted to identify prior work carried out as it relates to stigma-reduction strategies and interventions. Strategies and interventions identified were grouped according to the levels of the social ecological framework proposed by McLeroy *et al.* (1988).	Strategies to reduce stigma and discrimination: Intrapersonal level (treatment, counseling, cognitive-behavioural therapy, empowerment, group counseling, self-help, advocacy, support groups). Interpersonal level (care & support, home care teams, community-based rehabilitation). Organizational/Institutional level (training programmes, new policies). Community level (education, contact, advocacy, protest). Structural/Government level (legal & policy interventions, rights-based approaches).	To reduce discrimination and stigmatization significantly, single-target and single-level group procedures are not sufficient. A patient-centered approach is needed which begins with interventions that target the intrapersonal level and the execution of programmes targeted at reducing stigma.	
8. UNICEF (2006). Executive Summary, Africa's orphaned and vulnerable generations: Children affected by AIDS.	Children in sub-Saharan Africa	Executive Summary	None reported	AIDS epidemic places children at risk (emotionally, physically and economically). Children may be directly or indirectly affected when their communities are strained by the outcomes of the epidemic. Teachers and other health care professionals can become ill or die from AIDS, consequently affecting education and health care. Children may be required to	Repercussions of the HIV/AIDS epidemic of OVC in sub-Saharan Africa are grim but international agencies, governments, community groups and non-governmental organizations can change the course

				put on hold their education and take on new household and care giving responsibilities as well as work. Furthermore they may be subject to stigma and discrimination because of their relationship with an individual infected with HIV/AIDS. Children can become either single or double orphans to HIV/AIDS-related illness. Children have experienced the greatest parental loss in southern Africa (HIV prevalence rates highest). The experiences of orphaned and vulnerable children (OVC) considerably differ across families, communities and countries. Several studies have shown that OVC are at elevated risk of school absenteeism, suffer anxiety and depression, reside in households with less food security, and are at increased risk of HIV exposure. This is influenced by several factors namely child-caregiver relationship, household and community wealth in addition to prevalence of HIV in the community. Some studies have observed that the closer children stay to their biological family, the more likely they were to be properly	of the response. Challenges can be dealt with by providing caregivers, families and communities with support. Equal access to health and education as well as foster care, entails commitment and intervention from governments. In order to employ a suitable response at the required level, ample knowledge is needed to comprehend the situation of children affected by AIDS. Regardless of the meticulous study of the conditions of OVC in this region, and more efficient data collection, the knowledge base on the status of these children still needs to be developed and reinforced. Attempts to assess programme effectiveness that

				cared for and the greater the likelihood that they will attend school steadily irrespective of poverty level. Within a household, the relationship between the caregiver and the child strongly influences the outcome for the child.	support OVC and their families need to be improved. Advanced research must be interpreted into better responses at scale, and regular monitoring systems should be established to ensure that the needs of the children are met. Accelerating confirmed prevention measures for children and adults will lessen the future numbers of OVC.
9. Brown, L.; Trujillo, L. and Macintyre, K. (2001). Interventions to reduce HIV/AIDS stigma: What have we learned? Horizons Program.) (http://gametlibrary.worldbank.org/FILES/300_What%20have%20we%20learned%20about%20reducing%20stigma.pdf – accessed July 2, 2009.)	The studies below were reviewed by Brown et al. who demonstrated that stigma can be reduced, at least in the short term and on a small scale, through a variety of intervention strategies (counseling, information, contact and coping skills acquisition). Addressing the complexity of stigma is important in designing AIDS stigma interventions.				
Bean, J. *et al*. (1989). Methods for the reduction of AIDS social anxiety and social stigma. AIDS Education and Prevention 1(3): 194-221, Fall.	U.S. Psychology students/volunteers, *n = 58*	Randomized one-way fixed effects design with one control and three experimental groups. Posttest.	*Coping skill acquisition*: Experimenter-guided imagery, three variations tested - Mater imagery.	The three levels of imagery reduced AIDS anxiety and increased altruism as compared to control, but no differential effects between treatment groups.	

			- Empathy instruction. - Implosion (coping skills for anxiety)		
	U.S. Psychology students/volunteers, *n = 53*	Randomized three way fixed-effects experimental design with one control, two experimental groups, one stratified by subject gender, the other stratified by subject and experimenter gender.	*Coping skill acquisition:* Improvisational vs. controlled role play.	Improvisational group reported more positive attitude toward PLHA, higher scores on granting rights to PLHA. Intervention did not reduce measured fear. Experimenters with same sex subjects had stronger role play effects than with the opposite sex.	
	U.S. Psychology students/volunteers, *n = 192*	Randomized two-way fixed effects experimental design stratified by gender. One control and five treatment groups.	*Information, counseling, contact*: Combinations of AIDS/unsafe behavior facts, social contact, case studies, AIDS psychology, factual presentation with brief group Desensitization.	All treatment groups had higher knowledge scores and lower anxiety scores as compared to control group. The group that had brief desensitization showed lower score for social restriction of PLHA.	
Perry, S. *et al.* (1991). Effectiveness of psycho educational interventions in reducing emotional distress after human immunodeficiency virus antibody testing. Archives of General Psychiatry 48: 143-147.	U.S. - Asymptomatic at-risk adults testing for HIV *n = 307*	Randomized longitudinal design, no control, and three experimental groups. Pretest before HIV testing and posttest at three months.	*Information, counseling:* Standard post-HIV test counseling, a three session interactive video, or 6 one hour stress prevention programs (SPT).	Seronegative subjects' distress level decreased for all groups. No differential treatment effects. Seropositive subjects in SPT group had reduced distress as compared to other two groups. Distress levels did not increase for other two groups.	
Held, S.L. (1992). The effects of an AIDS education program on the knowledge and attitudes of a physical therapy class. Physical Therapy March 73(3): 156-64.	US Physical therapy Students, Convenience sample, *n = 103*	Randomized experimental design, one control, one experimental group. Posttest at one week	*Information, counseling, coping skill acquisition:* Four hour educational unit: factual information, resolving negative feelings.	Increased HIV/AIDS knowledge, increase in positive attitudes toward PLHA, increase in willingness to treat PLHA.	
Soskolne, V. *et al*. (1993).	Israel, Adult immigrants,	Randomly selected sample	*Information:* Thirty	Those who attended the	

Immigrants from a Developing Country in a Western Society: Evaluation of an HIV education program. Presented at the International Conference on AIDS, Berlin, Germany, 6-11 June, 9(2): 777.	PLHA, community, *n = 300*	for three month post-education test.	community members trained to act both as health educators and cultural mediators, lectures with posters, audio cassettes and leaflets with positive messages stressed. Used questionnaire, but no measurement details provided.	educational sessions given by the 30 trained community members had less misperceptions, better knowledge of modes of prevention, and more positive attitudes toward PLHA and toward condom use	
Ashworth, C.S. *et al.*, (1994). An experimental evaluation of an AIDS education intervention for WIC mothers. AIDS Education Prevention April 6(2): 154-62.	U.S./ Georgia, WIC Mothers (95% black), *n = 217*	Randomized experimental design with control and two experimental groups; pre- and posttest, and second posttest at two months.	*Information:* Videotape on AIDS (about 15 minutes); black nurse educator individually presented AIDS information. Measured by belief that PLHA should be isolated.	Both experimental groups showed higher tolerance for PLHA as compared to controls at first posttest, these effects did not differ across treatments. At second posttest all three groups the same.	
Kerry, K. and Margie C. (1996). Cost effective AIDS awareness program on commercial farms in Zimbabwe. Presented at the International Conference on AIDS, Vancouver, Canada, 7-12 July, 11(1): 45.	Zimbabwe/ Harare Commercial farmers and employees, communities, *n* not known	No details provided.	*Information, peer education:* Work-based peer education using individual communication, group meetings and workshops. IEC consisted of videos, drama, AIDS literature, and free condoms.	Reports a decline in stigma as evidenced by more open discussion. Also high levels of AIDS awareness, higher acceptance of condoms, and movement toward self-help and home care.	
Kiguli, A.R. (1996). Community initiatives against HIV, care for PWA and care for AIDS affected ones: a multicultural response. Presented at the International Conference on AIDS, Vancouver, Canada, 7-12 July, 11(2): 472.	Uganda/Kampala, (TASO), Community, *n* not known	No details provided.	*Coping skill acquisition, counseling:* Community planning and evaluation system. Through local leaders and assessment of the effect of AIDS. Test of shared	Reports stigma dying away, people are changing their sexual behavior and how to negotiate safer sex.	

			confidentiality, improved home care.		
Kikonyogo, N. *et al*. (1996). Sharing HIV/AIDS education in the communities: A Kampala traditional healer's experience. Presented at the International Conference on AIDS, Vancouver, Canada, 7-12 July, 11(2): 339.	Uganda/Kampala, Community, *n* not known	Implies a one-year follow up or measure of some sort but details not provided	*Information, counseling:* THECA group was started to be community educators for AIDS knowledge, attitudes and practices. Community education and counseling, targeting youth and women.	Reports change in community knowledge, attitudes and practices, higher trust and attendance at clinic, condom demand is up, PLHA getting better family care and report safer sex.	
Nansubuga, A.; Aneko F. and Kirega, L. (1996). Initiated Psycho-social Care by Informal Networking of PWAS. Presented at the International Conference on AIDS, Vancouver, Canada, 7-12 July, 11(1): 242.	Uganda/Gulu, Community, *n* not known	No information provided	*Contact, counseling:* Self help community intervention to bring PLHA together for support, education for communities and upholding PLHA morale. No measurement details provided.	Reports that communities have developed a positive attitude toward PLHA. Reduced social distance between PLHA and community.	
Venkataraman, R. *et al*. (1996). Using Docu-drama Films on Life Stories of PLWHAs as Media Strategy to Change Attitudes. Presented at the International Conference on AIDS, Vancouver, Canada, 7-12 July, 11(1): 46.	India, National, community, *n* not known	Focus groups conducted to test efficacy of intervention as a means of reducing isolation. No other design information provided.	*Information, contact (vicarious):* Mass media IEC campaign to foster acceptance of PLHA and to normalize HIV; a PLHA's life was turned into a 28-minute documentary video and telecast on National TV, volunteers and general public from various communities participated.	Focus groups report that this media effort increases acceptance and decreases stigma. Volunteers more willing to work in AIDS field, CBOs and NGOs willing to work with PLHA and use docu-dramas, policy makers sensitized.	
Wyness, M.A.; Goldstone, I. and Trussler, T. (1996). Outcomes of	Canada, Nursing students, *n* not known	Focus groups done at end of course and telephone	*Information, contact, coping skill acquisition:*	Students reexamined their attitudes, stigmas, and fears	

an undergraduate HIV/AIDS nursing elective: Insightful learning to promote quality care. Presented at the International Conference on AIDS, Vancouver, Canada, 7-12 July, 11(1): 21.		interviews at six months.	An HIV/AIDS elective class for undergraduate students taught by health professionals involved in HIV/AIDS prevention and care and PLHA.	about PLHA when taught by HIV/AIDS health professionals and PLHA. Small group teaching, in a climate that promotes reflection and sharing of thoughts and feeling, is essential	
Batson, C.D. *et al.* (1997). Empathy and attitudes: Can feeling for a member of a stigmatized group improve feelings toward the group? Journal of Personality and Social Psychology 72: 105-118.	U.S./Kansas Young women in Introductory psychology course , *n = 96*	Randomized-block 2 x 2 x 2 factorial design, pre-/posttest (12 per group).	*Contact*: Mock pilot radio broadcast testimonial of female PLHA with different acquisitions of HIV (blood transfusion and sexual behavior). Measured empathic feelings (tested high versus low empathy) for the PLHA and attitudes toward PLHA.	Empathy scores higher in high empathy group than in low; higher empathy for victim-not-responsible than for victim-responsible but both significant. Inducing empathy for a member of a stigmatized group (young woman with AIDS) can improve attitudes toward group as a whole.	
Herek, G. M. and Capitanio, J. P. (1997). AIDS stigma and contact with persons with AIDS: Effects of direct and vicarious contact. Journal of Applied Social Psychology 27(1): 1-36.	U.S. General population *n1 = 538, n2 = 382*, Intervention n = 40, oversample of Blacks *n1 = 607, n2 = 420*	Two-wave national telephone interviews using random-digit dialing. Earvin Johnson's disclosure took place three weeks before Wave II.	*Contact (vicarious and direct):* Earvin "Magic" Johnson's disclosure of having HIV as intervention. Measured by self-report impact on attitudes. Also measured stigma change for respondents who reported direct contact with a PLHA between Wave I and Wave II (*n = 40*).	Intent to avoid PLHA decreased for respondents who reported high level of influence from Johnson's disclosure ($p < .05$). This group also had high avoidance scores at outset. Direct contact with PLHA was associated (but not significant) with less support for coercive AIDS policies, less blame for, and less avoidance of, PLHA.	
Kaleeba, N. *et al*. (1997). Participatory evaluation of counseling, medical and social services of The AIDS Support Organization (TASO) in Uganda.	Uganda, Clients of (TASO) *n = 232*	Convenience sample; semi-structured interviews, focus groups, 24 key informant interviews, case studies of clients.	*Information, counseling:* One-on-one counseling approach. This is an evaluation of an on-	90% reported revealing serostatus to someone. Family support 79%, community acceptance 76%, HIV knowledge 98%, condom use	

AIDS Care 9(1): 13-26.			going PLHA support organization	33% and abstinence 45%.	
Klepp, K.I. *et al.* (1997). AIDS education in Tanzania: Promoting risk reduction among primary school children. American Journal of Public Health 87: 1931-1936.	Tanzania/ 2 districts, Primary school children *n = 814*	Randomized controlled community trial with baseline, intervention, and 12- month follow-up.	*Information, coping skill acquisition:* Provided factual information, students created posters, wrote/performed songs/poetry, small group discussions, performed plays, and role play.	Average score on attitudes toward PLHA scale significantly improved in the intervention group as compared to the control group.	
Hue, L. and Kauffman, C. (1998). Creating positive attitudes toward persons living with HIV/AIDS among young people in hostile environments. Presented at the International Conference on AIDS, Geneva, Switzerland, 28 June-3 July, 12: 970.	Jamaica Youth, *n = 320*	Pre/post-questionnaire, focus groups, and direct observation	*Information:* Peer education and workshop: pre-workshop assignments, street interviews to examine fears, one-on-one conversations with PLHA, and concerts. Measured by willingness to sit next to, eat with, visit and reduce isolation	Significant increase ($p < .001$) in positive attitudes toward PLHA on all three willingness measures, and reduced percent wanting isolation for PLHA.	
Mwambu, W. (1998). Knowledge, Attitudes and Practices of House girls on HIV/STDs Transmission and Risk Factors. Presented at the International Conference on AIDS, Geneva, Switzerland, 28 June-3 July, 12: 1018-9.	Tanzania House girls, other members of these household (employers) *n = 2,500*	No information provided.	*Information, coping skill acquisition*: Educational videos, posters, leaflets, newsletters, and condoms. Peer education for groups. All in addition to usual services provided by center.	Increase in HIV/STDs knowledge (98%), reported desire to change behavior (75%), empowered to negotiate safer sex, partner notification, counseling, and voluntary screening (50%). Increase in people coming to center for services and becoming clients. Shyness and stigma minimized.	
Mwandha, N.P. and Were, B. (1998). The Impact of Peer Education in Communities. Presented at the International	Uganda, Community served by TASO, *n* not known	No information provided.	*Information, contact*: PLHA testimonies, music, dance, and dramas, backed by a	Wide spread AIDS awareness, behavior change, reduction in stigma and discrimination of PLHA, better coping for	

Conference on AIDS, Geneva, Switzerland, 28 June-3 July, 12: 1170.			counselor and medical practitioner. Sensitized communities with: pre-contemplation, safer sex, demystifying false beliefs, positive living, assessed communities' attitudes toward PLHA.	PLHA, change in community attitude toward TASO, and more PLHA organizations formed.	
Simpson, W.M. *et al*. (1998). Uptake and acceptability of HIV testing: A randomized controlled trial of different methods of offering the test. British Medical Journal 316: 262-267.	Scotland/Edinburgh, Pregnant women, *n = 3,024*	Randomized controlled trial, one control, four experimental groups, only posttest.	*Information, counseling:* Four combinations of leaflets, duration of discussion, and midwives who discussed HIV in different depths of detail. All women in experimental groups offered HIV test. The *all blood test* pamphlet aimed to normalize HIV. Anxiety scale used to assess stigma.	Uptake rates for control was 6%, intervention was 35%. All intervention groups had significantly higher rates as compared to control group. Effects, including satisfaction and anxiety, did not differ by type of intervention.	

Table 4. HIV-related stigma: Intervention studies with children

REFERENCE	SAMPLE/STUDY DESIGN	METHODOLOGY	OUTCOME MEASURES	RESULTS	REMARKS
1.Klepp, K.; Ndeki, S.S.; Seha, A.M.; Hannan, P.; Lyimo, B.A.; Msuya, M.H.; Irema, M.N. and Schreiner, A. (1994). AIDS education for primary school children in Tanzania: An evaluation study. AIDS (8): 1157 – 1162.	Quasi-experimental, nested cross-sectional design (which included a baseline and 6 month follow up survey) was used to assess a theory based HIV/AIDS prevention programme. Evaluation conducted in all public primary schools in the Arusha and Kilimanjaro regions. Schools, stratified according to location (urban, semi-urban or rural), were randomly assigned to intervention (*n = 6*) or comparison groups (*n = 12*). Total of 2026 students (average age 14.0 ± 1.3 yrs.) participated at baseline (85% eligible population – March 1992) and 1785 at follow up (September 1992).	Administration of survey instrument to students pre- and post implementation of the HIV/AIDS intervention programme. 1 week training workshop for local teachers and health workers before programme implementation over a 2 – 3 month period (20 school hours per class). Implementation of specific programme activities to students by teachers post training.	Self-reported exposure to AIDS information, communication regarding AIDS; AIDS knowledge, attitudes towards people with AIDS (four Likert scale items), attitudes towards sexual intercourse, subjective norms regarding sexual intercourse and intention to engage in sexual intercourse.	There were significant differences between students from the intervention schools and comparison group on six of the seven HIV/AIDS related outcome measures following intervention: AIDS information (P = 0.0001), AIDS communication (P = 0.0001), AIDS knowledge (P = 0.0001), attitudes towards people with AIDS (P = 0.0008), subjective norms (P = 0.011) and intervention (P = 0.020). No programme effect was observed between intervention and comparison groups, for attitudes towards sexual intercourse (P = 0.44).	Practical to train and encourage teachers and health workers to execute a school-based programme designed to reduce children's risk of HIV infection and to help mitigate the consequences of HIV infection in their communities.
2. Gilborn, L.Z.; Nyonyintono, R.; Kabumbuli, R. and Jagwe-Wadda, G. (2001). Making a difference for children affected by AIDS: Baseline findings from Operations Research in Uganda. Horizons Program. (http://www.ceped.org/cdrom/orphelins_sida_2006/pdf/pnacm260.pdf - July2, 2009).	Quasi-experimental study with two study sites: the Luwero and Tororo districts of Uganda. There are 3 arms in each of the two study sites: control arm and 2 experimental arms. 353 parents with HIV+ serostatus, 495 children of PLHA's, 233 orphans and 326 current and standby	In PLHA households in-depth interviews were conducted with up to four respondents who met the investigation's criteria for eligibility. Selection of children in households with multiple eligible children was not random, but rather based upon the decision of the parents. In orphan	School attendance and performance. Exposure to negative events (abuse or property grabbing).	91% of younger children of PLHA, 92% of younger orphans, 89% of older children of PLHA and 96% of older orphans were enrolled in school. There are no significant differences in rates of school enrollment when compared by sex, age group or household type. Daily school attendance for	Adult illness may be taking a toll on the education of older children. Children of PHLA may be assisting at home to compensate for family illness. Staying home to take care of sick

	guardians were used as the baseline sample. Two types of households were recruited for the investigation: PLHA household (household with an HIV+ parent) and orphan household (households with an orphan). Respondents in PLHA households included an HIV+ parent, a younger child (ages 5-12yrs.), an older child (ages 13-17yrs.) and a standby guardian identified by the parent. PLHA's with children between 5-17yrs. were eligible for the research. Respondents in orphan households included a guardian, young orphan (ages 5-12yrs.) and an older orphan (13-17yrs.). Orphans and guardians were recruited by contacting children of deceased parents and the current guardians of these children.	households in-depth interviews were conducted with up to three respondents. Data were collected on school holidays.		older children (80.1%) in PLHA households lower than orphans (88.6%), but not sig. Older children of PLHA (*n = 181*, ages 13 – 18yrs.) reported a decline in school attendance (26%) and performance (28%) when parents became ill. Older orphans (21.9%) reported an improvement in school attendance when moved into foster housing. ¼ of adults reported that children of PLHA and orphans were treated differently because a member of the family had AIDS. 17% of older children believed AIDS affected children treated differently. The community, other children, guardians and step-parents were identified by adults as being most likely to discriminate against HIV+ children. 30.2% of adult respondents reported AIDS affected children verbally abused/ teased; 24.3% perceived AIDS affected children neglected; 16.6% believed they were physically abused and 6.9% believed they were sexually abused. 10.2% of younger children of PLHA and 6.3% of younger orphans were mistreated because family member had AIDS according to adult	parents and an increase in household responsibilities resulted in a decline in school attendance and performance.

				respondents. Among older children, 6.2% of children of PLHA and 7.7% of orphans report that they had been mistreated for that reason.	
3. King, E., De Silva M., Stein A., Patel.,V. (2009). Interventions for improving the psychosocial well-being of children affected by HIV and AIDS. Cochrane Database of Systemic Reviews, Issue 2. Art.No: CD006733. DOI: 10.1002/14651858.CD006733.pub2.	Review to assess the overall effectiveness of interventions that aim to improve different psychosocial outcomes including mental health and social measures including education and school attendance. Studies included randomised control trials,crossover trials,cluster-randomised trials and factorial trials. If less than two controlled trials were found,data from well-designed non-randomised intervention studies,cohort and case-control observational studies were included. Children under the age of18 years,affected or infected by HIV/AIDS . In case of studies including children orphaned or vulnerable due to other illnesses, they were reviewed only if 80% of the sample was orphaned or vulnerable as a result of HIV/AIDS	Search methods: Systematic search of electronic databases using a pre-defined search strategy coupled with review of websites and direct contact with local and international organisations, experts for unpublished studies, performed in any country and language.	Primary outcome measure: Psychosocial well-being in which either psychological, social or both psychological and social outcomes, including education and school attendance were measured using validated instruments.	No studies of interventions for improving the psychosocial well-being, including school outcomes for children affected by HIV and AIDS were identified, as it was noted that current practice is based on anecdotal. descriptive studies and situational analyses, which donot provide a strong evidence base for the effectiveness of these interventions.	

	Interventions aiming to improve psychosocial well-being of children affected by HIV and AIDS were included.				

Appendix II: Screening sheets, questionnaires, consent and assent forms

Education and HIV Survey **ID#_____**

Eligibility Screening Questionnaire – ***To be administered to parent/guardian***

Date of Screening: _____/_____/_____ Gender: Male Female

dd mm yr Country: 1 St. Lucia 2 Guyana

Instructions: Read statements in *italics* to the **primary caregiver** of the child. Responses are to be directly written on this form. Do not write the participant's name or contact information on this form. Contact information must be recorded separately on the contact sheet.

Hello, my name is (interviewer's name) _____. I am working with the University of the West Indies trying to find out certain things about people living with HIV. How people treat and behave towards them. I am going to ask you some questions to see if you and your child/children are able to take part in the study.

1.	*Is anybody in this family living with HIV?*	0 No	**1 Yes**
	(If NO, do not proceed. END OF SCREENING)		
2.	*Who?* (State relationship ONLY, not name)_____		
3.	*Has anybody in this family died from AIDS?*	0 No (→***go to 5)***	1 Yes
4.	*Who?* (State relationship ONLY, not name) _____		
5.	*Does your child/ward know that these family members have HIV?*	0 No	**1 Yes**
6.	*Does your child/ ward/ have HIV?*	0 No(→***go to 8)***	1 Yes
7.	*Does your child/ ward know that they have HIV?*	0 No	**1 Yes**
8.	*Does your child/ ward attend school?*	0 No	1 Yes
9.	*Does/Did the school know that anybody in this family has HIV?*	0 No	1 Yes

Criteria for eligibility: Question 1 = Yes,

Question 5 and/or 7 = Yes

If not eligible: *"I want to thank you for talking with me, but since the child/ward does not know about their/their family member's HIV status we do not want to ask them any questions that may upset them."*

If eligible***:*** *"You are able to take part in the study."* Issue parental consent form, and then proceed with interview.

Education and HIV Survey **ID#_____**

Eligibility Screening Questionnaire – *To be administered to child/youth*

Date of Screening: _____/_____/_____ Gender: Male Female

dd mm yr Country: 1 St. Lucia 2 Guyana

Instructions: Read statements in *italics* to the potential child. Responses are to be directly written on this form. Do not write the participant's name or contact information on this form. Contact information must be recorded separately on the contact sheet.

Hello, my name is (interviewer's name) _____. I am working with the University of the West Indies trying to find out how some people behave. I am going to ask you some questions to see if you are able to take part in this study.

People can get sick in different ways. They can get even a serious illness like cancer, diabetes or HIV.

1. *Do you know anybody with a serious illness like cancer, diabetes or HIV?* **1 Yes** 2 No

2. *Who?*(State relationship ONLY, not name) _____

3. ***(If NO family member is mentioned)***

   Do you know if anybody in your family has a serious illness like this? **1 Yes** 2 No

4. ***(If NO family member is mentioned)***

   Who? (State relationship ONLY, not name) _____

5. ***(If name of illness is NOT provided)***

   Which illness does (State relationship) _____ *have?*

   Cancer 1 Yes 2 No

   Diabetes 1 Yes 2 No

   HIV **1 Yes** 2 No

   Other (specify) _____

Criteria for eligibility: If any family member or self mentioned as having HIV then eligible, if no then not eligible

If not eligible: "*Thank you for talking with me, but based on the information you have given me you will not be able to take part in this study."*

If eligible***:*** *"It looks like you can take part in this study."* Issue youth assent form, and then proceed with interview.

ID# _____

Education and HIV Survey

For Children and Youth living with HIV aged 10 - 18yrs

Date of Interview: ____/_____/_____ **Country: 1 St. Lucia 2 Guyana**

dd mm yr

Hello, my name is *(interviewer's name)* _____. We are trying to find out how people behave towards children and youth living with HIV.

I am going to ask you questions about yourself – your feelings, your thoughts and what might have happened to you. There are no wrong or right answers. Remember, you do not have to answer any question that I may ask if it makes you uncomfortable. If there is anything you do not understand, please tell me and I will explain it to you. If you want me to repeat anything, tell me and I will repeat it for you.

First, I am going to ask you about yourself and your family.

Age: _____ Gender: 1 Male 2 Female

FAMILY BACKGROUND

1. Who do you live with now? (Indicate relationship of primary caregiver)

   1 Mother 2 Father 3 Grandmother 4 Aunt 5 Stepmother 6 Grandfather

   7 Other (specify) _____

2. Did you always live with this person? 1 Yes *(continue to question 4)* 2 No

3. Tell me who you lived with before (record relationship and how long)

Relationship	How Long

4. Do you have any brothers and/or sisters? 1 Yes 2 No ***(****skip to question 8)*

5. How many brothers and/or sisters do you have? Brothers *(indicate number)*_____

   Sisters *(indicate number)* _____

6. How old is/are your brother(s) and/or sister(s)? Brother(s) *(indicate age)*_____

   Sister(s) *(indicate age)* _____

7. Do your brother(s) and/or sister(s) live with you? 1 Yes 2 No 3 Some with, some without

ID# _____

SCHOOL EXPERIENCES

Now I would like to ask you some questions about school.

8. Do you go to school?	Yes 1 No 2	 →***go to 11***
9. What grade are you in? ***PROBE***	Record grade _____ Don't Know 88 Not applicable 99	
10. What kind of school do you go to?	Infant School 1 Primary/Elementary School 2 Secondary/High School 3 College/Vocational/Technical School 4 University 5 Don't Know 88 Not Applicable 99	→***go to 15***
11. Have you ever gone to school?	Yes 1 No 2	 →***go to 27***
12. What was the last grade you were in? ***PROBE***	Record grade _____ Don't Know/Don't Remember 88 Not applicable 99	
13. What kind of school did you go to?	Infant School 1 Primary/Elementary School 2 Secondary/High School 3 College/Vocational/Technical School 4 University 5 Don't Know 88 Not Applicable 99	
14. Why are you not going to school now? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Death of parent/caregiver 1 No school fees/ No money 2 No school uniform 3 I am ill 4 My parent/caregiver is ill 5 Lack of school space 6 Failed the grade 7 Other (specify) _____ 8 Don't Know 88 Not Applicable 99	
15. How often do/did you go to school?	Every day 1 Most of the time 2 Some of the time 3 Not often, mostly I stay at home 4 Not Applicable 99	

16. Since you started this grade in September, did you miss any days of school?	Yes 1 No 2 Not Applicable 99	→***go to 19***

ID# _____

17. Why did you not go to school for these days? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Death of parent/caregiver 1 No school fees/ No money 2 No school uniform 3 I was ill 4 My parent/caregiver was ill 5 Didn't want to go to school 6 School was not open 7 Other (specify)_____ 8 Don't Know 88 Not Applicable 99	
18. When you missed school (for any reason) how do you spend your day(s)? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Doing housework 1 Playing alone 2 Playing with other children 3 Caring for sick caregiver 4 Stay home sick 5 Other (specify)_____ 6 Not Applicable 99	
19. In general, how much (do/did) you like school?	Like(d) it very much 1 Like(d) it somewhat 2 Like(d) and dislike(d) it equally 3 Dislike(d) it somewhat 4 Dislike(d) it very much 5 Not Applicable 99	
20. How well are you doing/ did you do in school?	Very Good 1 Good 2 Fair 3 Poor 4 Very Poor 5 Not Applicable 99	
21. What are/were your grades (marks/percentages) like? ***PROBE. If answering numbers, e.g. 90's, confirm letter grade.***	Mostly A's 1 Mostly B's 2 Mostly C's 3 Failed or Mostly D's 4 Not Applicable 99	
22. How do/did you get along with your teachers?	Very Well 5 Well 4 Fairly Well 3 Badly 2 Very Badly 1 Not Applicable 99	
23. How do/did you get along with your classmates?	Very Well 5 Well 4 Fairly Well 3 Badly 2 Very Badly 1 Not Applicable 99	

24. Have you ever repeated a grade?	Yes 1 No 2 Not Applicable 99	→***go to 27***

ID# _____

25. What grade did you repeat?	Record grade _____ Not Applicable 99	
26. Why did you repeat that grade? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Failing class 1 I was ill so I missed many classes 2 I stayed home to care for sick caregiver 3 Other (specify)_____ 4 Don't Know 88 Not Applicable 99	

SHORT MOOD AND FEELINGS

The next section is about how you might have been feeling or acting recently. For each sentence, think about how much you have felt or acted this way in the PAST WEEK. For each sentence, tell me if you feel it is true about you most of the time; true about you sometimes, or not true about you .Remember there are no right or wrong answers, only you can tell me how you feel

In the PAST WEEK:	**True Most of the Time**	**True Sometimes**	**Not True**
27. You felt sad or unhappy	**2**	**1**	**0**
28. You did not enjoy anything at all. ***(Check)****(Did you enjoy anything last week?)*	**2**	**1**	**0**
29. You felt so tired you sat around and did nothing. ***(If true check** don't mean idle).*	**2**	**1**	**0**
30. You were very restless and could not settle to do things *(You feel haunted and you couldn't settle down)*	**2**	**1**	**0**
31. You felt you were of no use any more. *(Yuh nuh good fi nutten)*	**2**	**1**	**0**
32. You cried a lot	**2**	**1**	**0**
33. You found it hard to think properly or concentrate	**2**	**1**	**0**
34. You hated yourself	**2**	**1**	**0**
35. You felt you were a bad person. ***(If true check** don't mean just fighting)*.	**2**	**1**	**0**
36. You felt lonely.	**2**	**1**	**0**
37. You thought nobody really loved you. *(No one cared for you; somebody loves you)* ***(Check)***	**2**	**1**	**0**

38. You thought you could never be as good as other young people. ***(Check)*** *(You thought other young people would always be better than you; you are as good as other young persons)*	**2**	**1**	**0**
39. You did everything wrong	**2**	**1**	**0**

ID# _____

WHAT I THINK AND FEEL

Here are some sentences that tell how some young people think and feel about themselves. I'm going to read them to you and I want you to think about each sentence carefully. If, in the <u>PAST MONTH</u>, the sentence is true about you, then answer 'yes' or if you think it is not true about you answer 'no'. There are no right or wrong answers. Only you can tell us how you think and feel about yourself. Remember, after I read each sentence, ask yourself 'Is it true about me?' If it is, answer 'yes'. If it is not, answer 'no'.

In the PAST MONTH:	**Yes**	**No**
40. You have trouble making up your mind. *(Do you find it hard to choose?)*	**1**	**0**
41. You get nervous when things do not go your way.	**1**	**0**
42. Other people seem to do things easier than you can	**1**	**0**
43. You are always kind	**1**	**0**
44. You worry a lot of the time	**1**	**0**
45. You are afraid of a lot of things	**1**	**0**
46. You get upset and angry easily	**1**	**0**
47. You worry about what your parents will say to you	**1**	**0**
48. You always have good manners	**1**	**0**
49. When you go to bed at night it is hard for you to fall asleep	**1**	**0**
50. You worry about what other people think about you	**1**	**0**
51. You are always good	**1**	**0**
52. Your feelings get hurt easily	**1**	**0**
53. You are always nice to everyone	**1**	**0**
54. You are tired a lot	**1**	**0**
55. You worry about what is going to happen	**1**	**0**

56. Other people are happier than you are	**1**	**0**
57. You tell the truth every single time	**1**	**0**
58. You have bad dreams	**1**	**0**
59. Your feelings get hurt easily when people trouble or bother you	**1**	**0**
60. You feel someone will tell you that how you do things is wrong *(criticize you)*	**1**	**0**
61. You never get angry *(true or not true)*	**1**	**0**
62. You wake up worried	**1**	**0**
63. You worry when you go to bed at night	**1**	**0**

ID# _____

In the PAST MONTH:	**Yes**	**No**
64. It is hard for you to keep your mind on your schoolwork/tasks	**1**	**0**
65. You are nervous	**1**	**0**
66. You think a lot of people are against you	**1**	**0**
67. You never tell lies *(true or not true)*	**1**	**0**
68. You often worry about something bad happening to you	**1**	**0**

PERCEIVED STIGMA

Sometimes people living with HIV have problems. I am going to read sentences about how some people may behave towards you because of your/ your (insert relationship to child)_____ HIV status. Tell me how much you agree or disagree.

	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**
69. I feel that most people are uncomfortable around me because I have/my ((*insert relationship to child)* _____has HIV.	**1**	**2**	**3**	**4**
70. I feel most people stay away from me because I have/my *(insert relationship of child)* _____ has HIV.	**1**	**2**	**3**	**4**
71. I feel most people will stop being friends with me because I have/ my ((*insert relationship to child)* _____ has HIV.	**1**	**2**	**3**	**4**

72. Most people think I am disgusting (horrible) because I have/ my (*(insert relationship to child)* _____ has HIV.	**1**	**2**	**3**	**4**
73. Having HIV/ my (*(insert relationship to child)* _____ having HIV makes me a bad person.	**1**	**2**	**3**	**4**
74. I feel ashamed or guilty because I have HIV/ my (*(insert relationship to child)*_____ has HIV	**1**	**2**	**3**	**4**
75. I feel dirty/unclean/filthy because I have/my (*(insert relationship to child)* _____ has HIV.	**1**	**2**	**3**	**4**
76. Most people will judge me because I have/ my *(insert relationship to child)* _____ has HIV.	**1**	**2**	**3**	**4**
77. Most people who know I have HIV/ my *(insert relationship to child)* _____has HIV will tell others.	**1**	**2**	**3**	**4**
78. If I drank water from a pipe and people knew that I have HIV/ my *(insert relationship to child)*_____ has HIV, they would not drink water from the same pipe	**1**	**2**	**3**	**4**
79. Most people are afraid of me because I have/ my *(insert relationship to child)* _____ has HIV.	**1**	**2**	**3**	**4**

ID# _____

SHAME, BLAME AND JUDGEMENT

People have many different feelings when they think about persons who have HIV. As I read each of the following feelings to you, please tell me how much you agree or disagree.

	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**
80. I think HIV is a punishment for bad behaviour.	**1**	**2**	**3**	**4**
81. I think HIV is a punishment from GOD.	**1**	**2**	**3**	**4**
82. I think people with HIV deserve what they get.	**1**	**2**	**3**	**4**
83. I think people with HIV should be ashamed of themselves.	**1**	**2**	**3**	**4**
84. I think children with HIV should stay away from school.	**1**	**2**	**3**	**4**
85. I think people with HIV should be blamed for their infection.	**1**	**2**	**3**	**4**
86. I would be ashamed if someone in my family has HIV	**1**	**2**	**3**	**4**

ENACTED STIGMA

I'm going to read some things that may have happened to you at school. After each sentence, please tell me how often it happened to you because of your/ your (insert relationship to child) _____ HIV status.

	Never	Once or Twice	Sometimes	Most of the Time
87. Other children/people did not want to sit beside me	**1**	**2**	**3**	**4**
88. Other children/ people refused to eat beside me	**1**	**2**	**3**	**4**
89. My friends refused to hug me	**1**	**2**	**3**	**4**
90. I was told I must use my own fork or spoon to eat	**1**	**2**	**3**	**4**
91. Other children/people made fun of me.	**1**	**2**	**3**	**4**
92. Other children/people stopped being my friend	**1**	**2**	**3**	**4**
93. My friends would not play with me.	**1**	**2**	**3**	**4**
94. My friends would not talk to me	**1**	**2**	**3**	**4**
95. Other children/ people shouted at me	**1**	**2**	**3**	**4**
96. Parents refused to let me play with their children	**1**	**2**	**3**	**4**
97. Other children/people insulted or teased me	**1**	**2**	**3**	**4**
98. I was told I cannot touch other children.	**1**	**2**	**3**	**4**

ID# _____

	Never	Once or Twice	Sometimes	Most of the Time
99. I was told I could not go to class parties or school trips by my teacher(s)	**1**	**2**	**3**	**4**
100. I was hit, kicked or punched by other children/people	**1**	**2**	**3**	**4**
101. My teachers did not want to help me with my school work	**1**	**2**	**3**	**4**
102. My teachers ignored me in class.	**1**	**2**	**3**	**4**
103. My teachers did not want to touch me.	**1**	**2**	**3**	**4**
104. Other children/people gossiped about me.	**1**	**2**	**3**	**4**

HIV KNOWLEDGE

Now, I'm going to ask you some questions about the ways in which you think someone may get HIV.

Do you think that a person <u>can get HIV</u> from:	
105. Sharing food with someone who has HIV.	Yes 1 No 2 Don't Know 88
106. Playing with someone with HIV.	Yes 1 No 2 Don't Know 88
107. Sitting beside someone with HIV.	Yes 1 No 2 Don't Know 88
108. Touching someone who has HIV.	Yes 1 No 2 Don't Know 88
109. Using the same toilet seat as someone living with HIV.	Yes 1 No 2 Don't Know 88

SCHOOL ACTIVITIES

Now I would like to ask you some questions about your school's HIV activities and programmes.

110. Do you know if your school has/had any activities on HIV for children?	Yes 1 No 2 Don't Know 88	 →***go to 113*** →***go to 113***
111. Have you found these activities helpful?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
112. Do you think that that these HIV activities are enough?	Yes 1 No 2 Don't Know 88 Not Applicable 99	

ID# _____

DISCLOSURE

Finally, I would like to ask you some questions about revealing your/ your (insert relationship to child) _____ HIV status.

113. Do you think it is easy to know if someone has HIV?	Yes 1 No 2 Don't Know 88	 →***go to 115*** →***go to 115***

114. How would you know if someone has HIV? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	The infected person told me 1 From rumors 2 From the HIV + person's family 3 The HIV+ person's friends or neighbours 4 The person looks ill or lost a lot of weight 5 Other (specify)_____ 6 Not Applicable 99	
115. Is there anyone from your school who you know or suspect has HIV?	Yes 1 No 2 Don't Know 88	→***go to 117*** →***go to 117***
116. How did you find out they had HIV? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	The infected person told me 1 From rumors 2 From the HIV+ person's family 3 The HIV+ person's friends or neighbours 4 I heard it at school or in the community 5 Other(specify)_____ 6 Not Applicable 99	
117. Would you tell a person who has HIV that they should tell no one, tell only their family members or that they should tell everybody?	Tell no one/ keep a secret 1 Tell only family 2 Tell everybody 3 Don't know 88	→***go to 119*** →***go to 119***
118. Why do you think that persons with HIV should tell no one or tell only their family? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Personal/family problem 1 People act differently toward a person with HIV 2 People would keep away from a person with HIV 3 People would tease a person with HIV 4 Other (specify)_____ 5 Not Applicable 99	
119. Do you have friends at school living with HIV?	Yes 1 No 2 Don't Know 88	→***go to 122***
120. How would you feel if one of your friends told you that they have HIV? Would you be:	Afraid of them 1 Not afraid of them 2 Not Applicable 99	
121. Why would/wouldn't you be afraid of them?	Record Response _____ _____ _____ Not Applicable 99	→***go to 125***

ID# _____

122. How many do you know?	1 – 3 1 3 – 4 2 More than 4 3 Not applicable 99	
123. Are you still friends with them?	Yes 1 No 2 Not Applicable 99	
124. Why/ why not are you still friends with them?	Record response _____ _____ _____ Not Applicable 99	
125. How old were you when you learnt that you/your *(insert relationship to child)* _____ were/was living with HIV?	Record age _____ Don't Remember 88	
126. Who told you? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Caregiver 1 Doctor 2 Nurse 3 Relative 4 Other(specify)_____ 5 Don't Remember 88	
127. Have you told anyone at school?	Yes 1 No 2	→***go to 132***
128. Who have you told? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Classmate 1 Teacher 2 School principal 3 School Nurse 4 Other (specify)_____ 5 Not Applicable 99	
129. How did they treat you after you told them?	Record response _____ _____ _____ Not Applicable 99	
130. Has (*person identified from question 128*) ever told other people that you/ your *(insert relationship to child)* _____ have HIV without you wanting them to know?	Yes 1 No 2 Don't Know 88 Not Applicable 99	→***go to 131*** *END OF INTERVIEW*

ID# _____

131. Who did they tell? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Classmate 1 Teacher 2 School principal 3 Parent 4 School Nurse 5 Other (specify)_____ 6 Not Applicable 99	*END OF INTERVIEW*
132. Why not? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	I was told not to tell anyone by my *(insert relationship to child_____* 1 I was afraid I would by talked about/laughed at 2 I was afraid that whoever I told would tell 3 I was afraid that I would be treated badly 4 I was afraid that no one would be my friend anymore 5 I was afraid I would be teased 6 I was afraid that I would not be allowed to go to school anymore 7 I was afraid that I would be disliked 8 I was afraid that someone would hit, kick or punch me 9 Other (specify)_____ 10 Not Applicable 99	***→go to 133*** *END OF INTERVIEW*
133. Why did your *(insert relationship to child)* _____ tell you not to tell anyone? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Personal/family problem 1 People act differently toward a person with HIV 2 People would keep away from a person with HIV 3 People would tease a person with HIV 4 Other (specify)_____ 5 Not Applicable 99	*END OF INTERVIEW*

ID# _____

Education and HIV Survey

For Children and Youth aged 10 - 18yrs

Date of Interview: ____/_____/_____ **Country: 1 St. Lucia 2 Guyana**

dd mm yr

Hello, my name is *(interviewer's name)* _____. We are trying to find out how people behave towards children and youth living with HIV.

I am going to ask you questions about yourself – your feelings and your thoughts. There are no wrong or right answers. Remember, you do not have to answer any question that I may ask if it makes you uncomfortable. If there is anything you do not understand, please tell me and I will explain it to you. If you want me to repeat anything, tell me and I will repeat it for you.

First, I am going to ask you about yourself and your family.

Age: _____ Gender: 1 Male 2 Female

FAMILY BACKGROUND

134. Who do you live with right now? (Indicate relationship of primary caregiver)

1 Mother 2 Father 3 Grandmother 4 Aunt 5 Stepmother 6 Grandfather

7 Other (specify) _____

135. Did you always live with this person? 1 Yes (*continue to question 4)* 2 No

136. Tell me who you lived with before (record relationship and how long)

Relationship	How Long

137. Do you have any brothers and/or sisters? 1 Yes 2 No *(skip to question 8)*

138. How many brothers and/or sisters do you have? Brothers *(indicate number)*_____

Sisters *(indicate number)* _____

139. How old is/are your brother(s) and/or sister(s)? Brother(s) *(indicate age)*_____

Sister(s) *(indicate age)*_____

140. Do your brother(s) and/or sister(s) live with you? 1 Yes 2 No 3 Some with, some without

ID# _____

SCHOOL EXPERIENCES

Now I would like to ask you some questions about school.

141. Do you go to school?	Yes 1 No 2	 →***go to 11***
142. What grade are you in? ***PROBE***	Record grade _____ Don't Know 88 Not applicable 99	
143. What kind of school do you go to?	Infant School 1 Primary/Elementary School 2 Secondary/High School 3 College/Vocational/Technical School 4 University 5 Don't Know 88 Not Applicable 99	→***go to 15***
144. Have you ever gone to school?	Yes 1 No 2 Not Applicable 99	→***go to 27***
145. What was the last grade you were in? ***PROBE***	Record grade _____ Don't Know/Don't Remember 88 Not applicable 99	
146. What kind of school did you go to?	Infant School 1 Primary/Elementary School 2 Secondary/High School 3 College/Vocational/Technical School 4 University 5 Don't Know 88 Not Applicable 99	
147. Why are you not going to school now? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Death of parent/caregiver 1 No school fees/ No money 2 No school uniform 3 I am ill 4 My parent/caregiver is ill 5 Lack of school space 6 Failed the grade 7 Other (specify) _____ 8 Don't Know 88 Not Applicable 99	

148. How often do/did you go to school?	Every day 1 Most of the time 2 Some of the time 3 Not often, mostly I stay at home 4 Not Applicable 99	
149. Since you started this grade in September, did you miss any days of school?	Yes 1 No 2 Not Applicable 99	→***go to 19***

ID# _____

150. Why did you not go to school for these days? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Death of parent/caregiver 1 No school fees/ No money 2 No school uniform 3 I was ill 4 My parent/caregiver was ill 5 Didn't want to go to school 6 School was not open 7 Other (specify)_____ 8 Don't Know 88 Not Applicable 99	
151. When you missed school (for any reason) how do you spend your day(s)? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Doing housework 1 Playing alone 2 Playing with other children 3 Caring for sick caregiver 4 Stay home sick 5 Other (specify)_____ 6 Not Applicable 99	
152. In general, how much (do/did) you like school?	Like(d) it very much 1 Like(d) it somewhat 2 Like(d) and dislike(d) it equally 3 Dislike(d) it somewhat 4 Dislike(d) it very much 5 Not Applicable 99	
153. How well are you doing/ did you do in school?	Very Good 1 Good 2 Fair 3 Poor 4 Very Poor 5 Not Applicable 99	
154. What are/were your grades (marks/percentages) like? *Do NOT read out options*. ***PROBE. If answering numbers, e.g. 90's, confirm letter grade.***	Mostly A's 1 Mostly B's 2 Mostly C's 3 Failed or Mostly D's 4 Not Applicable 99	

155. How do/did you get along with your teachers?	Very Well 5 Well 4 Fairly Well 3 Badly 2 Very Badly 1 Not Applicable 99	
156. How do/did you get along with your classmates?	Very Well 5 Well 4 Fairly Well 3 Badly 2 Very Badly 1 Not Applicable 99	
157. Have you ever repeated a grade?	Yes 1 No 2 Not Applicable 99	→***go to 27***

ID# _____

158. What grade did you repeat?	Record grade _____ Not Applicable 99	
159. Why did you repeat that grade? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Failing class 1 I was ill so I missed many classes 2 I stayed home to care for sick caregiver 3 Other (specify)_____ 4 Don't Know 88 Not Applicable 99	

SHORT MOOD AND FEELINGS

The next section is about how you might have been feeling or acting recently. For each sentence, think about how much you have felt or acted this way in the <u>PAST WEEK</u>. For each sentence, tell me if you feel it is true about you most of the time; true about you sometimes, or not true about you .Remember there are no right or wrong answers, only you can tell me how you feel

In the PAST WEEK:	**True Most of the Time**	**True Sometimes**	**Not True**
160. You felt sad or unhappy	**2**	**1**	**0**
161. You did not enjoy anything at all. ***(Check)****(Did you enjoy anything last week?)*	**2**	**1**	**0**
162. You felt so tired you sat around and did nothing. ***(If true check** don't mean idle).*	**2**	**1**	**0**
163. You were very restless and could not settle to do things *(You feel haunted and you couldn't settle down)*	**2**	**1**	**0**

164. You felt you were of no use any more. *(Yuh nuh good fi nutten)*	**2**	**1**	**0**
165. You cried a lot	**2**	**1**	**0**
166. You found it hard to think properly or concentrate	**2**	**1**	**0**
167. You hated yourself	**2**	**1**	**0**
168. You felt you were a bad person. ***(If true check** don't mean just fighting)*.	**2**	**1**	**0**
169. You felt lonely.	**2**	**1**	**0**
170. You thought nobody really loved you. *(No one cared for you; somebody loves you)* ***(Check)***	**2**	**1**	**0**
171. You thought you could never be as good as other young people. ***(Check)*** *(You thought other young people would always be better than you; you are as good as other young persons)*	**2**	**1**	**0**
172. You did everything wrong	**2**	**1**	**0**

ID# _____

WHAT I THINK AND FEEL

Here are some sentences that tell how some young people think and feel about themselves. I'm going to read them to you and I want you to think about each sentence carefully. If, in the <u>PAST MONTH</u>, the sentence is true about you, then answer 'yes' or if you think it is not true about you answer 'no'. There are no right or wrong answers. Only you can tell us how you think and feel about yourself. Remember, after I read each sentence, ask yourself 'Is it true about me?' If it is, answer 'yes'. If it is not, answer 'no'.

In the PAST MONTH:	**Yes**	**No**
173. You have trouble making up your mind. *(Do you find it hard to choose?)*	**1**	**0**
174. You get nervous when things do not go your way.	**1**	**0**
175. Other people seem to do things easier than you can	**1**	**0**
176. You are always kind	**1**	**0**
177. You worry a lot of the time	**1**	**0**
178. You are afraid of a lot of things	**1**	**0**
179. You get upset and angry easily	**1**	**0**
180. You worry about what your parents will say to you	**1**	**0**

181. You always have good manners	**1**	**0**
182. When you go to bed at night it is hard for you to fall asleep	**1**	**0**
183. You worry about what other people think about you	**1**	**0**
184. You are always good	**1**	**0**
185. Your feelings get hurt easily	**1**	**0**
186. You are always nice to everyone	**1**	**0**
187. You are tired a lot	**1**	**0**
188. You worry about what is going to happen	**1**	**0**
189. Other people are happier than you are	**1**	**0**
190. You tell the truth every single time	**1**	**0**
191. You have bad dreams	**1**	**0**
192. Your feelings get hurt easily when people trouble or bother you	**1**	**0**
193. You feel someone will tell you that how you do things is wrong *(criticize you)*	**1**	**0**
194. You never get angry *(true or not true)*	**1**	**0**
195. You wake up worried	**1**	**0**
196. You worry when you go to bed at night	**1**	**0**

ID# _____

In the PAST MONTH:	**Yes**	**No**
197. It is hard for you to keep your mind on your schoolwork/tasks	**1**	**0**
198. You are nervous	**1**	**0**
199. You think a lot of people are against you	**1**	**0**
200. You never tell lies *(true or not true)*	**1**	**0**
201. You often worry about something bad happening to you	**1**	**0**

PERCEIVED STIGMA

Sometimes people living with HIV have problems. I am going to read some sentences about how some people may behave towards them. Tell me how you much you agree or disagree.

	Strongly Disagree	Disagree	Agree	Strongly Agree
202. I feel that most people are uncomfortable around someone with HIV.	**1**	**2**	**3**	**4**
203. I feel that most people stay away from someone with HIV.	**1**	**2**	**3**	**4**
204. I feel that most people will stop being friends with someone who has HIV.	**1**	**2**	**3**	**4**
205. Most people think someone with HIV is disgusting (horrible).	**1**	**2**	**3**	**4**
206. Most people think persons with HIV are bad.	**1**	**2**	**3**	**4**
207. Most people believe someone with HIV feel ashamed or guilty of themselves.	**1**	**2**	**3**	**4**
208. Most people think that persons with HIV are dirty, unclean or filthy.	**1**	**2**	**3**	**4**
209. Most people judge persons living with HIV.	**1**	**2**	**3**	**4**
210. Most people who know that someone has HIV will tell others.	**1**	**2**	**3**	**4**
211. Most people would not drink water from a pipe if a person with HIV had just drank from it.	**1**	**2**	**3**	**4**
212. Most people are afraid of persons with HIV.	**1**	**2**	**3**	**4**

ID# _____

SHAME, BLAME AND JUDGEMENT

People have many different feelings when they think about persons who have HIV. As I read each of the following feelings to you, please tell me how much you agree or disagree.

	Strongly Disagree	Disagree	Agree	Strongly Agree
213. I think HIV is a punishment for bad behaviour.	**1**	**2**	**3**	**4**
214. I think HIV is a punishment from GOD.	**1**	**2**	**3**	**4**
215. I think people with HIV deserve what they get.	**1**	**2**	**3**	**4**
216. I think people with HIV should be ashamed of themselves.	**1**	**2**	**3**	**4**
217. I think children with HIV should stay away from school.	**1**	**2**	**3**	**4**
218. I think people with HIV should be blamed for their infection.	**1**	**2**	**3**	**4**
219. I would be ashamed if someone in my family has HIV	**1**	**2**	**3**	**4**

ENACTED STIGMA

I'm going to read some things that could happen to someone at your school because they have HIV. After each sentence, please tell me how often you think it might happen.

	Never	Once or Twice	Sometimes	Most of the Time
220. Other children/people did not want to sit beside them.	**1**	**2**	**3**	**4**
221. Other children/ people refused to eat beside them	**1**	**2**	**3**	**4**
222. Their friends refused to hug them.	**1**	**2**	**3**	**4**
223. They were told they must use their own fork or spoon to eat	**1**	**2**	**3**	**4**
224. Other children/people made fun of them	**1**	**2**	**3**	**4**
225. Other children/people stopped being their friend	**1**	**2**	**3**	**4**
226. Their friends would not play with them	**1**	**2**	**3**	**4**
227. Their friends would not talk to them	**1**	**2**	**3**	**4**
228. Other children/ people shouted at them	**1**	**2**	**3**	**4**
229. Parents refused to let them play with their children	**1**	**2**	**3**	**4**
230. Other children/people insulted or teased them	**1**	**2**	**3**	**4**
231. They were told they cannot touch other children	**1**	**2**	**3**	**4**

ID# _____

	Never	Once or Twice	Sometimes	Most of the Time
232. They were told they could not go to class parties or school trips by their teacher(s)	**1**	**2**	**3**	**4**
233. They were hit, kicked or punched by other children/people	**1**	**2**	**3**	**4**
234. Their teachers did not want to help them with their school work	**1**	**2**	**3**	**4**
235. Their teachers ignored them in class.	**1**	**2**	**3**	**4**
236. Their teachers did not want to touch them.	**1**	**2**	**3**	**4**

237. Other children/people gossiped about them.	**1**	**2**	**3**	**4**

HIV KNOWLEDGE

Now, I'm going to ask you some questions about the ways in which you think someone may get HIV.

Do you think that a person <u>can get HIV</u> from:	
238. Sharing food with someone who has HIV.	Yes 1 No 2 Don't Know 88
239. Playing with someone with HIV.	Yes 1 No 2 Don't Know 88
240. Sitting beside someone with HIV.	Yes 1 No 2 Don't Know 88
241. Touching someone who has HIV.	Yes 1 No 2 Don't Know 88
242. Using the same toilet seat as someone living with HIV.	Yes 1 No 2 Don't Know 88

SCHOOL ACTIVITIES

Now I would like to ask you some questions about your school's HIV activities and programmes.

243. Do you know if your school has/had any activities on HIV for children?	Yes 1 No 2 Don't Know 88	 ***→go to 113*** ***→go to 113***
244. Have you found these activities helpful?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
245. Do you think that that these HIV activities are enough? ***PROBE***	Yes 1 No 2 Don't Know 88 Not Applicable 99	

ID# _____

DISCLOSURE

Finally, I would like to ask you some questions about your experience with learning about someone who has HIV.

246. Do you think it is easy to know if someone has HIV?	Yes 1 No 2 Don't Know 88	 →***go to 115*** →***go to 115***
247. How would you know if someone has HIV? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	The infected person told me 1 From rumors 2 From the HIV + person's family 3 The HIV+ person's friends or neighbours 4 The person looks ill or lost a lot of weight 5 Other (specify)_____ 6 Not Applicable 99	
248. Is there anyone from your school who you know or suspect has HIV?	Yes 1 No 2 Don't know 88	 →***go to 117*** →***go to 117***
249. How did you find out they had HIV? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	The infected person told me 1 From rumors 2 From the HIV+ person's family 3 The HIV+ person's friends or neighbours 4 I heard it at school or in the community 5 Other(specify)_____ 6 Not Applicable 99	
250. Would you tell a person who has HIV that they should tell no one, tell only their family members or that they should tell everybody?	Tell no one/ keep a secret 1 Tell only family 2 Tell everybody 3 Don't know 88	 →***go to 119*** →***go to 119***
251. Why do you think that persons with HIV should tell no one or tell only their family? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Personal/family problem 1 People act differently toward a person with HIV 2 People would keep away from a person with HIV 3 People would tease a person with HIV 4 Other (specify)_____ 5 Not Applicable 99	
252. Do you have friends at school living with HIV?	Yes 1 No 2 Don't Know 88	→***go to 122***
253. How would you feel if one of your friends told you that they have HIV? Would you be:	Afraid of them 1 Not afraid of them 2 Not Applicable 99	
254. Why would/wouldn't you be afraid of them?	Record Response _____ _____ _____ Not Applicable 99	 *END OF INTERVIEW*

ID# _____

255. How many do you know?	1 – 3 1 3 – 4 2 More than 4 3 Not applicable 99	
256. Are you still friends with them?	Yes 1 No 2 Not Applicable 99	
257. Why/ why not are you still friends with them?	Record response _____ _____ _____ Not Applicable 99	*END OF INTERVIEW*

ID# _____

Education and HIV Survey

For Caregivers

Date of Interview: _____/_____/_____ **Country: 1 St. Lucia 2 Guyana**

dd mm yr

Hello, my name is (*interviewer's name)* _____. We are trying to find out how people behave towards children and youth living with HIV.

I am going to ask you questions about the child and yourself. There are no wrong or right answers. You do not have to answer any question that I may ask if it makes you uncomfortable. If there is anything you do not understand, please tell me and I will explain it to you. If you want me to repeat anything I have read, tell me and I will repeat it for you.

First, I am going to ask you questions about the child and yourself.

Gender of Child: 1 Male 2 Female Gender of Parent/Guardian: 1 Male 2 Female

FAMILY BACKGROUND

1. What is the child's date of birth?	Date:_____/_____/_____ dd mm yr Don't Know 88	
2. How old were you at your last birthday?	Age in years: _____ Don't Know/Don't Remember 88	
3. What is your relation to the child? ***Do NOT read out options***	Mother 1 Father 2 Grandmother 3 Aunt 4 Stepmother 5 Grandfather 6 Other(specify)_____ 7	
4. What is the highest level of education you have completed?	No School 0 Primary/Elementary School 1 High School/Secondary School 2 College/Technical/ Vocational School 3 University 4 Other(specify)_____ 5 Don't Know 88	
5. What is your current marital status?	Single 1 Married 2 Common-Law 3 Divorced 4 Separated 5 Widow/ Widower 6	

6. How many people live in this house? *(including respondent)*	Total no. _____ Don't Know 88	
7. What are their ages? *(including respondent)*	Record age_____ Don't Know 88	

ID# _____

8. How many rooms are in your house? *(excluding bathroom and kitchen unless can sit and eat)*	No. of rooms _____ Don't Know 88	
9. What is your current job/was your last job? *Record response and circle job category*	Response_____ _____ Unskilled 1 Semi-skilled 2 Skilled 3 Highly skilled 4 Professional 5 Never worked 6	
10. Do you have the following possessions in your home? *Read each item and circle the number that corresponds.*	Yes No Oil, gas, electric stove 1 2 Television (working) 1 2 Cable 1 2 Fridge 1 2 DVD player 1 2 Computer 1 2 Motorcycle/bike/bicycle 1 2 Car/bus/truck (No._____) 1 2	
11. What kind of toilet facility do you have in your home?	Flush toilet 1 Pit toilet 2 No toilet 3	 → ***go to14***
12. Is your toilet facility inside or outside your house?	Inside 1 Outside 2 Not applicable 99	
13. Is your toilet used by your family alone or other families use it too?	Own 1 Shared 2 Not applicable 99	
14. Where do you get the water from that you use inside your house?	Pipe inside house 1 Pipe in yard 2 Pipe outside yard 3 River/spring 4 Other(specify)_____ 5	 → ***go to16*** → ***go to16*** → ***go to16***
15. Is water used by your family alone or other families use it too?	Own 1 Shared 2 Not applicable 99	

SCHOOL EXPERIENCES

Now I would like to ask you some questions about the child's school attendance and his/her grades.

16. Does this child go to school?	Yes 1 No 2	→ ***go to 19***
17. What grade is he/she in? ***PROBE***	Record grade _____ Don't Know 88 Not applicable 99	

ID# _____

18. What kind of school does he/she go to?	Infant School 1 Primary/Elementary School 2 Secondary/High School 3 College/Vocational/Technical School 4 University 5 Don't Know 88 Not Applicable 99	→ ***go to23***
19. Has the child ever gone to school?	Yes 1 No 2 Not Applicable 99	→ ***go to 35***
20. What was the last grade he/she was in? ***PROBE***	Record grade _____ Don't Know 88 Not applicable 99	
21. What kind of school did he/she go to?	Infant School 1 Primary/Elementary School 2 Secondary/High School 3 College/Vocational/Technical School 4 University 5 Don't Know 88 Not Applicable 99	
22. Why is he/she not going to school now? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Death of child's parent 1 No school fees/ No money 2 No school uniform 3 The child is ill 4 Child does not get along with other children 5 Child refuses to go to school 6 Child's performance in school was too poor 7 Other (specify) _____ 8 Don't Know 88 Not Applicable 99	
23. How often does/did the child go to school?	Every day 1 Most of the time 2 Some of the time 3 Not often, mostly he/she stay at home 4	

	Not Applicable 99	
24. Since the child started this grade in September, did he/she miss any days of school?	Yes 1 No 2 Not Applicable 99	→ ***go to 27***
25. Why did he/she not go to school for these days? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Death of child's parent 1 No school fees/ No money 2 No school uniform 3 The child was ill 4 Child refuses to go to school 5 School was not open 6 Other (specify)_____ 7 Don't Know 88 Not Applicable 99	

ID# _____

26. When the child missed school (for any reason) how does he/she spend his/her day(s)? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Doing housework 1 Playing alone 2 Playing with other children 3 Caring for sick parent/caregiver 4 Stay home sick 5 Other (specify)_____ 6 Not Applicable 99	
27. In general, how much does/did the child like school?	Like(d) it very much 1 Like(d) it somewhat 2 Like(d) and dislike(d) it equally 3 Dislike(d) it somewhat 4 Dislike(d) it very much 5 Not Applicable 99	
28. How well is he/she doing in school/ did he/she do in school?	Very Good 1 Good 2 Fair 3 Poor 4 Very Poor 5 Not Applicable 99	
29. What are/were his/her grades (marks/percentages) like? ***PROBE. If answering numbers, e.g. 90's, confirm letter grade.***	Mostly A's 1 Mostly B's 2 Mostly C's 3 Failed or Mostly D's 4 Not Applicable 99	
30. How does/did the child get along with his/her teachers?	Very Well 5 Well 4 Fairly Well 3 Badly 2 Very Badly 1 Not Applicable 99	

31. How does/did the child get along with his/her classmates?	Very Well 5 Well 4 Fairly Well 3 Badly 2 Very Badly 1 Not Applicable 99	
32. Has the child ever repeated a grade?	Yes 1 No 2 Not Applicable 99	→ ***go to 35***
33. What grade did he/she repeat?	Record grade _____ Not Applicable 99	
34. Why did he/she repeat that grade? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Failing class 1 Child was ill so he/she missed many classes 2 Child stayed home to care for sick caregiver 3 Other (specify)_____ 4 Don't Know 88 Not Applicable 99	

ID# _____

PARENT'S RATING OF CHILD'S BEHAVIOUR (Revised from Rutter)

I am going to read you some descriptions of behaviour often shown by children. After each statement I want you to tell me if your child definitely shows the behaviour described by the statement (Certainly Applies) or if he/she shows the behaviour described by the statement to a lesser degree or less often (Applies Somewhat). If, as far as you are aware, your child does not show the behaviour, you will tell me (Doesn't Apply). Please answer on the basis of your child's behaviour during the <u>PAST THREE MONTHS</u>.

During the PAST THREE MONTHS:	**Doesn't Apply**	**Applies Somewhat**	**Applies Certainly**
35. Tries to be fair when he/she is playing with other children.	**0**	**1**	**2**
36. Considerate of other people's feelings.	**0**	**1**	**2**
37. Will try to help someone who has been hurt.	**0**	**1**	**2**
38. Fights frequently or is extremely quarrelsome with other children.	**0**	**1**	**2**
39. Volunteers to help around the house or yard.	**0**	**1**	**2**
40. Kind to younger children.	**0**	**1**	**2**
41. Blames other people for things.	**0**	**1**	**2**
42. Comforts a child who is crying or upset.	**0**	**1**	**2**
43. Has stolen things on one or more occasions.	**0**	**1**	**2**
44. Is often disobedient.	**0**	**1**	**2**

45. Tries to stop quarrels or fights.	**0**	**1**	**2**
46. Shares out sweets and snacks with friends.	**0**	**1**	**2**
47. Kicks, bites or hits other children.	**0**	**1**	**2**
48. Helps other children who are feeling sick.	**0**	**1**	**2**
49. Often tells lies.	**0**	**1**	**2**
50. Bullies other children (bad bullying).	**0**	**1**	**2**
51. Kind to animals.	**0**	**1**	**2**
52. Inconsiderate of others.	**0**	**1**	**2**
53. Has many friends.	**0**	**1**	**2**
54. Prefers to do things alone.	**0**	**1**	**2**
55. Talks easily with other adults.	**0**	**1**	**2**

STIGMA AND DISCRIMINATION

People have many different feelings when they think about children and/or youth who have HIV going to school. I would like to ask you some questions about the child's experience learning about someone who has HIV.

56. Does the child know if anyone at school has HIV?	Yes 1 No 2 Don't Know 88	 →***go to 59*** →***go to 59***

ID# _____

57. Has it affected his/her behaviour?	Not at all 1 Just a little 2 Quit a bit 3 All the time 4 Don't Know 88 Not applicable 99	→***go to 59***
58. How?	Record response _____ _____ _____ Not applicable 99	
59. Have you ever talked to the child about HIV?	Yes 1 No 2	 →***go to 61***
60. What did you tell him/her?	Record response _____ _____ _____ Not applicable 99	

61. If a child living with HIV started going to school, do you think the principal should know?	Yes 1 No 2 Don't Know 88	
62. Do you think the teachers should know?	Yes 1 No 2 Don't Know 88	
63. Do you think the students should know?	Yes 1 No 2 Don't Know 88	
64. Do you think the parents of the students should know?	Yes 1 No 2 Don't Know 88	***If caregiver of control youth → <u>End of interview</u>*** ***If NOT →go to 65***

<u>Questions 65 – 75 are for caregivers of children and youth living with or affected by HIV ONLY.</u>

Now I would like to ask you a few questions about the child's experience learning about and revealing their/ their (insert relationship to child) _____HIV status.

65. How long has the child known that they/ their *(insert relationship to child*) _____have/has HIV?	Less than 1 year 1 1 – 5 years 2 6 – 10 years 3 More than 10 years 4 Don't Know 88 Not Applicable 99	

ID# _____

66. Who told the child? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Caregiver 1 Doctor 2 Nurse 3 Relative 4 Other(specify)_____ 5 Don't Know 88 Not Applicable 99	
67. Have you talked to the child about their/ their *(insert relationship to child)* _____HIV status?	Yes 1 No 2 Not applicable 99	***→go to 70***
68. Has it affected his/her daily life?	Not at all 1 Just a little 2 Quit a bit 3 All the time 4	***→go to 70***

	Don't Know 88 Not applicable 99	
69. How?	Record response _____ _____ _____ Not applicable 99	
70. Has it affected his/her behaviour?	Not at all 1 Just a little 2 Quite a bit 3 All the time 4 Don't Know 88 Not applicable 99	→***go to 72***
71. How?	Record response_____ _____ _____ Not applicable 99	
72. Has the child's school principal been told that the child/ the child's *(insert relationship to child)* _____ has HIV?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
73. Has the child's teachers been told?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
74. Has the child's classmates been told?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
75. Have other parents been told?	Yes 1 No 2 Don't Know 88 Not Applicable 99	***End of interview***

ID# _____

Education and HIV Survey

For Principals and Teachers

Date of Interview: _____/_____/_____ **Country: 1 St. Lucia 2 Guyana**

dd mm yr

Hello, my name is *(interviewer's name)* _____. We are carrying out a study to find out how people behave towards children and youth living with and affected by HIV.

I am going to ask you questions about yourself – your thoughts and feelings, *(insert name of country)*'s national HIV policies, this school's HIV policies and related programmes. Remember, you do not have to answer any question that I may ask if it makes you uncomfortable.

First, I would like to ask you a few questions about yourself.

Gender of Principal/Teacher: 1 Male 2 Female Grade /level taught: _____

Type of school: 1 Public 2 Private

BACKGROUND INFORMATION

1. How old are you?	Less than 29 1 30 – 39 2 40 – 49 3 50 – 59 4 60 and over 5	
2. What is the highest level of education you have completed?	Primary School 1 High School/Secondary School 2 College/Vocational/Technical School 3 University 4 Other(specify)_____ 5	→ ***go to 4*** → ***go to 4*** → ***go to 4***
3. What is the highest certificate/degree you hold?	Bachelors 1 Masters 2 Doctorate 3 Other (specify)_____ 4 Not applicable 99	
4. What school level are you working with?	Pre-school or Kindergarten 1 Primary School/ Preparatory School 2 All-Age School 3 Secondary/High School 4	
5. How long have you been a principal/ teacher?	Less than 1 year 1 1 to 5 years 2 5 to 10years 3 More than 10 years 4	

NATIONAL POLICIES AND PROGRAMMES

Now I would like to ask you some questions about (insert name of country) _____ national HIV policies and programmes.

6. Do you know if there are any national policies or laws that address HIV issues?	Yes 1 No 2 Don't Know 88	 → ***go to 8*** → ***go to 8***

ID# _____

7. Do you know which areas are addressed in the policy?	Yes / No / DK Human rights 1 2 88 Information and communications 1 2 88 Orphans 1 2 88 Youth 1 2 88 Vulnerable populations 1 2 88 Other(specify)_____ Not applicable 99	
8. Do you know of any organizations that parents and/or children affected by HIV can go to for support?	Yes 1 No 2	→ ***go to 10***
9. What organization is this? ***PROBE***	Name of organization(s)_____ _____ _____ Not applicable 99	
10. Do you know if *(insert name of country)* has an HIV policy for schools?	Yes 1 No 2 Don't Know 88	
11. Does *(insert name of country)* have an HIV education program for students at school?	Yes 1 No 2 Don't Know 88	

SCHOOL POLICIES, PROGRAMMES & ACTIVITIES

I am going to ask you some questions about your school's HIV policies, programmes and activities.

12. Is there an HIV education programme provided for students in **<u>this</u>** school?	Yes 1 No 2 Don't know 88	 → ***go to 15*** → ***go to 15***
13. Is it a one time class or incorporated into the curriculum?	One time class 1 Part of the curriculum 2 Not applicable 99	
14. What grades does it apply to?	All grades/levels 1 Certain grades/levels (specify)_____ 2 Not applicable 99	

15. Does **this** school have an HIV policy?	Yes 1 No 2 Don't know 88	 → ***go to 20*** → ***go to 20***
16. Is there anything that differs in this school policy from the national policy?	Yes 1 No 2 Don't know 88 Not applicable 99	 → ***go to 18*** → ***go to 18***
17. In what way?	Record response_____ _____ _____ Not applicable 99	

ID# _____

18. Is the school community that is the teachers, parents and students, aware of the policy?	Yes 1 No 2 Don't know 88 Not applicable 99	 → ***go to 20*** → ***go to 20***
19. In your opinion, is your school's HIV policy supported by the school community?	Yes 1 No 2 Don't Know 88 Not applicable 99	
20. Are you aware of students living with HIV in your school?	Yes 1 No 2	 → ***go to 22***
21. Do you have students in your class living with HIV?	Yes 1 No 2 Don't know 88 Not applicable 99	
22. Are there programs in this school designed to reduce HIV discrimination and stigmatization?	Yes 1 No 2 Don't know 88	
23. Have any activities been carried out to support children living with HIV in this school?	Yes 1 No 2 Don't know 88	 → ***go to 25*** → ***go to 25***
24. What activities? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	Training of staff 1 Film 2 Drama 3 Poster presentations 4 Other(specify)_____ 5 Not applicable 99	
25. Have any activities been implemented at this school to help children living with or affected by HIV?	Yes 1 No 2 Don't know 88	***For teachers → go to 36*** ***For principals → go to 27***

26. What activities? ***Do NOT read out options.*** ***PROBE 'any other"?*** ***Multiple responses allowed***	School support for OVC 1 Programs to pay school fees for OVC 2 Funding of school efforts to reduce the impact of stigma and discrimination 3 Specific school services that reduce the impact of stigma and discrimination 4 Other(specify)_____ 5 Not applicable 99	

ID# _____

Questions 27 - 35 are for school principals ONLY

27. How does the school handle an accident or injury with a bleed?	Record response_____ _____ _____ _____ Not applicable 99	
28. If you knew a child **living with HIV** was attending this school would you share this information with the teachers?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
29. Would you share this information with the school nurse?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
30. Would you share this information with other students?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
31. Would you share this information with parents?	Yes 1 No 2 Don't Know 88 Not applicable 99	
32. If you knew a child **affected by HIV** was attending this school would you share this information with the teachers?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
33. Would you share this information with the school nurse?	Yes 1 No 2 Don't Know 88 Not Applicable 99	
34. Would you share this information	Yes 1 No 2	

with other students?	Don't Know 88 Not Applicable 99	
35. Would you share this information with parents?	Yes 1 No 2 Don't Know 88 Not Applicable 99	

ID# _____

STIGMA AND DISCRIMINATION

People have many different feelings when they think about children and/or youth living with or affected by HIV attending school. Please tell me the response that best describes how you feel.

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
36. Children who live with an HIV positive person should not be allowed to attend school.	**1**	**2**	**3**	**4**	**5**
37. A child who is HIV positive should not be allowed to attend school.	**1**	**2**	**3**	**4**	**5**
38. If it were up to me, I would allow a child with HIV to remain in my school.	**1**	**2**	**3**	**4**	**5**
39. Principals should be told if there is a student who has HIV in their school.	**1**	**2**	**3**	**4**	**5**
40. Teachers should be told if there is a student who has HIV in their class.	**1**	**2**	**3**	**4**	**5**
41. Children should be told if there is a student who has HIV in their class.	**1**	**2**	**3**	**4**	**5**
42. Parents should be told if there is a student who has HIV in their child's class.	**1**	**2**	**3**	**4**	**5**
43. If I had a student who had HIV in my school I would not treat him/her differently from other students.	**1**	**2**	**3**	**4**	**5**
44. If there were a separate class for students with HIV I would be willing to teach it.	**1**	**2**	**3**	**4**	**5**
45. If there were a separate class for students with HIV I would be willing to teach it on an occasional basis.	**1**	**2**	**3**	**4**	**5**
46. It would be my responsibility to alert parents to the fact that a particular student has HIV.	**1**	**2**	**3**	**4**	**5**
47. HIV positive students should be segregated for certain classroom activities.	**1**	**2**	**3**	**4**	**5**
48. I feel that HIV is a punishment for sin.	**1**	**2**	**3**	**4**	**5**
49. I think people with HIV deserve what they get.	**1**	**2**	**3**	**4**	**5**
50. I think people with HIV should be ashamed of themselves.	**1**	**2**	**3**	**4**	**5**

51. I think people with HIV should be blamed for their infection.	**1**	**2**	**3**	**4**	**5**
52. If I contracted HIV I would leave the teaching profession.	**1**	**2**	**3**	**4**	**5**
53. I would be comfortable having a student with HIV in the school I work in.	**1**	**2**	**3**	**4**	**5**
54. Schools should conduct HIV education programs in different grade levels from basic/primary school through high school.	**1**	**2**	**3**	**4**	**5**
55. HIV education should begin at basic/primary school.	**1**	**2**	**3**	**4**	**5**
56. All people with HIV should be quarantined.	**1**	**2**	**3**	**4**	**5**

Education and HIV

Dear Parent/Guardian,

The Caribbean Child Development Centre of the University of the West Indies is carrying out a study to find out how people behave towards children and youth affected by HIV and how this may affect their school experiences. The study will compare two groups of children, those affected by HIV (Cases) vs. those not affected by HIV (Controls). Your child/ ward may fall into either of the two categories, and has been identified as a possible participant in this study.

Taking part in this study is completely voluntary. If you or your child/ward does not wish to take part you are free not to do so. Not taking part will not affect you or your child/ward personally in any way nor cause you to lose any benefits you now enjoy such as going to school, the doctor or clinic. For this study we would like to ask you some questions about yourself and your child/ward about himself/herself. There would be two interview sessions. The first interview would be with you; the second interview would be with your child/ward. We would prefer to interview your child/ward privately; however you may be present if you wish. In both interviews we would like to ask you some questions about yourselves, your feelings and thoughts. Each interview should last 30 to 40 minutes. You will be free to not answer any questions that may make you uncomfortable.

There are risks associated with this study. It is possible that your participation may result in some loss of privacy; however we will seek to ensure confidentiality at all times. The following steps will be taken: i) the information would be kept confidential and at no time would your or your child/ward's name be put together with the answers given, ii) your information would be labeled only with a number, never with your name, iii) once completed, the questionnaires would be kept in a locked filing cabinet. When all the questionnaires are completed they will be sent to Jamaica, but names will not be sent. The reports produced would not include any names.

You may ask me any questions that you have. If you have a question that you didn't think of now, you can stop me and ask. Remember you will be free to not answer any questions that may make you uncomfortable.

If you agree to participate and or allow your child to take part in this study, please complete and sign the statement of consent below.

If you have any questions about the study at any time, you may contact Professor Julie Meeks Gardner in Jamaica at the Caribbean Child Development Centre at (876)927-1618 or (876)977-6982; in Barbados, Dr. Glenford Howe, Office of the Principal at the University of the West Indies Open Campus, Cave Hill at (246)417-4024; in St. Lucia, Mrs. Veronica Simon at (758)451-1128 or (758)285-1182; in Guyana , Mr. Andrew Hicks at (592)222-6006.

Yours sincerely,

Professor Julie Meeks Gardner
Principal Investigator

Statement of Consent

The above information has been read by me or read to me and I understand what it says. I was allowed enough time in which to think about whether or not myself and my child would participate in this study.

I _____ agree to take part in the study being conducted by the Caribbean Child Development

(Parent/Guardian's name here)

Centre.

I _____parent/guardian of _____ give permission for him/her to *(Parent/Guardian's name here)* *(Child/Ward's name here)*

take part in the study being conducted by the Caribbean Child Development Centre.

Signature of Parent/Guardian: _____ Date: _____

Signature of Witness: _____ Date: _____

Signature of Interviewer: _____ Date: _____

Education and HIV

Dear Participant,

The Caribbean Child Development Centre of the University of the West Indies is carrying out a study to find out how people behave towards children and youth affected by HIV and how this may affect their school experiences. The study will compare two groups of children, those affected by HIV (Cases) vs. those not affected by HIV (Controls). You may fall into either of the two categories, and have been identified as a possible participant in this study. We would like to ask you some questions about yourself, your feelings and your thoughts. In all, the interview should take about half an hour.

Taking part in this study is completely voluntary. If you do not wish to take part you are free not to do so. Not taking part will not affect you personally in any way nor cause you to lose any benefits you now enjoy such as going to school, the doctor or clinic. You will be free to not answer any questions that may make you uncomfortable. Your taking part is your choice. If you agree to participate then change your mind and want to stop, that is fine. No one would be upset with you. We would like to ask you the questions privately, but your parent/guardian can be present if you want.

There are risks associated with this study. It is possible that your participation may result in some loss of privacy; however we will seek to ensure confidentiality at all times. The following steps will be taken: i) the information would be kept confidential and at no time would your name be put together with the answers given, ii) your information would be labeled only with a number, never with your name, iii) once completed, the questionnaires would be kept in a locked filing cabinet. When all the questionnaires are completed they will be sent to Jamaica, but names will not be sent. The reports produced would not include any names.

You can ask me any questions that you have. If you have a question that you didn't think of now, you can stop me and ask. Remember you do not have to answer any question that may make you uncomfortable. If you would like another adult to be present with you during the interview, that is okay.

If you agree to participate in this study, please complete and sign the statement of consent below.

If you have any questions about the study at any time, you may contact Professor Julie Meeks Gardner in Jamaica at the Caribbean Child Development Centre at (876)927-1618 or (876)977-6982; in Barbados, Dr. Glenford Howe,

Office of the Principal at the University of the West Indies Open Campus, Cave Hill at (246)417-4024; in St. Lucia, Mrs. Veronica Simon at (758)451-1128 or (758)285-1182; in Guyana , Mr. Andrew Hicks at (592)222-6006.

Yours sincerely,

Professor Julie Meeks Gardner
Principal Investigator

Statement of Consent

The above information has been read by me or read to me and I understand what it says. I was allowed enough time in which to think about whether or not I would participate in this study.

I _____ agree to take part in the study being conducted by the Caribbean Child
(Respondent's name here)

Development Centre.

Signature of Respondent: _____ Date: _____

Signature of Witness: _____ Date: _____

Signature of Interviewer: _____ Date: _____

Education and HIV

Hello, my name is (*identify yourself to the child by name).* The Caribbean Child Development Centre of the University of the West Indies is carrying out a study to find out how people behave towards children and youth affected by HIV and how this may affect their school experiences. The study will compare two groups of children, those affected by HIV (Cases) vs. those not affected by HIV (Controls). You may fall into either of the two categories, and have been identified as a possible participant in this study. We would like to ask you some questions about yourself, your feelings and your thoughts. In all, the questions should take about half an hour.

Your taking part is your choice. If you do not want to be in this study, you don't have to be. Remember, being in this study is up to you. You do not have to answer any questions that we may ask if they make you uncomfortable. You can stop me at any time. If you agree to participate then change your mind and want to stop, that is okay. No one would be upset with you. This would not stop you from getting any services or privileges you now get such as going to school, the doctor or clinic. We would like to ask you the questions privately, but your parent/guardian can be present if you want.

There are risks involved in this study for you. If you agree to take part, it is possible that other people may find out private things about you, but we will try at all times to keep this information secret. We will not use your name with any of the answers. All the information that you give us would be given a number, never your name. When completed, your questionnaire will be kept in a locked filing cabinet that only I will be able to open. When all the questionnaires are completed they will be sent to Jamaica, but names will not be sent. The reports produced would not include any names.

You can ask me any questions that you have. If you have a question that you didn't think of now, you can stop me and ask. Remember you do not have to answer any question that may make you uncomfortable. If you would like an adult to be present with you during the interview, that is okay.

If you agree sign the form below. Signing your name at the bottom means that you agree to take part in this study.

If you later have any questions about the study at any time, you may contact Professor Julie Meeks Gardner in Jamaica at the Caribbean Child Development Centre at (876)927-1618 or (876)977-6982; in Barbados, Dr. Glenford Howe, Office of the Principal at the University of the West Indies Open Campus, Cave Hill at (246)417-4024; in St. Lucia, Mrs. Veronica Simon at (758)451-1128 or (758)285-1182; in Guyana, Mr. Andrew Hicks at (592)222-6006.

Yours sincerely,

Professor Julie Meeks Gardner
Principal Investigator

Statement of Assent

The above information has been read by me or read to me and I understand what it says. I was allowed enough time in which to think about whether or not I would participate in this study.

I _____ agree to take part in the study being conducted by the Caribbean Child Development
(Name of child)

Centre.

Signature of Respondent: _____ Date: _____

Signature of Witness: _____ Date: _____

Signature of Interviewer: _____ Date: _____

Education and HIV

Dear Principal/Teacher,

The Caribbean Child Development Centre of the University of the West Indies is carrying out a study to find out how people behave towards children and youth affected by HIV and how this may affect their school experiences. The study will compare two groups of children, those affected by HIV (Cases) vs. those not affected by HIV (Controls). You have been identified as a possible participant in this study.

Taking part in this study is completely voluntary. If you do not wish to take part you are free not to do so. Not taking part will not affect you personally in any way nor cause you to lose any benefits you now enjoy. For this study we

would like to ask you some questions about national HIV policies, school HIV policies and related programmes. Each interview should last 20 to 30 minutes. You will be free to not answer any questions that may make you uncomfortable.

There are minimal risks involved. It is possible that your participation may result in some loss of privacy; however we will seek to ensure confidentiality at all times. The following steps will be taken: i) the information would be kept confidential and at no time would your or your school's name be associated with the answers given, ii) your information would be labeled only with a number, never with your or your school's name, iii) once completed, the questionnaires would be kept in a locked filing cabinet. When all the questionnaires are completed they will be sent to Jamaica, but names will not be sent. The reports produced would not include any names.

If you agree to participate please complete and sign the statement of consent below.

If you have any questions about the study at any time, you may contact Professor Julie Meeks Gardner in Jamaica at the Caribbean Child Development Centre at (876)927-1618 or (876)977-6982; in Barbados, Dr. Glenford Howe, Office of the Principal at the University of the West Indies Open Campus, Cave Hill at (246)417-4024; in St. Lucia, Mrs. Veronica Simon at (758)451-1128 or (758)285-1182; in Guyana, Mr. Andrew Hicks at (592)222-6006.

Yours sincerely,

Professor Julie Meeks Gardner
Principal Investigator

Statement of Consent

I have read and understand the above information. I was allowed enough time in which to think about whether or not I would participate in this study.

I _____ agree to take part in the study being conducted by the Caribbean Child
(Principal/Teacher's name here)

Development Centre.

Signature of Principal/Teacher: _____ Date: _____

Signature of Witness: _____ Date: _____

Signature of Interviewer: _____ Date: _____

Appendix III: Ethical Approval for the study

THE UNIVERSITY OF THE WEST INDIES
OPEN CAMPUS

E.P. BRANDON, SENIOR PLANNING OFFICER, PLANNING AND DEVELOPMENT

OFFICE OF THE PRO-VICE-CHANCELLOR AND PRINCIPAL

P.O. Box 1341, Bridgetown BB11000, BARBADOS

Phone: (246)417-4023; Fax: (246) 424-0722; email: ed.brandon@open.uwi.edu

9 December 2009

Professor Julie Meeks Gardner
Director, Consortium for Social Development and Research
c/o Caribbean Child Development Centre (CCDC)
P.O. Box 141,
UWI, Mona
Kingston 7
Jamaica

Dear Professor Meeks Gardner

On behalf of the Research Ethics Committee of the Open Campus, I am writing to say that the Committee now approves your proposed study, "Strengthening HIV AIDS and Education Research in the Caribbean," following acceptable amendments to the instruments and other adjustments as requested.

.

Yours sincerely

E P Brandon

E.P. Brandon

Appendix IV: List of project steering committee members

Project Steering Committee members in St. Lucia

Ms. Brenda Emmanuel – Human Rights Advocate, Human Rights Desk.

Mrs. Natasha Lloyd – Felix – Line Ministries and Civil Society Coordinator, National AIDS Programme Secretariat.

Ms. Tara Leonard – Social Worker (OVC), Department of Human Services.

Mrs. Joan Didier – Director, AIDS Action Foundation.

Mrs. Sonia Alexander – Director (Ag) National AIDS Programme, Ministry of Health.

Mrs. Sophia Edwards-Gabriel – HIV/AIDS Focal Point, Ministry of Education.

Mrs. Veronica Simon – Head, UWI Open Campus, St. Lucia

Project Steering Committee members in Guyana

Ms. Inge Nathoo – Secretary General, Guyana National Commission for UNESCO.

Ms. Janelle Sweatnam – HIV Focal Point, Ministry of Education.

Mr. Andrew Hicks – Head, Department of Sociology, University of Guyana.

Ms. Dionne Brown – Ministry of Education

Dr. Rosalinda Hernandez – PAHO

Ms. Samantha Hall – UNAIDS

Mr. Ajay Baksh – UNAIDS

Dr. Karen Gordon – Boyle – GHARP II

Mr. Dale Browne – GHARP II

Ms. Diana Lawrence – Ministry of Human Services

Dr. Shanti Singh – National AIDS Programme Secretariat

Mr. Lyndon Welch – People Living with HIV Community

Mr. Dimitri Nicholson – Youth Challenge Guyana

2 UNICEF Representatives

Appendix V: Stakeholders' Consultation reports – St. Lucia

Report

Of

Consultation to Present the Findings of a Research Project

On

"The Impact of HIV Related Stigma and Discrimination on Children's Learning Outcomes and School Related Experiences"

Prepared by: Patricia Joseph

Table of Contents

Report

of Consultation to Present the Findings of a Research Project on "The Impact of HIV Related Stigma and Discrimination on Children's Learning Outcomes and School Related Experiences"

Date: Wednesday October 13, 2010

Venue: Conference Room, University of the West Indies, Open Campus, Morne Fortune, Castries

Chair: Mrs. Natasha Lloyd – Felix

Participants: Twenty four (24) persons attended the exercise (Appendix 1)

In addition to participating officials and presenters other participants included representatives of the Ministry of Education, Non- governmental Organizations (NGOs) such as the network of persons living with /affected by HIV & AIDS and the AIDS Action Foundation (AAF), the National AIDS Programme Secretariat (NAPS) of the Ministry of Health, and the Division of Human Services.

Three (3) parents who had participated in the research were also in attendance.

The attendance represents less than half of persons invited from various sectors, organizations and government ministries. All parents and schools participating in the research were formally invited.

Programme:

The programme for the day was guided by a prepared agenda

Opening Session:

Prayer:
Prayers were done by Mrs. P. Joseph at the start of the opening session.

Introductions:
The exercise began with the introduction of the members of the head table by the chairperson.

Opening Remarks by Ms. Marcia Symphorien, Secretary General Saint Lucia National Commission for UNESCO:

In her remarks the Secretary General indicated that UNESCO regarded an education sector response to HIV and AIDS as being extremely significant and also a priority for UNESCO. She also posited that a national HIV program would be incomplete without a response by the education sector.

The Secretary General also spoke of the research as having been one involving major collaborators such as UNESCO, UWI (CCDC), and the Ministry of Education with a Multi – Agency Project Steering Committee guiding the process.

The importance of the research and other much needed ones was underscored in order to move from reliance on anecdotes to a place where policies, comprehensive programs and plans within the education sector will be evidence – informed.

Presentation on HIV and AIDS and the National Response in Saint Lucia by Mrs. Erma Jules – Smith, M&E Officer, National AIDS Programme Secretariat (NAPS):

Mrs. Jules - Smith informed the gathering that the establishment of the NAPS in 2005 had been a mandate from the Cabinet of Ministers to coordinate HIV and AIDS activities at the national level, with funding from the World Bank.

The main activities undertaken by the NAPS during the previous five years according to Mrs. Jules - Smith were:

- Sensitization and awareness – raising among the general population
- Monitoring and evaluation
- Support for persons living with HIV or AIDS (PLHAs) as well as orphans and vulnerable children (OVCs)
- Community outreach to and mobilization of the most – at – risk populations (e.g. prisoners, MSM, sex workers, drug –users)
- Counselling and Testing in HIV
- Treatment including Antiretroviral
- Policy development
- Support
- Reducing stigma and discrimination

Activities were undertaken with the support of the private sector, NGOs and FBOs and other government ministries

Mrs. Jules – Smith identified the major successes of the programme as:

- A reduction in HIV – related mortality
- A reduction in perinatal transmission of HIV

- Increased number of patients in care on ARVs leading to reduction in morbidity and mortality

On the way forward for the national programme the priorities were said to include:

- A greater emphasis on research
- A revised National Strategic Plan with a greater focus on the Most – at - risk populations (MARPS)
- Increased care and support for PLHIVs
- Reducing stigma and discrimination

Presentation on the Education Sector's Response to HIV and AIDS in Saint Lucia by Mrs. Sophia Edward – Gabriel, Chairperson Project Steering Committee:

Mrs. Gabriel was also the HIV & AIDS Focal Point for the education sector in the recent past and is currently the HFLE Curriculum Specialist in the Ministry of Education.

Mrs. Gabriel began her presentation by providing a brief background to and status of the epidemic in Saint Lucia. She then went on to highlight the social, cultural, behavioural, and economic and development factors driving the HIV epidemic

Mrs. Gabriel paid special attention to adolescents with regard to sexual initiation and contraceptive use.

In response to the question "why education?", Mrs. Gabriel aptly summed it up with a quote from the 2008 EDUCAIDS Framework for Action.

"Education is one of the most effective "social vaccines" to prevent HIV/AIDS"

"It has become increasingly clear that in order to achieve EFA and the education related MDGs… it is essential for the education sector to address HIV and AIDS" (EDUCAIDS Framework for Action 2008)

The possible impact of HIV on the education sector as outlined by Mrs. Gabriel included effects on the demand and supply side of the sector, the quality as well as the sector's ability to plan effectively.

The key elements of an effective response to HIV by the education sector identified include comprehensiveness, quality, curriculum content and training materials, educator training and support, and issues relating to policy, management structures and appropriate systems.

The challenges to an effective response by the education sector were also identified:

- HIV policy for the education sector still at "draft" stage and not ratified by the Cabinet of Ministers
- Absence of a specific management structure to guide and monitor the sector's response
- Weaknesses in the sector's advocacy and resource mobilization efforts
- The inadequacy of the HFLE curriculum which needs to be revised and updated
- Lack of appreciation for the importance of HFLE within the school system
- Scarcity of teaching and learning materials
- Paucity of research to inform and assess programmes
- The continued existence of stigma and discrimination

Mrs. Gabriel summed up her presentation with the following recommendations:

1. Establish a functional HIV committee for the education sector
2. Revive HIV & AIDS committees at the district level
3. Adopt and implement the HIV policy for the education sector
4. Revise and cost the strategic plan for the education sector
5. Include the HIV strategic plan into the education sector's strategic plan
6. Revise the HFLE curriculum to include life skills as also strengthen the HIV component of the curriculum
7. Engage partners in a consultative and collaborative process in order to strengthen the education sector's response

Presentation on the Situation of Children Living With and Affected by HIV and AIDS in Saint Lucia by Ms. Tara Leonard, School Counsellor/Social Worker:

Ms. Leonard began her presentation by defining the terms "child", "vulnerability", "child vulnerability", and "OVC"

Ms. Leonard then informed the gathering that to date one hundred and ninety nine (199) infected and affected children were on the Orphans and Vulnerable Children (OVC) register.

Prior to the start of the HIV project in 2005 there had not been a system in place to effectively deal with OVCs. Ms. Leonard noted the absence of the following:

- A database of infected/affected children
- A specific programme for OVCs
- Psychosocial support

- Parental support for OVC involvement in programmes or names being recorded with the department for fear of stigma and discrimination

Ms. Leonard identified the various services provided for OVCs under the HIV & AIDS programme:

- Skills building programme
- School books and other school supplies
- Foster Care/Public Assistance
- Food Bank
- Referrals to appropriate services and organizations
- Assistance with public transportation

Ms. Leonard highlighted the importance of programmes for OVCs when she identified the link between OVC care and support and the Millennium Development Goals (MDGs). She indicated that this was linked to six (6) of the eight (8) MDG goals and directly to goals two and six (2 & 6) and indirectly to goals three, four and five (3, 4, & 5).

Ms. Leonard in her final words warned of the cost of exclusion of OVCs from HIV programming. This quote by her does justice to her sentiments. “Inequality and social exclusion have been proven to hamper economic development and social stability”.

Closing Remarks:

The closing remarks were done by Mrs. Veronica Simon who expressed pleasure at having been able to facilitate the process through the office of Open Campus.

However she expressed her disappointment at the absence of some key players especially those with responsibility for policy making. But she did indicate that those present were in a position to still make a difference within their own sphere of influence.

Presentation of Research Findings: Methodology, Data and Analysis By Ms. Joan Thomas, Research Fellow, Caribbean Child Development Centre, Consortium for Social Development and Research, UWI Open Campus and the UNESCO Kingston Cluster Office

Introduction:

Ms. Thomas began her presentation with an overview of the research project and the steps and processes that were involved.

The goal and objectives of the research project were identified.

Project Goal

To strengthen HIV and AIDS and Education research in the Caribbean in support of evidence-based policies and practices in education on HIV prevention, care, support and treatment

The Main Objective:

To describe the nature and extent of HIV-related stigma and discrimination among school-aged children in the Caribbean

Specific Objectives:

- To describe experiences of HIV-related stigma and discrimination by children infected and affected by HIV

- To describe the school experiences and learning outcomes of children infected and affected by HIV
- To relate HIV-related stigma and discrimination to school outcomes

Ms. Thomas then outlined the other key elements of the research such as the methodology used, criteria for inclusion/exclusion, the sample size and the challenges in obtaining a sample frame in order to be able to get an adequate sample that would yield statistically sound results.

In the final analysis the number of respondents that were interviewed with the questionnaires were; ten (10) infected/affected children, ten (10) comparison children, twenty (20) caregivers which included the infected/affected as well as the comparison children, ten (10) teachers and seven (7) school principals.

Early on in the presentation Ms. Thomas indicated to participants that because of the small sample, caution would have to be used in the interpretation of the results. As in many instances while differences were noted between the target group and the comparison, these were not found to be statistically significant enough to draw a definitive conclusion.

Results:

Ms. Thomas presented the background information and specific demographics regarding the children in the study.
The same was done for parents as well as teachers.

The presentation of the study results focussed on the following areas:

1. School attendance
2. School experiences

3. School performance
4. Symptoms of/experience with anxiety and depression
5. Manifestations of prosocial behaviours and conduct problems
6. Perceived and enacted stigma for infected and affected
7. Perception of stigma by comparison children with reference to infected/affected
8. How stigma and discrimination relate to school outcomes for both groups
9. Knowledge of HIV transmission
10. Knowledge of classmates/peers who are infected
11. Knowledge of students infected in school or class by teachers
12. Children's opinions on HIV disclosure
13. Parents' opinions on disclosure of HIV status to school personnel and other parents and students
14. Parents' opinions on disclosure of HIV status to school personnel and other parents and students
15. HIV disclosure by infected/affected children and parents
16. Attitude of other children, teachers and principals towards children infected/affected by HIV
17. Knowledge of national, ministerial and school level HIV policies, programmes and education activities by principals and teachers
18. Students' knowledge of and participation in school HIV activities

Ms. Thomas concluded her presentation by stating that the findings could be used to develop HIV policies and programmes however there is need for caution because of the small sample size of the target population.

Ms. Thomas also took time out to express gratitude to those who had participated in the process of getting the research study done

Plenary and Discussion:

The exercise generated a great deal of discussion among participants. The following key areas of concern stood out.

- It was recognized that there was still a need for strengthening the capacity of all the sectors in order to improve on the HIV response especially to youth
- Concern was raised and echoed by various individuals with regard to the end of the HIV project and the gaps which it now left especially for OVCs and their families
- The inability of adolescents to access appropriate health care due to legal and other barriers was seen as a major stumbling block to effectively deal with the sexual and reproductive health issues of that age – group
- Support systems, policies, adequate structures and budgetary allocations are critical to an effective and sustained response
- A great deal of discussion ensued on the disclosure that most principals and teachers in the study had indicated little or no knowledge of HIV programmes and activities within the education sector or at the school level
- The monitoring and evaluation of Health and Family Life Education (HFLE) activities at the school level was also identified as a critical issue since the main vehicle used for HIV education and HIV related activities is HFLE

- It was suggested that special interventions were needed with principals in the areas of policy, HIV programming and advocacy
- The need for the adoption of the HFLE and HIV policies was cited as being very important in order to ensure standardization of the teaching of HFLE throughout the education and other sectors
- The civil society organizations present expressed that there was need for their greater participation in the HIV response especially within the education sector and by extension at the school level
- Other research findings with regard to the vulnerability of the 15 – 24 year olds (to which the target population of this study would belong) was highlighted as pointing to a need for prevention activities within a multi – sectoral response
- There was a call for the revival of the District HIV Committees within the education sector in order for the HIV education and HIV related activities at the district and school level to be effective and sustained
- Some were hopeful that with Mrs. Gabriel now responsible for HFLE curriculum activities, and her own keen interest and HIV experience in the education sector, that things would begin to happen to make a difference in the system and by extension in the lives of the children
- The research effort was commended and participants expressed the need for more research to inform programmes and evaluate existing ones

Appendix 1

Consultation to Present the Findings of a Research Project on "the Impact of HIV Related Stigma and Discrimination on Children's Learning Outcomes and School Related Experiences"

Participants' List

NAME	INSTITUTION/ORGANIZATION
Celestine Mederick	Parent
Brenda Emmanuel	AAF/TLC
Patricia Joseph	Independent Consultant
Leah Goring	Division of Human Services and Family Affairs
Petrona Clovis	TLC
Bianca Lawrence	Ministry of Education
Cashona Emmanuel	Ministry of Education
Elizabeth Mathurin	Parent
Lisa Albert	TLC
Joan Didier	AAF/OECS RCM
Virginia d'Auvergne	Ministry of Education, Student Support Services
Kady Fletcher	Soufriere Comprehensive Secondary School
Erma Jules	National AIDS Programme Secretariat (NAPS)
Pius Stephen	Counsellor, Ministry of Education
Josephine Romain	Counsellor, Ministry of Education
Suzanna P. Gabriel - Valcin	Counsellor, Ministry of Education
Dianne Charlery	Parent
A. Emmanuel	Counsellor, Ministry of Education
Sophia Edwards Gabriel	Curriculum Specialist HFLE – Ministry of Education
Natasha Lloyd - Felix	NAPS
Marcia Symphorien	Secretary General, National Commission for UNESCO
Tara Leonard	School Counsellor, Ministry of Education
Veronica Simon	Head, UWI Open Campus, St. Lucia

Joan Thomas	Research Fellow CCDC,CSDR, UWI Open Campus, Jamaica

Appendix VI: Stakeholders' Consultation reports – Guyana

Report

Stakeholder's Meeting to present the findings of the HIV Stigma Research Project:

The impact of stigma against children living with and affected by HIV on their learning outcomes and school experience

Grand coastal Inn

Friday October 15th, 2010

8:30- 1:30pm

Report compiled by:

UNESCO, Guyana Secretariat & Ministry of Education, Guyana

Objective

To present the findings of the research on the impact of stigma against children living with and affected by HIV on their learning outcomes and school experience.

Introduction

The stakeholders' meeting on the presentation of the findings for the HIV Stigma Research Project commenced at 9:00 am on Friday October 15th, 2010 at the Grand Coastal Inn. Forty stakeholder representatives working with or affiliated with OVC attended the meeting.

Also in attendance was the Honorable Minister of Health, Dr. Leslie Ramsammy, Ms. Inge Nathoo, Secretary General, Guyana National Commission for UNESCO, who chaired the proceedings; Ms. Donna Chapman, Acting Deputy Chief Education Officer, Administration, who gave opening remarks, Mr. Nicholas Persaud of the National AIDS Programme Secreatariat, who shared the National Response to HIV and AIDS in Guyana, and Ms. Janelle Sweatnam, HIV and AIDS Focal Point, who facilitated a working group session on Policy and Programming for the Education's Sector HIV and AIDS response.

Media

Coverage was extensive from the following media houses that attended the function: Stabroek Newspaper, Kaieteur Newspaper, Channel 28, Channel 9, and Channel 65. Stabroek Newspaper of (16th October), Guyana Times Newspaper (16th and 18th) and Kaieteur Newspaper of (16th and 19th October) published articles on the presentation.

The Meeting

-Opening Remarks

Ministry of Education- Ms. Donna Chapman

Ms. Donna Chapman, Acting Deputy Chief Education Officer, Administration, gave opening remarks on behalf of the Minister of Education. She bemoaned that the 'dark shadow' that still hovers over HIV&AIDS is the shadow of stigma and discrimination. See complete speech in appendix.

Ministry of Health- Honorable Leslie Ramsammy

The Honorable Minister of Health, Minister Leslie Ramsammy shared on Stigma and Dissemination in Guyana and the fact that stigma in any form should not be tolerated. He further said that stigma is a cancer that destroys and it is evil and should be rejected outright. See Newspaper articles in appendix for a complete report on his speech.

-Presentations

National AIDS Programme Secretariat- Nicholas Persaud

Mr. Nicholas Persaud of the National AIDS Programme Secretariat shared the National Response to HIV and AIDS in Guyana. He provided a graphic description of the National HIV Response, highlighting the various services available through the response. See appendices for complete presentation.

-Overview of the Project- Ms.Inge Nathoo-Secretary General, UNESCO

Ms. Inge Nathoo, UNESCO Secretary General, Guyana National Commission for UNESCO, chaired the proceedings and also presented the overview of the project to the stakeholders. Ms. Nathoo highlighted the purpose of the research and the partnerships involved in project and a chronological account of the project implementation was given. See appendix for complete speech presented to the stakeholders.

-Presentation of Findings

Ms. Joan Thomas, Research Fellow, CCDC's Consortium for Social Development and Research, UWI, Open Campus, presented the findings of the research. Printed copies of the summary of the findings were presented to the working group participants while a power point presentation with in depth analysis and explanations of the findings was given in the presence of the media and special speakers. Participants question and answer segment was facilitated in the after break session. No major concerns were noted in this session. See appendices for summary of findings which was disseminated to participants.

-Sharing of experience by Committee Member- Mr. Lyndon Welch

Mr. Lyndon Welch in his brief remarks about his experience on the Project Steering Committee shared that at we must protect our children socially and economically. He noted that more work in the field of stigma and discrimination is needed. He said that it was a great experience to be involved in the work of the project steering committee as the PLWHIV community representative. Mr. Welch reiterated that the lessons learnt would be of tremendous benefit to the HIV Community Support Group.

-Working Groups Session- Facilitated by HIV Focal Point, Ministry of Education, Ms. Janelle Sweatnam

Participants of the working groups were introduced to this session with an introduction to the aim of the research as it related to HIV policies and programming for the education sector. The following was stated:

AIM: Strengthen HIV & AIDS and Education research in the Caribbean and to provide evidence based policies and practices in education on HIV Prevention, Care, Support and Treatment.

Purpose of Session: To provide a minimum of five (5) Policy and Programme Recommendations for the education sector response to HIV & AIDS as it relates to Orphan & Vulnerable Children:

Responses obtained from the participants within the working groups:

Group 1

1. Have trained social workers who are knowledgeable and experienced in HIV &AIDS
2. Return Guidance and counseling to the school curriculum from primary school level.
3. Use of edutainment in the dissemination of information to the schools.
4. Allow for Non Governmental Organizations to be involved in disseminating information in HIV and STD.
5. Strict Policy on confidentiality to protect student's information.
6. Consistent training of teachers on information pertinent to the transmission, prevention and treatment of HIV

Group 2

Policies:

1. Protection of children against being discriminated
2. Policies that target in –School Youth and Stigma and discrimination

Programmes:

1. Foundation programmes should be in place before purely HIV&AIDS programme are presented- (Positive parenting & life skills)
2. Basic training for responsible teachers and parents about HIV transmission and HIV counseling.

3. Teaching of family planning methods to children from an early age.
4. Revision of pamphlets to meet the needs of various target groups, (N.B the beneficiaries should be involved in the development of the pamphlet.

Group 3

1. Provide continuous counseling and support for children infected and affected with HIV.
2. Create awareness about policies and laws. Get principals and teachers involved in developing action plans based on the policies.
3. Build self worth in Children- Parenting programs, guidance & counseling, referral to spiritual enhancement.
4. Improved HIV education programs targeting, principles, teachers & children.
5. Nutrition & Health programs to maintain positive school outcomes.- PTAs

Group 4

1. MOE should continue to integrate HIV in the HFLE programme.
2. The present study should be replicated at the national level.
3. Collaboration between relevant ministries (Ministry of Education, Ministry of Health, and Ministry of Human Services &Social Security) should be enhanced.
4. MOE should introduce systems for mandatory staff development training on HIV & related issues.
5. MOE School Health, Nutrition and HIV&AIDS Policy should be more widely disseminated and operationalised in the public and private schools.

Group 5

1. Dissemination of the School Health, Nutrition & HIV&AIDS Policy to the principals through workshop sessions.
2. Provision of and training in the existing School Health, Nutrition & HIV&AIDS policy for teachers/educators.

3. Development of school specific code of ethics.
4. Every school should have a Health and Family Life Education programme.
5. Education and awareness sessions for parents and guardians.
6. Organised community forums for the dissemination of the School Health, Nutrition and HIV&AIDS Policy and other relevant information relating to HIV&AIDS.

Conclusion

Challenges

The challenges experienced were mainly in the roll out of the project in Guyana. These are as follows:

- Communication gaps existed between the oversight and the implementing body throughout the duration of project. Regular Project Steering committee meetings could not have been held because of the delay in the commencement of the data collection process and timely feedback from the relevant persons to the oversight body. Calling a meeting to order deemed fruitless at many stages of the project.
- Protocols with the RA and the Ministry of Education were not followed as RA approached the Principals and Class Teachers during the data collection process without the support of the Ministry of Education. Hence the Ministry is without the information as to the schools that were involved in the research.
- The entire quorum of stakeholder representatives was not present for the workgroup session and the necessary adjustments had to be made to work with the reduced participants.

Next Steps

The recommendations emanating from the working group presentation will be shared with the honorable Minister of Education and Senior Officers within the Ministry so that the necessary actions can be taken.

The recommendations for policy and programming will also be used to guide the work of the HIV Focal point in the education sector response to HIV &AIDS.

The findings of the research revealed little or no knowledge of HIV awareness programs and Policies in the schools. Based on this finding, a rapid roll out of the School Health, Nutrition and HIV&AIDS Policy & the Guyana National HIV Strategic Plan will be undertaken commencing at the schools utilized in the research.

Appendix VII: Abstract for Caribbean Child Research Conference

ABSTRACT

Submitted to the Caribbean Child Research Conference 2010

TITLE: Children Infected and Affected by HIV: School Experiences and Stigma and Discrimination

AUTHORS: Joan Thomas, Amika Wright, Julie Meeks Gardner

INSTITUTION: Caribbean Child Development Centre, The University of the West Indies, Open Campus

ABSTRACT:

Few data exist regarding Caribbean children affected by HIV. We report on school experiences and HIV-related stigma and discrimination in St. Lucia. Children (12-17 years: 2 HIV+ and 8 affected by HIV) and 10 age- and gender-matched classmates were asked about HIV-related stigma/discrimination and school experiences. School achievement was assessed with WRAT III. Caregivers (n=20), principals (n=7) and teachers (n=10) were also interviewed: caregivers about stigma/discrimination, their children's behaviours and school experiences, and principals and teachers about stigma/discrimination and HIV policies and programmes. Infected/affected children and their classmates reported similar school experiences; liking school, classmates and teachers; school achievement and behavior (child and parent reports). More classmates blamed/ judged HIV+ people for their illness. Some infected/affected children reported stigmatization/ discrimination. Most principals and teachers reported knowledge of national HIV policies and HIV education programmes, but no school-specific HIV policies. This information should be considered in future policies and actions.

(Word count: 149 words)