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## **Protecting HIV+ Children in Jamaica: Exploring Policy, Practice and Institutional Responses**

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### **Abstract**

HIV/AIDS is widespread in Jamaica with circa 32,000 individuals, including circa 2,700 children and young people, a prevalence rate of approximately 1.7% of the adult population (Ministry of Health, Jamaica, 2011). This is a threat to development in a country of 2.7 million. Lack of education, stigma and discrimination are among the key drivers behind the spread of HIV in Jamaica. This study was convened to understand the schooling experience of HIV+/AIDS children and young people in Jamaica. At the moment, there is only a limited body of research literature on this topic in the Caribbean. The theoretical perspective used to scaffold this study was based in Human Rights. Documentary Analysis, Focus Groups and In-depth Interview were the main qualitative methods used in this two-phase socio-legal study. The main conclusions arrived at are that HIV+/AIDS children and young people are well supported by a tapestry of international, national laws and policies, and local support services that coalesce to safeguard the status and personhood of an HIV+ young person.

**Keywords:** HIV/AIDS, Children, Jamaica, Schooling, Policy, Practice, Institutional Responses, Human Rights.

## **Table of Contents**

1.0 Introduction

2.0 Conceptual Framework

2.1.1 International Legal Context

2.1.2 Inclusion, Participation and Non-discrimination

3.0 Literature Review

3.1 The Global Scale and Scope of HIV/AIDS

3.2 HIV and AIDS in the Caribbean

3.3 HIV/AIDS in Jamaica

3.4 Government Intervention

4.0 Methodology

5.0 Findings, Discussion and Conclusions

5.1 Jamaica's Legislative Framework

5.2 Jamaica's Policy Framework

5.3 Policy – Practice Environments

5.3.1 Policy Awareness

5.3.2 Stigma and Discrimination

5.3.3 Promoting Inclusion

5.4 Evaluation of Policy, Practice and Institutional Responses

5.5 Conclusions

References

Appendices

Appendix A: Legislative and Policy Environments

## 1.0 Introduction

Perhaps not many individuals could conceive that the HIV/AIDS pandemic could well be one of earth's worst weapons of mass destruction, endangering young and old alike. Its spread has had a severe impact on many of the world's poorest and most under resourced peoples. Consequently Jamaica, like other countries across the world, must continue to combat ignorance, denial, stigma and discrimination which are themselves potent agents contributing to the spread of HIV/AIDS.

George Alleyne, a former medicine professor at the University of the West Indies and a former Director of the Pan American Health Organisation (PAHO), in a speech to the Jamaican parliament in 2002 suggested the HIV epidemic 'requires appropriate policies and a legal framework so that organising against AIDS is supported, and the corrosive impact of discrimination countered, including that against those groups and individuals in society who are most vulnerable to AIDS' (Kelly, 2003, p.21). Alleyne also advocated for the Caribbean to be free from a cycle of mental slavery which he argued was fuelling homophobia and discrimination against persons perceived as living a lifestyle of which others in society did not or do not approve.

At a Regional Meeting of Ministers of Education in Latin America and the Caribbean in 2002, it was discussed that education is integral to the fight against HIV and AIDS, and that the disease will not be overcome without the full involvement of the education sector. For example, the education ministers present at the meeting acknowledged that more could be done through the education of teachers and students to prevent the spread of HIV. They also affirmed the need to provide support and care to affected and infected educators and learners, and they recognised that creative measures were required to limit the impact of the epidemic on the region's education sector (UNESCO, 2002).

Health and education demand serious investment since each has to do with the trajectory of humans. Freedom from disease is closely related to freedom from ignorance and both can lead

to other freedoms. All three conditions - disease, ignorance and hunger - promote poverty, and their alleviation and eradication underpins a nation's development agenda. National development therefore makes more sense when human beings, in terms of their health and wellbeing, their education and aspirations, are placed at the heart of the process of development. When this is done, good health, a widely recognised indicator of the quality of life and a positive measure of social capital, takes on new meaning.

But education must not be only for the young. Affette McCaw-Binns observed that "the control of the major chronic diseases will require renewed health promotion efforts at community level to bring about the lifestyle changes needed to reduce the risks associated with the development of HIV" (Kelly, 2003, p.23). In other words, education at all ages is necessary to clarify myths and allay fears associated with HIV/AIDS. Linking policy leadership to educational leadership and the potential for change through combining them, Miller asserts that, "if sound leadership at the policy level is a seed of development, then sound leadership of educational institutions and at the classroom level is arguably a flower of development (Miller, 2012. p.9).

In the Caribbean the spread of HIV is second only to that occurring in southern Africa; and within the Caribbean region itself, Jamaica has the second highest rate of HIV+ persons, behind Hispaniola (UNAIDS, 2010). The social and economic implications are extensive since the disease threatens to deprive the entire region of much of its youth who are, put simply, tomorrow's generation. In the words of Nettleford "The HIV/AIDS pandemic is to this generation of Caribbean people what tuberculosis was to the generation of the 50s-60s" (Kelly, 2003, p.24).

Although new HIV infections in Jamaica have declined by 25% in the last decade (UNAIDS, 2014), children and young people in Jamaica are at risk of losing their lives due to the spread of the disease among young men, young women of child-bearing age, and children born to mothers with the virus. Consequently, and in addition, Jamaica must do all it can to not replicate the tragedy of some southern African countries where tens of thousands of children are orphaned and are left

to raise themselves; up from 0.2% of all children in 1980 to 3.2% in 2010 (Avert, Caribbean, 2015).

## **2.0 Conceptual Framework**

### 2.1.1 International Legal Context

Human rights concerns of the HIV/AIDS epidemic cover the full range of civil, political, economic, social and cultural rights. There is only limited discussion about human rights and HIV in the Caribbean (Chill News, 2011). Nevertheless, customary international law and international legal treaties, signed by Jamaica, underpin the basis of the international law of human rights. The International Covenant on Economic, Social and Cultural Rights (1966); the International Covenant on Civil and Political Rights (1966); the Convention on the Elimination of all forms of Discrimination against Women and the Convention on the Rights of the Child (1989) are all examples. The treaties of the International Labour Organisation (ILO) on issues such as workplace discrimination are also important, as are general comments of UN treaty committees, resolutions of the Commission on Human Rights, and the International Guidelines on HIV/AIDS and Human Rights. The Office of the High Commissioner on Human Rights (OCHR, 2002) outlines the following human rights relevant to HIV and AIDS.

The right to non-discrimination, equal protection and equality before the law

The right to life

The right to the highest attainable standard of physical and mental health

The right to freedom of expression

The right to freedom of movement

The right to seek and enjoy asylum

The right to privacy

The right to freedom of opinion and expression and the right to freely receive and impart information

The right to freedom of association

The right to work

The right to marry and found a family

The right to equal access to education

The right to an adequate standard of living

The right to social security, assistance and welfare

The right to share in scientific advancements and its benefits

The right to participate in public and cultural life

The right to be free from torture and cruel, inhuman or degrading treatment or punishment

(OCHR, 1998; OCHR/UNAIDS, 2002)

International law recognises that some rights, such as those relating to universal education or health care, must necessarily be achieved progressively in developing countries such as Jamaica. However, even among these rights, are 'core obligations' (such as essential primary health care, basic housing and education) which should be met immediately. In all cases, State parties should take deliberate, tangible and targeted steps towards fulfilling these obligations. Where appropriate legislation does not exist, States parties are expected to adopt legislation to ensure services are provided without discrimination of any kind (United Nations CESCR, 1990).

### 2.1.2 Inclusion, Participation and Non-discrimination

A key principle that has come from decades of responding to HIV/AIDS is that people living with and affected by HIV/AIDS are at the centre of a human rights approach. Referred to as the 'GIPA Principle', i.e. the Greater Involvement of People Living with HIV/AIDS (GIPA), this principle supports the non-discrimination agenda and underlines the importance of participation by all

persons infected or affected by HIV/AIDS as set out in the pyramid of involvement (UNAIDS, 1999).

Discrimination leads to fear, denial, apathy, and isolation. By limiting or preventing the participation of people who are infected and affected by HIV/AIDS, discrimination retards public health prevention and care efforts. Respecting and enforcing human rights are essential to securing meaningful inclusion and effective participation. As suggested by the United Nations, 'An environment in which human rights are respected ensures that vulnerability to HIV/AIDS is reduced' (United Nations, 1998). Additionally, as has been suggested by the Canadian International Development Agency (CIDA), a human rights approach to HIV/AIDS is both objective (safeguarding human dignity) and goals orientated (providing an enabling environment). In other words, both *processes* (such as: participation, transparency, accountability) and *substantive elements* (such as: the protection of the vulnerable - especially women and children; and protection from discrimination) must be seen to be in sync (United Nations, 1998).

### **3.0 Literature Review**

#### **3.1 The Global Scale and Scope of HIV/AIDS**

In 2013, UNAIDS reported some 35.3 million (32.2 million–38.8 million) people were living with HIV; 2.5 million (1.6 million–3.4 million) of them were children under 15 years (notably the number of children newly infected in 2012 was 35% lower than in 2009) and about 15.9 million (14.8 million–17.2 million) were women. UNAIDS also suggests that every day, circa 7,000 persons become infected with HIV and circa 5,000 persons die from AIDS, due mostly to lack of access to HIV prevention, care and treatment services. Globally, AIDS-related illnesses remain a leading cause of death (UNAIDS, 2013).

The spread of HIV/AIDS has resulted in the continued upward revisions of HIV/AIDS estimates and projections. The disease continues to exceed even the most cynical projections and reveals

two things. First, at the start of the twenty-first century, the world was experiencing an early phase of the epidemic. Prevalence levels climbed higher than previously believed possible in the worst affected countries, while the disease continued to spread rapidly into new populations in Africa, Asia, Eastern Europe and the Caribbean (UNAIDS, 2010). Second, HIV/AIDS is showing itself to be an ever changing epidemic, manifesting itself in different ways in different situations. Its outcomes are complex and surprising and it's not possible to anticipate all of them (Kelly, 2008). As a result, any response, especially those from the health and education sectors should remain flexible *enough* to accommodate the unexpected.

The epidemic has spared no country in the world, although in some countries prevalence rates are still low. At the end of 2012, the adult prevalence rate was below one percent in two-thirds of the 147 countries for which data was available (UNAIDS, 2013). It should be noted however that low prevalence rates at national level can mask pockets within a country where the rate is high.

### **3.2 HIV and AIDS in the Caribbean**

The AIDS epidemic in the Caribbean is believed to have started in 1981 when the first cases of AIDS were recorded in Haiti. However, retrospective analysis of patients affected by Kaposi's sarcoma has shown that the first cases of AIDS were documented in 1979 (UNAIDS, 2010). Cases of AIDS had also been documented among Haitians living in the United States at that time (Gilbert et al, 2007). In 1982, cases were reported in Jamaica and Bermuda (Caribbean Epidemiology Centre, 2004) and, by 1987, all Caribbean countries had reported at least one case. By 2001 there were an estimated 210, 000 people living with HIV/AIDS (PLHIV) and, in 2013, UNAIDS estimated this number had increased to circa 250,000, (UNAIDS, 2013) 16,000 of these children.

The largest number of people living with the virus is on the island of Hispaniola, where the combined number of PLHIV in Haiti and the Dominican Republic is 182,000 (Avert, 2014). This

accounts for approximately 70% of all PLHIV in the Caribbean. In the English-speaking Caribbean, Jamaica has the largest number of individuals living with HIV, at an estimated 30,265 (Ministry of Health, Jamaica, 2014). However, the data on adult HIV prevalence offers a different perspective (UNAIDS, 2010). The Bahamas (3%) has the highest adult HIV prevalence, followed by Suriname (2.4%) and Haiti (2.2%). Though there is some variation in terms of those persons living with HIV in the Caribbean, it is to be understood that 9 of the 10 larger countries have generalised epidemics, with prevalence of over 1% among the adult population.<sup>1</sup> It should be noted however that, increased access to antiretroviral treatment (ART) has led to a decrease in the mortality associated with AIDS (UNAIDS, 2013).

And since 2001, there has been a 40% decline in AIDS-related mortality in the Caribbean. Furthermore, the most pronounced decline in new cases of HIV infections since 2001 (49%) has occurred in the Caribbean (UNAIDS, 2013). This level of decline is noticeable among children and young people also and is believed to be the result of scaled-up HIV prevention services, which saw, between 2001 to 2012, a 52% decline in new HIV infections among children and young people (UNAIDS, 2013).

### **3.3 HIV/AIDS in Jamaica**

Jamaica currently has no law that criminalises the transmission of HIV. UNAIDS estimates that as at 2012, 30,265 persons or approximately 1.7% of the Jamaican adult population is HIV infected and that almost two thirds of HIV infected persons are unaware of their status. Higher HIV prevalence has been recorded in such vulnerable groups as Sex Workers (4.2%), Men who have Sex with Men (32.9%), and individuals with other sexually transmitted infections (3.6%), homeless persons/drug users (8.2%), and prison inmates (2.5%). Between 1982 and 2011, 29,069 persons were reported with HIV in Jamaica and the cumulative number of reported AIDS

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<sup>1</sup> With the exception of Cuba, Bahamas, Barbados, Belize, Dominican Republic, Guyana, Haiti, Jamaica, Suriname, Trinidad and Tobago each have HIV prevalence rates over 1%.

deaths was 8,498. Circa 79% of all reported AIDS cases in Jamaica are in the 20-49 year old age group, and 90% of reported AIDS cases are individuals between 20 and 60 years old. In 2006 the number of newly reported AIDS cases in young girls aged 15-24 was twice as high compared with boys in the same age group. More HIV+ men are reported in the age group 20 to 60 compared with women in that age group, though this gap is continuing to narrow. All 14 parishes in Jamaica are affected by the HIV epidemic though urban parishes have higher numbers of HIV+ individuals (Ministry of Health, Jamaica, 2011).

### 3.3.1 HIV/AIDS and Children and Young People in Jamaica

Despite vigorous national efforts, the HIV/AIDS epidemic continues to spread in Jamaica. Of the estimated 30,265 people in Jamaica living with HIV close to 10% are children under 18, and 20% are aged 20-29 years. This suggests many may have been infected during their adolescent years.

Efforts to prevent mother-to-child transmission (PMTCT) in the public services have resulted in significant reductions in the mother-to-child transmission rate, from 25% in 2002 to fewer than 5% in 2008 and less than 1% currently (Ministry of Health, Jamaica, 2011). 84% of HIV+ pregnant women in Jamaica now receive antiretroviral medication, and more than 90% of infants born to HIV+ mothers receive ARV treatment. According to UNICEF (2015), Jamaica has made significant progress in treating more HIV-positive children.

However, increased knowledge about HIV among Jamaican children and young people, due largely to targeted interventions in schools and communities, is yet to bring significant results in terms of reducing risky sexual behaviour. According to the Youth Risk and Resiliency Behaviour Survey conducted among 4,320 sexually active children (aged 10-14) and young people (aged 15-24); 76% of males and 21.4% of females reported being involved in multiple partner relationships. In addition, 23% of males and 43.5% of females did not use a condom during their last sexual encounter. Transactional sexual relationships have emerged as a serious cause for

concern among young people, with 39% reporting they have either given or received money or gifts in exchange for sex. Almost 13% of the young people (aged 15-24) reported they have been forced to have sex, whilst 14% admitted to forcing someone else to have sex with them.

### **3.4 Government Intervention**

Jamaica's response to the HIV epidemic is outlined in the HIV/AIDS/STI National Strategic Plan (JHANSP) (Ministry of Health, Jamaica, 2002). This plan acknowledges the seriousness of the HIV epidemic and its negative consequences for national development. HIV and AIDS are key government priorities and alleviating the effects of stigma and discrimination is among a range of policy issues the government seeks to tackle. The goals of the JHANSP are to build an effective multi-sectoral response to HIV and AIDS; mitigate the socio-economic and health effects of HIV and AIDS; decrease individual vulnerability to HIV infection; reduce the transmission of HIV infection; and improve care, support and treatment services of PLHAs.

The education ministry's response is part of a national multi-sectoral approach aimed at reducing individual vulnerability to HIV infection through the revised Health and Family Life Education [HFLE] curriculum. The HFLE curriculum is part of the Behaviour Change Intervention and Communication (BCIC) initiative which promotes the ministry's HIV and AIDS policy. This was reinforced in the Ministry of Education's work plan as set out in the Jamaica HIV/AIDS/STI National Strategic Plan (JHANSP) which aims to, inter alia:

- produce appropriate teaching and learning materials to generate awareness;
- provide training for teachers in order to develop competence in the delivery of the HIV/AIDS/STI education programme including the development of peer educators;
- increase awareness by the Ministry's personnel and stakeholders of the need for greater responsibility for adopting programmes and workplace policies relating to HIV/AIDS/STI.

In addition to the generalised JHANSP and the BCIC initiatives, there has also been the “Hold on, Hold Off” programme delivered by Regional Health Authorities since 2008; the “Sex Ed, Best Said” programme delivered by Jamaica Youth Advocacy Network [JYAN], 2009; a revision, in 2008, of the Health and Family Life Education curriculum that embeds HIV and AIDS issues in the education system (in 2011, some 87% of schools were delivering HFLE to 418,517 students) ; the Ministry of Education/Secondary Schools Council 2008 anti-discrimination campaign called “Yes I Can Support Someone Living with HIV”; and the 2009 “Children First” and “Safe Kids”, projects aimed specifically at primary school children aged nine to twelve which promotes personal safety and well-being. We should note that a number of these initiatives are *donor* funded (and initiated) and at times their objectives seem to overlap one another.

In addition partnership between both the government and non- government sectors have enriched the response with policies and programmes derived from supra-national bodies, such as those instigated through the ILO (International Labour Organisation, 2002). At the local level, the Jamaica Employers Federation in collaboration with both the ILO and the Ministry of Health initiated a Workplace Education Programme. This initiative not only sensitised the core labour force but assisted in driving policy nationally, firstly for a National Workplace Policy for HIV/AIDS, to be followed by its incorporation into the forthcoming Occupational Safety and Health Act. Currently over 200 companies are in *voluntary compliance* with the policy, of which 58 have been visited by the Ministry of Labour and Social Security. Furthermore, since 2008 the Jamaica Employers Federation has published and distributed a handbook to its members and beyond so as to sensitise employers and employees to information regarding HIV/AIDS and its related impact in the workplace (Jamaica Employers Federation, 2008).

#### **4.0 Methodology**

The findings presented from this study were gathered during two phases. The first phase was conducted between June 2011 and August 2011. The second phase, a continuation study, was conducted between October and December 2014. Both phases sought to gather data in reference to the effectiveness of national policy and institutional responses in seeking to protect HIV+ children in Jamaica. Additionally, the second phase was undertaken to examine the extent to which phase one findings, completed three years earlier, were still the case. Participants in the study were selected through a combination of deterministic and snowball sampling and representatives of relevant actors within including education, health, employment federation and industry. The content of this study was thus gathered through face to face interviewing, focus groups and documentary analysis.

The main research questions in phase one were, “To what extent does the HIV+/AIDS status of children in Jamaica impact their learning/schooling experience?” “How have these impacts been identified and assessed by education and health care professionals?” The main question in phase two was, “To what extent, are HIV+ children and young people in Jamaica adequately protected by existing legal, policy and other frameworks?” Phase one included 3 HIV+ young persons, one health care worker, one manager of services at a facility for HIV+ homeless children and young people, two officials from the ministry of education and two officials from the ministry of health. Phase two data collection included a senior official from a worker lobby group, two officials from the ministry of health and an HIV+ young person. Phase one had two males and eight females whereas phase two had two females and two males.

## **5.0 Findings, Discussion and Conclusions**

The findings from this study are presented in three sub-subsections below: Jamaica’s legislative framework; Jamaica’s policy framework; and Jamaica’s policy-practice frameworks.

### **5.1 Jamaica’s Legislative Framework**

There is no specific legislation addressing a range of HIV and AIDS related issues in Jamaica. However, national legislations relevant to a study on the schooling experiences of HIV+ children and young people are identified below (for a more detailed list, see Appendix A).

**The Education Act 1980:**

A number of parts of the Act may assist in protecting school children affected by HIV/AIDS, significantly though it enshrines rights for both the administration and the child as regard to when for health reasons a student may be excluded from school, but must not be deprived of the opportunity to complete schooling.

**Public Health Act 2003:**

No distinction is made between HIV/AIDS and any other notifiable disease thereby *normalising* its status (and thus that of its sufferers!) as one of a number of life threatening conditions.

**The Childcare and Protection Act 2004:**

The Act, worded as such, whilst protecting a child's rights, ensures the mandatory nature of formal schooling

## **5.2 Jamaica's Policy Framework**

Jamaica has in place several policies regarding the management of HIV and AIDS in society. These have benefited from several sector based policies including:

**National Policy on Children (MoH, 1997):**

This policy supports the rights of children so as to enable them to reach their full potential, mentally, physically and emotionally, whilst also protecting those most vulnerable.

**National HIV/AIDS Policy (MoH, 2005):**

Principally aimed at preventing new HIV infections and strongly aligned to the International Labour Organisation's (ILO) "10 Guiding Principles" (International Labour Organisation, 2001).

**National Policy for the Management of HIV/AIDS in Schools (MoE 2004, revised 2010):**

This important policy is centered on the UNGASS Declaration of Commitment on HIV and AIDS, the Millennium Development Goals, the Dakar Framework for Action for "Education for All", the ICPD Programme of Action, the Vienna Declaration of Human Rights. It aims to assure the rights of children to access to and participation in education. Further, for both students and school staff it propagates open access, equity and the inviolability of one's human rights.

**5.3 Policy - Practice Environments**

5.3.1. Policy Awareness

Those interviewed during the course of the study displayed a well formed knowledge of much of the legislation relating to the country's response to HIV/AIDS, whether it be in regard to education, health (including services), the workplace and thus had a clear understanding of how, in all its facets, it should act to ensure that in all aspects of an individual's human rights, the law should *seamlessly* protect. The multi-sectoral approach was one that all recognised as a strong and important component of the overarching country response to the epidemic, notably this topic drew much comment and criticism in relation to the perceived (some with actual experiences of) effectiveness of the parties to this approach.

Policy particularly relevant to this study included the National Policy for the Management of HIV/AIDS in Schools (2004, revised 2010). The 2004 policy has 8 tenets. The revised policy has 9 tenets. The newly introduced tenet is about access or referral of students to reproductive health services. The policy speaks to reducing new incidents of HIV/AIDS among school-aged children; management of the disease for those infected with it; confidentiality and the right to access education and work regardless of one's status; responsibility of the education ministry to provide

prevention education programmes. The policy also addresses non-discrimination and universal precautions to be employed in schools. Expressly, this new tenet should further protect children whilst within the school system in their *day to day* experiences; thus recognising the need for policy to seriously drive real protection at the practice level?

### 5.3.2 Stigma and Discrimination

Evidence of stigma and discrimination is reported anecdotally by many within the education sector, particularly in the secondary sector, however, due to fear, very little or no reporting occurs. As reported by Miller et al (2011), many individuals working in schools will admit *off the record* to being aware of instances of stigma and discrimination against children at school, but feel unwilling or unable to report this due to socio-cultural pressures and for fear of repercussions. Many of those involved in this study cited instances of such child abuse that they were aware of, ranging from name calling, alienation, segregation through to sexual and physical abuse being experienced by children with (or labelled as) HIV+. These instances occurring in school, in the family and in the local and wider community and normally recounted with no *happy ending!*

Oftentimes people are uneducated about HIV/AIDS stated one education officer, this statement furthered by one health ministry official who cited a “lack of (correct) information” [in the public domain] which “breeds fear and ignorance” and which is underpinned by a strong anti-homosexual culture manifested in the music, especially among secondary school pupils. The “High level of stigma and poor level of understanding of the issues and a clear disconnect between: medics, teachers, researchers and parents” stated one state agency researcher is surely furthering stigma and discrimination.

Compared to the aforementioned, one education ministry policy official was quick to point out that stigma may often be ‘self-inflicted’ a position seemingly indexed by a health ministry Human

Rights Officer who explained that many individuals in society saw those persons who are HIV+ as having a form of 'Judgment on themselves'.

Reluctance thus to act *on the ground* utilising appropriate policy seems apparent and thus the formation of the National HIV Related Discrimination Reporting and Redress System (NHDRRS) is a positive one, so as to drive interventions and address such incidences. However, its effectiveness is dependent upon its reporting, appropriate staffing and physical and financial resources. In 2011 (Ministry of Health, Jamaica, 2011) it received a total of 19 cases of discrimination, noticeably the number of complaints has reduced from 2008 to date by 62%. One commentator expressing the view that "this is not due to reduced incidences of stigma and discrimination, it's because redress has *no teeth*." Thus, whilst reporting is limited, it remains a serious problem.

### 5.3.3. Promoting Inclusion

One education ministry official reported successfully delivering workshops to principals and to close to 1000 staff (all categories) working in schools. In collaboration with the Ministry of Health and assistance from persons infected with the HIV/AIDS virus and civil society organisations, a number of sensitisation campaigns have also been staged in the nation's schools. In her view, "When HIV+ individuals can contribute to intervention plans, this provides a definite benefit to both students and staff". In our view, this also underlines the fundamental principle of GIPA which asserts the involvement of persons with HIV/AIDS.

Inclusion efforts at both the strategic and operational levels are also actively driven by the Ministry of Education. The education ministry official pointed to national policy, "Every child can learn; every child must learn", arguing that the ministry has a role to play in supporting children at school no matter their health, socio-economic or other conditions. The regulatory role played by the

ministry is underlined by Section 31 of the Education Act which stipulates that if a child's illness does not [directly] affect the wider school population they should not be denied entry...

At the operational level, the Ministry of Education provides a range of sensitisation and public awareness engagements for teachers, the school community and parents, aimed at countering popular myths associated with HIV and AIDS. The introduction of Health and Family Lifestyle Education (HFLE) curriculum in all schools is also a part of this process of sensitisation. Furthermore, the Ministry of Health provides social workers who work in Regional Health Authorities and schools to provide psychosocial support for children affected by HIV and AIDS.

The education ministry also operates a Safety and Security Programme which is now being implemented across the country. In addition to the already 164 participating schools, in September, 2014 implementation began in a further 595 primary schools (Jamaica Information Service, 2014) backed by a Ministry of Education led - Behaviour Modification Programme. In addition to these, safety and security policy guidelines are in place in schools, underpinning Critical Incident Management Plans which have established procedures for handling a wide range of issues such as contact sports and bullying.

#### **5.4 Evaluation of Policy, Practice and Institutional Responses**

Having a range of policy and programmes in place to support the treatment and care of HIV+ children and young people is important. This shows good leadership and a degree of forward thinking by leaders at different levels. However, regardless of the range of policies and/or programmes in place, effective change will only come about when leaders at all levels apply and enforce the policies - whether already in place or newly created.

At the moment, the monitoring of national policy implementation is by regional education officers, one of whom pointed to gaps in the current arrangements: "[T]o have better monitoring of the policies and interventions, it is important that the parents, students and entire school population

be involved.” Once more this requires leadership; and leadership of a kind that follows through. Monitoring of what goes on in schools is undertaken by the Health Promotion Officers appointed by the education ministry to monitor such intervention as the delivery of and response to the HFLE curriculum. Health Promotion Officers also engage in “follow up” activities with school principals and students affected or infected with HIV. In addition to these processes, principals provide regular updates to the education ministry’s Guidance and Counselling Unit.

There are obvious challenges in terms of the appropriateness of the level and type of response provided to HIV+ students. Pointing to a mismatch, one participant suggested, (an educational ministry official) HIV+ persons need to do more to help themselves. Although it is not immediately clear what is meant by this, one could argue that effective self-leadership is a crucial component in enabling an infected child or young person to exercise restraint when jeered or mocked, or simply to turn their ‘misfortune’ into a lesson for others. But these can only occur in an environment where tolerance is promoted and where discrimination is frowned upon, such that notions of HIV being ‘self-inflicted’ and/or that HIV+ individuals have called down a form of ‘Judgment on themselves’ are isolated from everyday thinking.

There is ample evidence that the government and related agencies have done and are doing much to safeguard HIV+ children in Jamaica through a range of policy and practice based initiatives. It is also apparent that those who support HIV+ children, on a day to day basis, have done much to protect and safeguard them. In both cases, these sets of actions are found to be consistent with the Jamaica’s Child Care and Protection Act and a number of international legal instruments including the Convention and the Rights of the Child and guidelines from the Office of the High Commissioner on Human Rights. Nevertheless, the current system of monitoring appears to be fragmented and disjointed. In 2011 Miller quoted one participant in his original study as saying the monitoring of associated HIV policies will be overseen by the National Education Inspectorate. There is no evidence of this being done. Furthermore, there is no indication that

there is a coherent approach to monitoring the implementation of policies and procedures nor is there a consistent plan that can be deployed across the island in all schools, context aside. Once more this calls for leadership that connects the dots; that reduces waste and does not duplicate efforts; and that publicise and use success stories as capacity building artefacts. For example, as a developing country, Jamaica is reliant upon donor funds from international entities which are often tied to specific donor targets. In pursuit of such financial assistance, there may be, at times, several concurrent initiatives, contributing to what appears a fragmented approach in the implementation and monitoring of cross-sectoral campaigns and initiatives.

## **5.5. Conclusions**

Our conclusion is, despite the impressive list of local and international legislations and policies, and despite some evidence of good practice, there remains - in some cases, a clear mismatch between what the law and/or policies demand versus what is actually done. To achieve greater coherence between intent and outcomes, we also propose the implementation of fewer, deeper and more meaningful initiatives rather than the current practice of having several initiatives running at any one time - without unequivocal evidence of their effectiveness. For this to be achieved however, there needs to be an interlocking of leadership energy and activities at national, regional and local levels, demanding that all efforts contribute to national development through robust accountability mechanisms in the implementation and monitoring of activities and initiatives aimed at safeguarding and protecting HIV+ young persons.

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## **Appendices:**

### **Appendix A**

## Legislative and Policy Environments

The table below indicates specific legal and policy references as appropriate within each legislative Act or Policy as per section 5.1/5.2

<b>Legislation/Policy</b>	<b>Details of supporting applicable sections</b>
<b>The Education Act 1980:</b>	<p>Exclusions for health reasons:</p> <p>31.1 A student shall be excluded from attending a public educational institution during any period in which he is known to be suffering from a communicable disease or infestation.</p> <p>31.3 Arrangements may be made to enable students who have been suspended, or excluded from school for pregnancy or other health reasons, to sit important examinations in connection with the completion of their education.</p>
<b>Public Health Act 2003:</b>	<p>2.1 In this Act, unless the context otherwise requires- "communicable (or notifiable) disease" means any disease due to a specific infectious agent or its toxic products, which arises through transmission of that agent or its products from an infected person to another, or from animal to a susceptible person either directly or indirectly....</p> <p>Both HIV and AIDs are considered Class 1 Notifiable Diseases.</p>
<b>The Childcare and Protection Act 2004:</b>	<p>2.2 Where there is a reference in this Act to the best interests of a child, the factors to be taken into account in determining the child's best interests shall include the:</p> <p>(a) safety of the child;</p> <p>(b) child's physical and emotional needs and level of development</p>
<b>National Policy on Children (Ministry of Health, 1997)</b>	<p>(a) To ensure the right of every child to life and the attainment of the highest standard of health for children</p> <p>(b) To guarantee protection from all forms of maltreatment and special care for the disabled children and children without families</p> <p>(c) To ensure protection from interference with privacy</p> <p>(d) To recognise children as whole human beings having an inalienable right to participate in society's affairs within their intellectual and emotional capacities</p> <p>(e) To ensure special care, education and training for all children with disabilities to enable them to reach their fullest potential</p> <p>(f) To facilitate the involvement of children in all aspects of Civil Society in keeping with the child's evolving capacity</p>
<b>National HIV/AIDS Policy (Ministry of Health, 2005)</b>	<p>2.1 The principle focus of the national response is the prevention of new HIV infections; the treatment, care, and support of those infected or affected by HIV/AIDS; mitigation of the impact of the epidemic; strengthening of the enabling environment including legislative changes and the reduction of HIV/AIDS related stigma and discrimination.</p>
<b>National Policy for the Management of HIV/AIDS in Schools (Ministry of Education 2004, (revised 2010)</b>	<p>(a) Access to Education: Every child has the right to education. No student shall be denied access to education on the basis of his or her actual or perceived HIV status.</p> <p>(b) Access to Information: All Ministry of Education staff and students have the right to relevant and factual HIV and AIDS information and behaviour change communication that is appropriate to their age, developmental level, gender, culture, language and context.</p>

	<p>(c) Participation: The meaningful involvement of people living with and affected by HIV and AIDS and most vulnerable groups, including youth, in the design, implementation, monitoring and evaluation of the response to achieve stated outcomes.</p> <p>(d) Equity: All responses to HIV and AIDS should ensure that no student or staff will be denied access to prevention, knowledge, skills and services or treatment, care and support services on the basis of their real or perceived HIV status, gender, age, disability, religious or other beliefs, socio-economic status, geographical location, level of literacy, capacity to understand the nature of HIV/AIDS and how it is prevented and treated or vulnerability to exposure. This includes orphans, wards of the state, street and working children, out of school youth and children living with disabilities.</p> <p>(e) Promotion and Protection of Human Rights: An important aspect of the response to the epidemic requires that the rights to equality before the law and freedom from discrimination are respected, protected and fulfilled. Discriminatory practices create and sustain conditions leading to vulnerability to HIV infection and to inadequate treatment, care and support as well as access to preventive services. Promotion and protection of human rights ensures that there is no discrimination based on race, class, gender, sex, sexual orientation, religious or cultural beliefs.</p> <p>(f) Political Leadership and Commitment: Strong political leadership and commitment at all levels of Education is essential for a sustained and effective response to HIV and AIDS.</p>
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