

**A RAPID ASSESSMENT OF THE SITUATION OF**

# **ORPHANS**

**& OTHER CHILDREN  
LIVING IN HOUSEHOLDS AFFECTED BY**

**HIV/AIDS**

**IN JAMAICA**

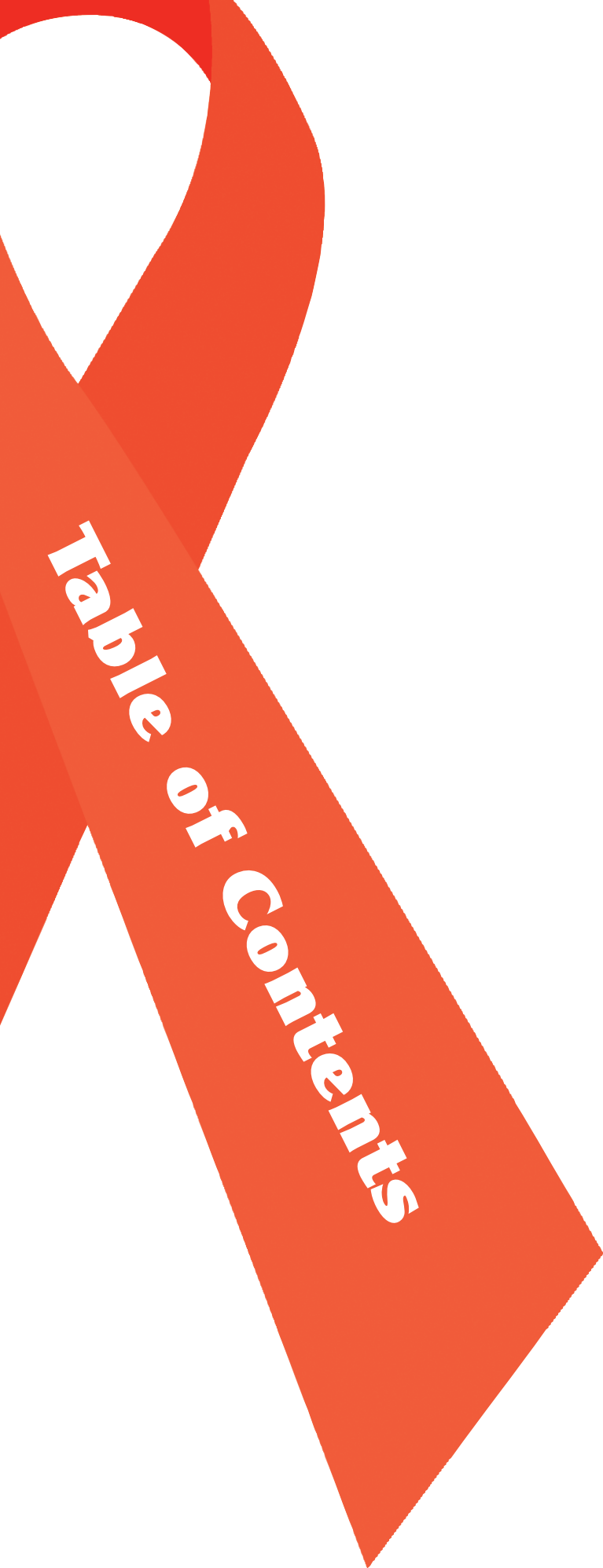
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**National AIDS Committee**

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# LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CARICOM	Caribbean Community and Common Market
CBO	Community Based Organization
CEDRO	Information and Education Centre for the Prevention of Drug Abuse
CINDI	Children in Distress
COPE	Community Based Orphan Support Project
CRC	Convention on the Rights of the Child
DCOF	Displaced Children and Orphans Fund
FACT	Family AIDS Caring Trust
FHI	Family Health International
FOCUS	Families, Orphans and Children under Stress
HIV	Human Immuno-Deficiency Virus
HFLE	Health and Family Life Education
MOEYC	Ministry of Education, Youth and Culture
MOH	Ministry of Health
MTCT	Mother to Child Transmission
NAC	National AIDS Committee
NGO	Non-Governmental Organization
OVC	Orphans and Other Children made Vulnerable by HIV/AIDS
PIOJ	Planning Institute of Jamaica
PLWHA	Persons Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
STD	Sexually Transmitted Disease
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development



## EXECUTIVE SUMMARY

The Caribbean region is second only to sub-Saharan Africa in terms of HIV prevalence, with 2.2%<sup>1</sup> of all adults infected by the end of 2001. Among the larger countries of this region, Jamaica has one of the lower prevalence rates, at about 1.5%<sup>2</sup>. Although the statistics on HIV and the numbers of orphans bear very little resemblance to those of many African countries, it is clear that Jamaica is facing a significant challenge, not only in reducing the incidence of HIV but in caring for the thousands of children who are left without one or both parents as a result of AIDS.

Community health workers and NGOs interviewed for this study are deeply worried about the number of adults already living secretly with HIV; about the numbers of children staying away from school or turning to the street to survive; about the incidence of child abandonment, sexual abuse, violence, exploitation and crime; and about the number of Jamaicans who are not able to access the services that are supposed to be available to them.

Most of the reasons for these things are well understood, and go back many years – long before the unwelcome appearance of HIV/AIDS. Poverty, early initiation of sex, and teenage pregnancy are “old news” to people in the caring professions in Jamaica. So are the adaptations that families make to care for children growing up in this environment. Female-headed households and “child-shifting” – the informal placement of children with relatives – are commonplace, particularly in poorer communities.

But even before HIV/AIDS appeared, the cracks were showing in these coping mechanisms, with an increasing number of adults refusing to provide a home to the children of their brothers and sisters because of poverty and changing values, among other factors.

HIV/AIDS has emerged within this social context. Poverty and multiple sexual partnerships provide a fertile ground for the spread of the virus. Caring for those who are suffering from AIDS-related illnesses, and finding homes for their children, are proving to be the last straw for many extended

families. Child-headed households – already a common phenomenon in Africa – are now a reality in Jamaica and, according to community-workers, they are not hard to find.

The number of children who will lose their mothers and fathers to AIDS is alarming. In 2001, there were about 1.4 million Jamaicans between the ages of 15 and 49<sup>3</sup>. An adult HIV prevalence of 1.5% means about 20,000 of these adults are already HIV-positive. Many of these people were parents before they became infected, and many will have more children before they die.

More work is needed to determine the ratio between people living with HIV/AIDS and dependent children, but it appears from this study that it could be as high as 1:2.5. On the other hand, the overall ratio between adults (aged 15- 49) and children (0-14) in Jamaica is 1.58:1<sup>4</sup>. The Joint United Nations Programme on HIV/AIDS, in its AIDS Epidemic Update of December 2002, revealed that there are 5,100 children already orphaned in Jamaica because of HIV/AIDS<sup>5</sup>. Yet, with a prevalence rate of 1.5% and the population of persons in the 15 - 49 age group being 1.4 million, it means that between 10,000 and 20,000 children are at risk of losing one or both parents to AIDS.

But it gets worse. As this report explains, the “average lifetime risk” of dying from AIDS is believed to be anywhere between three and five times higher than HIV prevalence in a given country. This means that, without an aggressive intervention to curtail the epidemic and to keep those already infected alive, many more Jamaican children could live through the horror of watching one or both parents die, and of facing a very uncertain future.

Everyone is shaped by their childhood experience. We know that abandoned, abused and neglected children are less likely to grow up to be productive adults, and responsible parents and when orphans grow up and have their own children, those children will not have grandparents to act as a safety-net and a moderating influence. Many orphans are frighteningly alone.

1. United Nations & Partners Theme Group on HIV/AIDS, 'Towards an Integrated Plan of Action' 2000-2001

2. Jamaica HIV/AIDS/STI National Strategic Plan 2002-2006, Ministry of Health (version January 2002)

3. Demographic Statistics Report, The Statistical Institute of Jamaica, 2001

4. Ibid.

5. UNAIDS' AIDS Epidemic Update December 2002" and UNAIDS Epidemiological Fact Sheets by Country, amended by Steve Berry, 2002



But so much can be done. It is worth reminding ourselves that, for as long as HIV-positive parents are alive and well, their children are not orphans. Drugs – anti-retrovirals and others – can help many adults survive long enough to raise and provide for their children. Universal and confidential access to these drugs will not totally prevent children from being orphaned by AIDS, but it will keep the number of orphans down to far more manageable levels. The ready availability of these drugs would also encourage more people to be tested for HIV, helping us to fully understand the scale of the challenge we are facing.

When it comes to caring for orphaned children, community workers are constantly told the real problem is money: “Help us to earn a living, and we’ll take care of the kids.” International experience is that even very small sums of money, when accompanied by good advice and practical support, can kick-start economic activity at the household level and restore the pride and confidence of caregivers. At least two programmes in Jamaica are finding it works here, too.

There is already a wide range of public services and social benefits in Jamaica. However, it seems that many of the people who should be accessing these services are either unaware of them, or are effectively prevented from using them. It nearly always costs less, in the long term, to provide these services than to withhold them. A major effort should be made to publicise these benefits, and to identify and remove the barriers that prevent people from receiving them.

The experience of children orphaned by AIDS will never be forgotten, but the psychological damage can be healed. In many countries, networks of community counsellors are being trained and deployed to help young people deal with grief and anger, and to cope with the stigma that confronts them. Children interviewed for this study described how their lives had improved after they talked to school guidance counsellors or found positive adult role-models.

Stigma is a particularly unpleasant aspect of the HIV/AIDS pandemic. In Jamaica, as in other countries, it is both a

cause of profound distress and a real barrier to getting help. This research found that stigma is actively propagated by some staff in schools, clinics and children’s homes. It is unacceptable that such ignorance should be found in places of learning, and such a lack of compassion in institutions of care. Changing public attitudes is a massive task, but setting and enforcing standards of behaviour among those paid to serve the public should be achievable.

The challenge of raising orphans to become valuable members of society is too big and too diverse for any one organisation – even the government – to meet alone. But there are a multitude of organisations that are well placed to be a part of the solution. However, many are unaware of the role they could play, and where they can find funding. The building of partnerships and the co-ordination of action are absolutely essential elements of an effective response.

Public policy and legislation, and the objectives and programmes of many organisations, will need to be re-assessed against the needs of a new and uniquely challenged generation. Steps must be taken to protect the rights of children (a concept to which Jamaica committed herself when she ratified the International Convention on the Rights of the Child), and to support those who are accountable for fulfilling those rights from the household level upwards. Jamaica also needs to prepare a National Plan of Action for Orphans and Other Vulnerable Children, in line with the declaration of commitment at the June 2001 UN General Assembly Special Session on HIV/AIDS.

This short study has done no more than scratch the surface of the challenge posed to Jamaica by children orphaned or made vulnerable by HIV/AIDS. There is a need for more work, especially at the parish level, to understand the scale and nature of the predicament facing these children and their caregivers, and to pinpoint actions that will enable families and institutions to respond more effectively to their needs. It is recommended that stakeholders in Jamaica urgently establish a Steering Committee, including representation from government, NGOs, faith-based organisations, People Living with HIV/AIDS and donors, to map out and implement this process.



# BACKGROUND

In May 2001, UNICEF hosted a workshop in Ocho Rios, Jamaica, entitled: "Orphans and Children in Families Made Vulnerable by HIV/AIDS" (usually shortened to OVC). The objectives of the workshop were to develop more effective strategies for accelerating the response to OVC in Jamaica, and to contribute to the development of programming principles for interventions targeting these children.

The following month, the United Nations General Assembly Special Session on HIV/AIDS approved a Declaration of Commitment. This commitment included the following paragraphs under the heading "Children orphaned and affected by HIV/AIDS need special assistance":

*"Paragraph 65. By 2003 develop and by 2005 implement national policies and strategies to:*

- *build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS including appropriate counselling and psycho-social support;*
- *ensure their enrolment in school and access to shelter, good nutrition, health and social services on an equal basis with other children;*
- *protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance;*

*Paragraph 66. Ensure non-discrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of de-stigmatisation of children orphaned and made vulnerable by HIV/AIDS;*

*Paragraph 67. Urge the international community, particularly donor countries, civil society, as well as the private sector to... support programmes for children orphaned or made vulnerable by HIV/AIDS in affected regions, in countries at high risk and to direct special assistance to sub-Saharan Africa."*

This study was undertaken by the National AIDS Committee, in collaboration with UNICEF, as a follow-up to the Ocho Rios workshop, and to begin the process of fulfilling the Declaration of Commitment at the UN Special Session on HIV/AIDS.

## Objective

The objective of the Rapid Assessment is to identify gaps and priority areas for interventions for orphans and children in families made vulnerable by HIV/AIDS.

## Methodology

The Rapid Assessment was conducted during May 2002 by Jamaican consultant Hope Ramsay, assisted by international consultant Mark Loudon. The assessment consisted of:

- A survey of key informants, including children orphaned by AIDS, children at risk of being orphaned by AIDS, adult caregivers/custodians of children who are orphaned by AIDS, and professionals who work with these children and their caregivers.
- A literature review; and
- An inventory of organisational and individual role-players.

The purpose of the survey was to provide an insight into:

- The impact of HIV/AIDS on the lives of individual Jamaican children who are orphaned or are living in households that are affected by HIV/AIDS, and are therefore vulnerable;
- The capacity of extended families (i.e. relatives); communities (non-relatives); public-sector institutions (children's services, schools, hospitals, etc.) and civil society (NGOs, CBOs and FBOs) to meet the needs and fulfil the human rights of these children;



- The scale and scope of the challenge facing Jamaica as it attempts to raise a generation of functioning and responsible citizens, in the face of the HIV/AIDS epidemic.

It must be emphasised that time and resources did not allow for more than a small sampling of the children, caregivers, professionals and institutions that have key roles in this human drama. Also, the evidence presented in this report is largely anecdotal, emerging from a series of key-informant interviews and focus-group discussions over a 10-day period.

Part of the process was the presentation of the main findings of this report at a workshop of role-players at the end of May 2002 to stimulate and focus further action. A separate report is available on the outcomes of that workshop.

The consultants would like to thank the Care and Counselling Sub-Committee of the National AIDS Committee for initiating this Assessment, particularly Verity Rushton and Nasolo Jacobs (NAC); Penelope Campbell and Monica Dias (UNICEF) and Valerie Marshall (USAID), for their support and advice. A special word of thanks is due to Caroline Mahfood for assisting with the literature review, and to Sheila Evans for reporting on the workshop.

To all the respondents who made the time to meet with the consultants and who shared their expertise and, in many cases, their deepest secrets, we are also profoundly grateful. We hope we have done justice to the gifts you gave, and that they benefit the children of Jamaica.





# THE CHILDREN OF JAMAICA

## Demographics

The population of Jamaica at the end of 2001 was estimated at 2.62 million, with roughly equal numbers of males and females<sup>6</sup>.

The Jamaican population is getting older as a result of declining birth rates, increasing life-expectancy and continuing high levels of migration off the island. The proportion of children under 15 has fallen from 45% of the total population in 1970 to 33% in 2001, while the number of adults aged 15-49 (who are most vulnerable to HIV infection) has grown from 39% to 53% over the same period<sup>7</sup>.

At the same time, the size of households is shrinking. In 1975, just over half of Jamaicans were living in households of less than five people. This has risen to three-quarters of the population; and the average Jamaican household now consists of three-and-a-half persons. However, households among the poorest fifth of Jamaicans include an average of 5.3 persons. This is above the national mean, and approximately twice as large as the richest households<sup>8</sup>.

Around 45% of Jamaican households are headed by females – one of the highest levels in the world. Female headed households tend to be poorer, making up more than half of all households in the poorest fifth of Jamaican society, and to have more children than male-headed households<sup>9</sup>.

## Poverty

Based on consumption expenditure, the number of Jamaican households living in poverty has come down from a high of 45% in 1991 to under 17%. However, rural areas have nearly twice as many households living in poverty as the towns, and three times as many as the Kingston Metropolitan Area (KMA). In rural areas, 23% of children under six who are registered at a public health clinic receive food stamps, against 12% in other towns and 2% in the KMA<sup>10</sup>.

In terms of household expenditure, there are startling – and growing – discrepancies between the richest and poorest sectors of Jamaican society. In 2001, the wealthiest 20% of households spent 50 times more on non-essentials than the poorest 20%.

UNICEF reports that about 190,000 Jamaican children are living in poverty. More than a quarter of all children in rural areas live in families that are poor. In the worst affected parishes of St. Mary and Westmoreland, between 35% and 40% of all children are living in poverty. If one includes children living in families that are “economically vulnerable” – that is borderline poverty – the number of affected children more than doubles<sup>11</sup>.

Wherever it manifests itself, AIDS causes a sharp drop in household income as breadwinners stay away from work – to care for their partner or because they themselves are ill – and it also causes a depletion of assets as savings are spent on medical costs.

Poverty and inequality in the development of human capital are closely linked. Poor nutrition before birth and in the first years of life can seriously interfere with brain development and lead to behavioural problems and reduce labour productivity and earnings potential in later years. Poverty is associated with increased father absenteeism, domestic violence and child abuse. Parents who are poor often have limited education and their children are more likely to be inadequately prepared for primary school. During periods of financial difficulty, poor families are more likely to keep their children out of school and to reduce expenditures on meals and health care<sup>12</sup>.

Several professionals pointed out during this research that many people who are entitled to public services and benefits are unaware of their rights. It was suggested that one or more social workers should be available to facilitate their access to these services.

6. Demographic Statistics Report, The Statistical Institute of Jamaica, 2001

7. Jamaica Survey of Living Conditions 2001, Planning Institute of Jamaica and the Statistical Institute of Jamaica, 2002

8. The Jamaican Child, A Report on the Social Indicators Monitoring System, Planning Institute of Jamaica, 2002

9. Ibid.

10. Ibid.

11. Situation Assessment and Analysis of Jamaican Children and their Families, 2000. UNICEF

12. Situation Assessment and Analysis of Jamaican Children and their Families, 2000. UNICEF.



## HIV/AIDS

UNAIDS estimates that in the Caribbean, by the end of 2001, some 420,000 people were living with HIV – 60,000 of whom contracted the virus during the past year. The number of infected people is evenly divided between men and women<sup>13</sup>.

HIV/AIDS is a notifiable disease in Jamaica. Since the first AIDS case was reported in 1982 until December 2001, a cumulative total of 6,038 cases have been reported, 479 of whom were children under 10. A total of 3,720 Jamaicans have died from AIDS, including 252 children.

During 2001, 939 new AIDS cases were reported, including 66 children. Ten adults died every week from AIDS, while one child died from AIDS every two weeks<sup>14</sup>.

Adult HIV prevalence in Jamaica is around 1.5%<sup>15</sup>. If this level of prevalence is sustained, it means the risk that the average 15-year-old Jamaican child will die from AIDS before they turn 50 is somewhere between 4.5% and 7.5% (see Panel 1).

Given the extreme social stigma attached to AIDS in Jamaica, and the fact that testing is still optional for pregnant women, it seems possible that even larger numbers of people are living with HIV/AIDS than is currently recognised.

## Education

Enrolment in primary school (age 6–11) and the first cycle of secondary school (age 12–14) remains universal for all socio-economic groups in Jamaica. However, concerns have been expressed about irregular attendance, particularly among children from poor families. Children from the poorest fifth of society had an attendance rate of just under 60%, against a rate of around 87% for children from the more affluent families<sup>17</sup>.

### PANEL 1: The real risk of HIV

HIV prevalence indicates how many people between the ages of 15 and 49 are infected with the virus at a particular time. However, this “snapshot” excludes people who will become infected in the future, and people who have already died from AIDS. **In other words, “prevalence” does not tell you how likely it is that a Jamaican child turning 15 will survive to the age of 50 without dying from AIDS.**

To give a more realistic picture, researchers have developed models that track people through different age groups, looking at their exposure to HIV infection at each age<sup>16</sup>. Their findings suggest that the chances that a 15-year-old will die from AIDS before he/she turns 50 is **three to five times higher than the HIV prevalence** in their country.

Even if the risk of infection is halved – for example through successful prevention campaigns – the risk of premature death from AIDS remains far higher than HIV prevalence may suggest.

About a third of all secondary school children take advantage of government assistance with school fees, while two thirds of children participate in school-based feeding programmes. All scholars are allowed to participate in these programmes and in 2001 there was no difference in participation by region, school level or the relative wealth of the child’s household.

There are impediments to accessing financial relief for schooling that need to be studied and overcome. A set of guidelines for schools on how to deal with HIV-positive children, and children whose parents are known to be HIV positive, is being prepared by the Ministry of Education, Youth and Culture.



13. AIDS Epidemic Update, December 2001, UNAIDS  
14. National HIV/STD Prevention and Control Program Facts and Figures, 2002, Ministry of Health.  
15. Jamaica HIV/AIDS/STI National Strategic Plan 2002-2006, Ministry of Health (version January 2002)  
16. Report on the Global HIV/AIDS Epidemic – Waking up to Devastation, UNAIDS, June 2000  
17. Jamaica Survey of Living Conditions 2001, Planning Institute of Jamaica, Statistical Institute of Jamaica.

## Health

Overall, 6.4% of Jamaican children display low weight for age (under nutrition), 5.9% low height for age (stunting), and 2.8% low weight for height (wasting). There are no significant differences among these indicators by region, household consumption or sex. These indicators are all worse than the internationally accepted reference standards of 2-2.3%.<sup>18</sup>

Access to primary health care facilities in Jamaica is good, with two thirds of the poorest sector using public health care facilities, and two thirds of the richest using private facilities. There is no suggestion in the Survey of Living Conditions that anyone was unable to access health care.

However, anecdotal evidence collected during this research suggests that not all patients attending clinics are able to get the help they need. One child reported that her mother would often cry when she did not have the money to fill a prescription. A community worker said there was an overwhelming need for basic drugs to treat the symptoms of AIDS-related illnesses, such as diarrhoea, thrush and skin rashes.

The UN Theme Group says HIV/AIDS is increasingly the disease of the poor. Poor people are less likely to be reached by information and education messages and more likely to have inadequate health-seeking behaviours. Care, treatment facilities and medication are almost inaccessible to poor people, and social support services, such as social security, food subsidies, unemployment and housing benefits, are non-existent, substandard or difficult to access.<sup>19</sup>

## Quality of life

In 1999, almost 40% of households reported feeling dissatisfied with life; 56% were unsure of the future; and almost 30% had emotional difficulties. People blamed stress, job insecurity or unemployment, future fears, domestic problems and crime. In the context of apparently widening depression, the increasing suicide rate – especially among teenagers – is an alarming concern.<sup>20</sup>

In a 1997 survey, more than a third of Jamaican children said a family member had died as a result of violence, and two thirds knew someone (well enough to talk to) who had been a victim of violence or had been killed. Over 80% of students said they knew of children who carried weapons, and 40% of urban children said that students at their school threaten the teachers.<sup>21</sup>

Several respondents interviewed for this study said that HIV-positive children were recruited by drug-dealers to carry drugs, using the argument that if they are caught they will get free medication from the government, but if they swallow drugs in condoms, and the condom bursts, they were going to die anyway!

Ironically, drug dealers do provide some care and protection for these children. Some respondents said destitute mothers sometimes ask the local ‘don’, “to take in their children,” and one mentioned a case where a drug dealer was imprisoned, leaving four or five HIV-positive children homeless.

## Parenting

Most Jamaican children are born while their parents are in a common-law relationship or “visiting union.” However, almost half of these relationships dissolve by the time the child is 5 or 6 years old<sup>22</sup>. There is some (rather dated) research to show that about half of all Jamaican men have children by more than one woman, and 10% have children by four or more women. An estimated 55-70% of men in a co-residential union have children “outside” that relationship<sup>23</sup>.

Nevertheless, existing data suggest that men are more involved in contributing to the development of their children than popular stereotypes suggest. Approximately half of children under the age of six live with their fathers, and about four out of five fathers support their children financially. More than 60% of fathers live with at least one child in their household<sup>24</sup>.

Almost 65% of children have both biological parents performing the chief parenting role – even if the mother and father are not living together. The extent to which both

18. Jamaica Survey of Living Conditions 2001, Planning Institute of Jamaica, Statistical Institute of Jamaica.  
19. United Nations & Partners Theme Group on HIV/AIDS, 'Towards an Integrated Plan of Action' 2000-2001  
20. Jamaica Survey of Living Conditions 1999, Planning Institute of Jamaica, Statistical Institute of Jamaica.  
21. Urban Poverty and Violence in Jamaica. Caroline Moser and Jeremy Holland, World Bank, 1997.  
22. Situation Assessment and Analysis of Jamaican Children and their Families, 2000. UNICEF.  
23. The Contribution of Caribbean Men to the Family. Janet Brown, Patricia Anderson and Barry Chevannes, 1993.  
24. Situation Assessment and Analysis of Jamaican Children and their Families, 2000. UNICEF.



parents take an active role in their children's upbringing is related to household income. In households where the head is a professional person, three quarters of children have their biological parents as parenting figures. However, this drops to below 50% in households where the head is an unskilled person.

Neglect and abuse of children, including sexual abuse and reliance on authoritarian child-rearing practices, are thought to be widespread in Jamaica. Half of all sexual abuse cases seen in hospitals are children. Child rearing practices, especially in poor families, emphasise harsh physical punishment. Violence is very much a part of the parent-child relationship and is often accepted as natural and normal.

Researchers have found there is a communication gap between parents and children, and that prevailing communication styles generally discourage the development of self-esteem. Communication tends to be punitive, aiming to shame or embarrass the child. Physical violence against children is seen as an alternative to productive communication.<sup>25</sup>

The UN & Partners Theme Group describes a breakdown in family structures and values that they ascribe to a lack of positive parental role models and "a total breakdown of the nuclear family, with the majority of low-income households headed by a single female parent who is often indifferent to, or encourages daughters to have sex with older men."

The Theme Group ascribes the lack of parenting skills to teenage pregnancies and early fatherhood, which leads to a self-perpetuating cycle of unskilled parents and socially- and emotionally-dysfunctional children<sup>26</sup>.

## Parental support

Parents are directly responsible for protecting and fulfilling their children's rights, while the extended family, community, civil society and government are duty-bound to support parents in this responsibility<sup>27</sup>. One of the more positive aspects of the situation of children in Jamaica is that there are many well-established programmes to support

caregivers, and that the public are becoming more aware of these services, and their obligations toward children.

The increasing caseload of domestic violence cases in the family courts, and in the number of fathers seeking custody of children, suggest that both mothers and fathers are becoming more active in protecting their children's – and their own – rights<sup>28</sup>. And the fact that the legal machinery exists to hear these cases indicates that the Government of Jamaica is serious about implementing international conventions to protect the rights of children and women.

A wide range of counselling, training and support services, both in the government and non-government sectors, exists for parents, people living with HIV/AIDS and victims of crime. Many NGOs and umbrella organisations have been established and some of these, in turn, are supported by donor and inter-governmental agencies. Parenting workshops have been organised by schools, religious bodies and communities.

However, much more is needed. Existing programmes are reaching only a small proportion of those who need them. Many people have expressed doubts that Jamaicans know what is available to them and, even when they do, that there are barriers to their use.

More needs to be done to prevent violence against women and children, and to protect victims. Targeted programmes for boys and young men are needed to help them fulfil their role as fathers. Ways must be found for parents, and mothers in particular, to earn a living without leaving their children behind. Much more attention is needed in rural areas, which are deprived of many of the services available in the cities and larger towns.



25. The Family Unit: An Elusive Dream? Wilma Bailey, Clement Branche and Elsie Le Franc, Caribbean Dialogue, 4, 1, 1998.  
26. United Nations & Partners Theme Group on HIV/AIDS, 'Towards an Integrated Plan of Action' 2000-2001  
27. Since Jamaica has ratified the International Convention on the Rights of the Child, these duties are enforceable.  
28. Situation Assessment and Analysis of Jamaican Children and their Families, 2000. UNICEF.

## Care and custody

There seems to be a general consensus among health and social welfare professionals in Jamaica that more children are being orphaned and abandoned, more children are turning to the streets to survive, and more children are showing symptoms of psychological distress, such as antisocial behaviour and depression. HIV/AIDS and poverty are generally believed to be among the main contributory factors.

Analysis of data from the 1996 Jamaica Survey of Living Conditions indicates that almost 20% of children do not live with either their mother or father. Children from rural areas, and poorer households, are more likely to be “shifted” to live with other family members.

Children are separated from their parents for a variety of reasons, including death, abandonment, changes in adult relationships (for example: a mother who is living with a man, who does not want the children of her previous partner living in his household) and migration in search of work. Migration leads to the phenomenon of “barrel children,” named after the shipping barrels that sometimes arrive bearing gifts and resources from parents abroad.

Unfortunately, this separation often leads to antisocial behaviour, including prostitution and crime. The absence of a parent, especially the mother, is a primary determinant of criminal behaviour among boys. Other determinants include absence of positive role models, frequent changes in parental authority figures, and frequent changes in living arrangements<sup>29</sup>.

Child shifting is not always negative. Shifting may allow mothers to provide additional financial support for their children. In many cases, the standard of living of the child improves when they are living away from their parents. School attendance and health may also improve.

However, the tragedy for many children is that temporary separation from their parent(s) too often becomes permanent, with 17% of mothers and 25% of fathers who separate from their children not remaining in contact<sup>30</sup>.

The professionals interviewed during this study agreed strongly with the statement: “Children are more at risk if they are separated from their birth parents.” While most professionals said the best place for an orphaned or separated child was within their extended family, it is clear that many relatives are unwilling or unable to take in additional children, either through fear of HIV/AIDS or financial difficulties. The shrinking size of the average Jamaican household may also be an important clue to the growing resistance to taking in extra children.

HIV-positive mothers often refuse to disclose their status to their own families for fear their children may be stigmatised or rejected by relatives after their death. Grandmothers seldom turn children away, however, and many have to care for very large numbers of children in very disadvantaged circumstances.

Professionals say orphaned children are sometimes discriminated against or abused when placed with reluctant family members, being kept back from school if household finances are limited, or subjected to sexual abuse. “We had one case of a stepfather trying to infect a 13-year-old girl because he said he was infected by her mother,” said one respondent.

In some cases, parents living with HIV/AIDS make arrangements for their children to be fostered by non-relatives who they believe can provide a better quality of life than their own relatives. In other cases, children are being removed from the custody of relatives by community or social workers and placed with unrelated foster-parents who can provide better care.

Child-headed households are a reality in Jamaica and, according to several social work professionals, it is “not unusual” to find elder brothers – sometimes as young as 17 – acting as household heads and caregivers. Many children who are even younger are having to act as caregivers of their siblings or ill parents, and some assume the burden of earning an income for their family by selling goods on the streets, carrying drugs or engaging in “transactional sex.” Still others are becoming “early independents” and are living on their own.

29. Situation Assessment and Analysis of Jamaican Children and their Families, 2000. UNICEF.

30. Cognition, Educational Attainment and Behaviour in a Cohort of Jamaican Children, draft report. Maureen Samms-Vaughan. Planning Institute of Jamaica, 2000.



There is general agreement among child-care professionals that more men are becoming caregivers for children, taking on tasks that were previously the exclusive preserve of women – such as taking infants to the clinic. “The situation is pushing them (into performing maternal tasks) but they are rising to the challenge.” However, the number of men who are filling the role of family caregiver is still very small in proportion to women and, as one respondent observed, some men are not able to cope as well as their female counterparts with the emotional distress associated with caring for a child who is dying from AIDS.

There is also evidence that, with appropriate external support, families are able to cope with – and even grow stronger through – the emotional and financial trauma of caring for AIDS-ill members. A supportive church congregation is one example. Unfortunately, fear of disclosure means that these support structures are effectively denied to many who need them.

## Psycho-Social Support

The fact that many parents do not disclose their HIV status, even to their own families, means they cannot prepare their families for the practical or psycho-social impact of their illness and death. This was borne out by interviews with HIV-positive caregivers; most of whom had not written wills or broached the subject of their possible death with the people they hoped would take in their children.

Another concern is the phenomenon of “multiple caregivers,” where children are repeatedly shifted from one household to another, having to adapt to a new set of “laws” in each household. Many of these children are subjected to the additional trauma of being separated from their siblings. Older children who are orphaned by AIDS are often the most emotionally scarred: “The older kids bear the secret, and the shame, of their parents,” according to a prominent activist in Montego Bay.

There is limited psycho-social support available to children affected by AIDS. One agency is providing counselling to 27 children but they are aware of some who are suffering

severe mental health problems and are in need of professional help that is beyond their capacity or budget.

Social and health workers say there is evidence that children are repeating the mistakes of their parents, rather than learning from them. The professionals are clearly worried by the implications of an increasing number of Jamaican children growing up in abusive situations, which is setting them up to become incompetent parents, themselves.

## Stigmatisation

Some teachers, employees in children’s homes, and clerics display ignorance of the ways in which HIV is, and is not, transmitted. Sometimes this results in stigmatisation and discrimination against children who are suspected of being HIV positive – for example, insisting they use different cups, or be isolated from other children.

“In some institutions – sad to say – the staff are not educated and use the children’s (HIV) status to curse them,” said one child-care professional.

It is tempting to believe that these are isolated cases, but the researchers were alarmed at the number of times this “institutional stigmatisation” was mentioned during this brief project.

There is a clear need for intensive HIV-awareness training of all workers who come into contact with children, whether those children are HIV-positive or not. This training should start with the public sector, and should be backed up by disciplinary measures where appropriate.

## Orphaning and vulnerability

Information on orphaning in Jamaica is patchy. The 1996 Jamaica Survey of Living Conditions suggests that about 13,000 Jamaican children – or one percent of the total child population – were orphaned from all causes (not only HIV).

UNAIDS reports that in six Latin American and Caribbean countries surveyed, there were just under 250,000 AIDS orphans, with Haiti ranking highest with 200,000 and Jamaica ranking third with 5100 cases in 2001<sup>31</sup>. The Jamaican Ministry of Health estimated that some 125 or more children were orphaned during 2001 by the loss of a mother or both parents to AIDS<sup>32</sup>. The ratio between adult



31. Joint United Nations Programme on HIV/AIDS: “AIDS Epidemic Update December 2002” and UNAIDS Epidemiological Fact Sheets by country, amended by Steve Berry.

32. National HIV/STD Prevention and Control Program Facts and Figures, Jamaica AIDS Report 2002, Ministry of Health

AIDS deaths and orphaning that emerged during this study suggests that each adult dying from HIV/AIDS left behind an average of 2.5 children between 0-18 years. It would therefore be valuable to examine the reporting of deaths more closely, to establish what the true picture is.

Three NGOs interviewed during the course of this study, between them serve 274 HIV-positive adults. These adults, in turn, listed 701 dependent children. This gives a ratio of 2.5 HIV-positive adults to dependent children. There is a high level of consistency between the three NGOs' figures.

However, the adult figures include both mothers and fathers. If the men are removed from the calculation, the ratio of mothers to children is likely to be 1:4 or even higher.

A well-known community worker in the St. James area said that, in her experience, HIV-positive mothers have an average of five children, most of them born before the mother was infected.

A local health official said he believed most women who had been diagnosed with HIV were already mothers. In addition, a significant number of women who knew they were HIV-positive – he could think of three or four in his Parish alone – went on to become pregnant again.

Very few of these children will be HIV-positive themselves (see Panel 2). However, most of them will have to deal with the horrors of watching their mothers die, the stigmatisation of being associated with her illness, and the difficulties of adjusting to life in new surroundings.

According to the Children's Services Division, around 5,000 children are in alternative care in Jamaica (institutional or foster).

## Institutional care

Internationally, it is accepted that institutional care of children is not a practical solution for the care of large numbers of children orphaned or otherwise separated from their parents. For one thing, it is far too expensive – typically ten times the cost of family care – while, for another, it requires a massive infrastructure of buildings, trained staff, and regulatory mechanisms to protect the interests of the children committed to those institutions.

### PANEL 2:

#### Orphans and HIV-positive children

There is a tendency to think that children orphaned by AIDS are likely to be infected, themselves. In fact, the reverse is true. There are three main reasons for this.

*Firstly*, two thirds of babies who are born to women **who are already infected** with HIV are not infected themselves<sup>33</sup>, although they will usually test positive for up to 18 months until their mothers' antibodies disappear from their blood. The most common HIV tests check for antibodies – not the virus itself.

*Secondly*, babies who are born to women **before they become infected** with HIV will obviously not be infected themselves. This study suggests most HIV-positive mothers in Jamaica have two or three children by the time they are infected.

*Finally*, it is important to remember that babies who are infected with HIV tend to die quickly – mostly before their mothers. Only a few HIV-positive children survive long enough to become orphans.

Using the ratio from this study, it seems likely that for every 25 Jamaican mothers who die from AIDS there will be around 100 HIV-negative children, and perhaps one or two HIV-positive children, in need of alternative care and support by the time their mothers die.

Even where all these elements are in place, institutional care is considered by most social workers to be an undesirable way for children to grow up, providing a fertile ground for abuse and denying the children the kind of family life that they will one day be expected to replicate.

Nevertheless, even among professionals who strongly oppose the institutionalisation of children, there is an acknowledgement that some form of short-term institutional care is often necessary – for example, while suitable family placement is being arranged for children, or for “problem children” who cannot be cared for in regular households.

33. The Challenge of the HIV/AIDS Pandemic for the Reform and Strengthening of Health Systems and Services in the Americas. PAHO/WHO and others, February 2002



Children's homes in Jamaica are either government-run or licensed privately-run institutions, which are subsidised at \$1,200 (US \$25) per week per child, which is estimated to be a third or less of actual cost. The balance is made up through fund-raising and donations.

There are 52 children's homes and places of safety in Jamaica. The Children's Services Division currently has a number of applications to license more (private) orphanages. Some appear to be well funded (from the United States, mainly), so capacity could be increased quite quickly, if necessary.

One children's home caters exclusively to HIV-positive children under the age of 9 (although a few children stay on after this age) and has a capacity of 20. At the time this assessment was conducted, the home was full, with one child waiting to be admitted. Older HIV-positive children, and those who cannot be accommodated elsewhere, are integrated into "regular" children's homes. There are currently no government-led measures under way to provide additional capacity for HIV-positive children, but it seems likely that faith-based organisations and NGOs will rise to the challenge of caring for these children, if allowed to do so.

However, institutional care appears to be failing some children, particularly adolescents, who are unable to adjust to the restrictions imposed on them, and are "escaping" to the streets, where they are exposed to more abuse and exploitation.

## **Fostering and adoptions**

The preferred method of alternative care is with foster or adoptive parents.

Formal fostering is done through a "fit person's order" by the Children's Courts, and foster parents are entitled to a government grant of J\$3,500 (US \$73) per month, although some refuse the money. Additional funds can be found for special expenses, such as school fees (for secondary education), books, examination fees, etc. Foster

parents also receive training and supervision from the Children's Services Division of the Ministry of Health.

According to the Division, there is a shortage of foster parents and the Division, together with a (recently established) Foster Parent Association, engage in recruitment activities. For example, during "Child Care Week" senior-staff undertake speaking engagements at service clubs and PTAs, as well as through the media.

However, a community worker in Montego Bay said she had no difficulty recruiting foster parents for formal placements – even when she limited herself to women who were within the same community as the child needing care – if she offered short-term material support and practical assistance in developing a sustainable source of income. Another respondent reported similar success with income generating activities for foster-parents in the Kingston area.

Formal fostering and institutional placement (both of which require court orders) are considered a last resort by the Children's Services Division – social workers try to work with families to ensure satisfactory informal fostering with relatives.

In terms of adoptions, there is a waiting list of prospective adoptive parents in Jamaica, with a greater demand for girls than boys. There appears to be no cultural resistance to the adoption of un-related children in Jamaica, as in many African countries, but it is often difficult to match children to prospective parents' requirements in terms of age, sex and physical appearance. People from certain countries (such as the US, UK) are able to adopt Jamaican children.

Family reconstruction is actively pursued by the Children's Services Division – for example, through a "home on trial" programme. Between 160 and 200 children are restored to their families each year.

The Division employs over 300 staff, and provides a reactive service – it is only aware of cases drawn to their attention, and does not do research to establish latent demand.

In general, it is clear that the public-sector safety net for children is "first world" in nature. It was beyond the scope of this research to assess the quality of care delivered or





to establish efficiency levels – that is what proportion of children are “slipping through the net” – but it would be valuable to ask these questions at the Parish level.

It seems likely the capacity of institutional care could be increased if required, while increasing the number of foster parents (the preferred model, in the absence of care within the extended family) would take a sustained social marketing exercise.

## **Organisational Response**

Several professionals pointed out that many people who are entitled to public services and benefits are unaware of their rights. It was suggested that one or more social workers should be available to facilitate their access to these services.

The role of faith-based organisations should be expanded. Unfortunately, many people are going back to religious institutions “for the wrong reasons” – for example, financial support – and congregations are resisting this. Confidentiality cannot always be maintained when these institutions provide financial support, as this expenditure is invariably approved by the members of a board.

Stigma and discrimination make it difficult for many parents and caregivers to apply for government assistance to cover the costs of schooling for their children. Ways need to be found to apply for and receive these benefits confidentially.

A set of guidelines for schools on how to deal with HIV-positive children, and children whose parents are known to be HIV-positive, was being prepared by the Ministry of Education at the time of this study.



# INTERVIEWS WITH CHILDREN

*Note that most of the quotations below are interpreted from patois and edited for clarity.*

## Respondents

In all, 34 children were interviewed, aged seven -17 (median age 12), comprising 19 girls and 15 boys.

Of these, 16 were orphaned, seven having lost their mothers, six their fathers and three having lost both parents. Another 18 children were “vulnerable” – being cared for by parents who were ill from infections associated with AIDS. In 15 cases the mother was ill, two fathers were ill, and one 14-year-old boy had a mother and father who “look after each other – usually they are not ill at the same time.”

The number of children (by same mother) in each of these families ranges from one - six, with an average of 2.88. It was noted that the families of the 18 “vulnerable” children were much larger, averaging 3.6 children against 2.06 for the 16 orphaned children. It is not clear whether this is significant or not. None of the respondents made mention of the death of siblings.

Only one of the children was not in school – she was pregnant, but trying to make arrangements to resume schooling.

## Care and support

Among the orphans, four of the 16 were living with their mother (and said their fathers were deceased), nine with relatives, two with neighbours and one with foster parents after time in an institution. Among those living with an ill parent, 16 out of 18 were ill mothers.

Care for sick parent(s) was mainly provided by relatives, especially aunts and grandmothers. Four fathers and one step-father were mentioned as caregivers, all but one in association with a female relative. A number of the children shared responsibility for caring for sick parents among themselves, or with visiting adults – in some cases involving children as young as 10.

Most had made no use of institutional support, or accessed the health care system themselves. However, among those who had, seven mentioned long delays in receiving attention. One blames the hospital for contributing to her father's death by “not wanting to care for him.” Several spoke of unpleasant incidents with hospital staff – one recalled an incident where a doctor looked at her late mother and said: “Oh, she has AIDS – that is not an emergency.” Another said her late mother would cry when she got a prescription, as she could not afford to buy the medicines.

Asked whether people treated them differently since their parents became ill or died, 10 reported positive changes (for example people were friendly and helpful), 13 reported no change (one said people have been helpful, just as when mother was alive) and eight reported negative changes in their treatment at school or in the community.

However, asked specifically whether things had changed at school after the illness or death of a parent, only six out of 34 said “no.” Many spoke of enforced absence from school and/or falling grades, but most had recovered or were improving after interventions by teachers or relatives. One said her grades deteriorated after her step-father started abusing her sexually when her mother died. Ill treatment by other students or teachers featured in five responses.

When asked who had been particularly helpful to them, most of the children mentioned relatives. Five of 16 orphaned children and two vulnerable children mentioned teachers who had been helpful, while others named relatives and one said a neighbour brings Sunday dinner and buys books and pays school fees for him and his older brother. Three respondents specifically said “nobody” had been particularly helpful.

When asked what aspects of their lives are better or worse since their parent's death, the orphans gave mixed responses. Eight said they were no better off, and seven said they were no worse off. Some said their situations have improved. One said her father insisted that she not keep bad company, unlike her late mother. Another is allowed to



bring friends home now. A third has his own room, goes on holidays, and has cousins to play with.

But one 16-year-old probably spoke for them all when he said, after a long silence: "I cannot be better off without my parents."

## HIV/AIDS

Children were not questioned about their parents' HIV status unless they indicated they were aware that their parent was ill or had died from AIDS. When they did so, however, they were asked what they had been told, when and by whom – and how it made them feel. Only five of the children broached the subject of HIV/AIDS within their families.

- One said his father told him two days before his death, but they never spoke about it again. "I can't explain how it made me feel. If I was able to discuss it with him I guess I would feel better. I have not told anyone – not even my sister. When she gets to 15 I will tell her (he explained that until then she would be too young to deal with it)."
- Two children said they had been told – one by his father and another by people in the community – but they didn't believe it.
- A fourth said her mother told her after her first hospitalisation, three years ago. She met a counsellor at the hospital, who she still goes to see. "I was confused and angry – I couldn't believe it."

The three children (out of 34) who acknowledged their parents' sero-status (as the other two did not believe it) were asked who else knew, and whether they were treated differently. One was not sure, and the other two gave short lists of relatives and friends who knew. Two said these people were not treating them any differently, and the third said the family was more protective and generous.

These children were asked what advice they would give HIV-positive parents about telling their children. All three said without hesitation that the parents should tell their children about their status:

- "Tell them – they won't feel any differently about you."
- "Tell them – it could save their lives, and make you closer to your children."

- "Tell them; don't let them find out from other people."

Finally, they were asked what advice they would give to children who learned their parents were HIV-positive:

- "Learn as much as possible (about HIV) so you can be of help to your parents."
- "Stand by them (this girl recalled how badly it affected her mother when her relatives did not want to have anything to do with her)."
- "Treat them the same, because nothing has changed. The disease does not make your mother less of a parent."

## Psycho-social impact

All the children were asked: "What advice would you give to children in your own situation." A number stressed the importance of education (8) and helping around the home (7). Others spoke of the value of having someone to confide in – either a guidance counsellor or friend. "Talk to someone you trust – it will help you not to cry too much," said a 13-year-old girl.

Three children said they would advise other kids to "get to know your father," two spoke of running away, and two more advised others to "watch your company." One was very clear: "Don't have sex."

One said she cannot tell anyone what she is going through – she recently told her teacher, but the teacher said she will tell her aunt, and the child is now afraid the aunt will curse her father and take her away permanently. Another spoke of the few times he spent with his late father "that made them close." A third said: "Being a stranger in someone's home doesn't make you feel the same."

The orphaned children were also asked: "If you wrote a letter to your parent in heaven, what would you say?" Some of the answers included:

- "I would ask my dad what killed him – was it really AIDS as people say? And does he know what is wrong with my mother? And that I am sorry I got pregnant..."



- “I wish I knew him, and why didn't he marry my mother? Grandmother (his mother) is always saying negative things about him.”
- “Life is rough – I work at a supermarket on weekends to maintain myself and my sister, and we miss them. I wish my father had told me earlier, so we could talk about it.”
- “Father is saying bad things about her, that she died of AIDS, and is it true?”
- That friends at school tease her about her inability to read well, and she is behind in her class. She blames her late mother because she was kept out of school to care for her mother.
- “That uncle is treating me well, and I love living with him, and aunty, and my cousins.”
- “That I miss him.”
- “I am glad he isn't sick anymore, but we miss him.”
- “That I miss her, and that my stepfather takes advantage of me... (describes sexual abuse).”
- “Why someone so young has to die – he was only 42 – no one seems to know, some say diabetes, some leukaemia, but from what I'm learning I don't know.”
- “I miss her, but I am comfortable.”
- “I miss you – why did you have to get AIDS?”
- “That I want to run away, grandmother beats me for everything.”
- “I miss her, but I'm glad she gave me her name.”
- “I wouldn't know what to say to him – I wasn't close to him.”



## INTERVIEWS WITH CAREGIVERS

**T**wenty-six caregivers were interviewed. Twelve are HIV-positive mothers and 9 are grandmothers, with the rest being aunts, foster parents and a neighbour, all caring for children whose parent died from AIDS. Two respondents are men – foster-fathers.

One respondent is a professional caregiver, running an institution with 20 abandoned or orphaned HIV-positive children. Another is a grandmother who is caring for 13 children – five of her own children, two nieces, four grandchildren and “a boy who was left by a man who asked her to look after his son while he went to buy groceries,” 13 years ago. This child turned out to be HIV-positive two years after she got him, but she elected to keep him.

Asked about their greatest needs, 18 caregivers referred to money or material items, such as food or clothing. A few spoke of love, friendship and help with schoolwork. The professional caregiver mentioned anti-retroviral therapy to extend the lives of her children. Four said stigma was the greatest barrier to getting these needs met. Another four were embarrassed at having to ask for help all the time.

Ten caregivers said the children were better off now, seven said worse off, and eight said their living conditions had not changed. All but one of the HIV-positive caregivers said they thought their own emotions had affected their children.

When the caregivers were asked how they help their child cope with the loss or illness of a parent or sibling, or adjust to changes in their lives, only the professional caregiver referred to counselling. Others gave a variety of answers, including distracting or reassuring their children, having visitors or disclaiming responsibility for their situation.

Interestingly, a number of the caregivers are, themselves, receiving counselling. It appears there may be a misconception that counselling is something that is exclusively for adults living with HIV/AIDS, and is not relevant to children having to cope with grief, anger and depression as a consequence of their parent's illness and possible death.

Asked whether they had spoken to their children about dealing with emotional impact and stigma, eight said they had done so, with at least one of the children in their care. Some said they had broached the subject only in a roundabout way. However, one said “we speak about it all the time – I want him to grow up and not make the same mistakes as his father. I also want him to know how to treat a woman.”

Asked what advice they would give to HIV-positive parents on telling their children about their condition, the respondents gave answers ranging from: “Better to tell them than let them find out,” to: “No way – don't tell.” Several felt that children should not be told if they were “too young.” One said: “Someone should talk to the children – but not me!” Overall there was a preference for not telling children at all, or only “if necessary.”

Most of the respondents said they were not treated any differently due to their association with HIV/AIDS. However, most have not revealed their status or the cause of death of the child's parents to anyone, or have kept it within the family. In only one case was it clear that the community had been aware that a mother was dying from AIDS. The caregiver, who was a neighbour, said there was a “scandal” and people were constantly visiting the house, but she thought it was “because they were inquisitive – not because they wanted to help.”

In terms of support, 19 out of 26 caregivers received support from one or more organisations, such as NGOs, faith-based organisations, service clubs, and PLWA support groups. Two respondents said they got help from a counsellor. In many cases, other individuals had helped. Only one – the neighbour caring for a child orphaned by AIDS – said no help had been received from anyone.

The public health service received mixed reviews – nine were positive, eight negative and nine expressed opinions



such as “sometimes good, sometimes bad, it depends on where I go.” Lack of respect, stigma and delays were mentioned as specific problems.

One woman described an incident in a waiting room where a doctor called out for “the lady with C13.” Later he called her by name, and asked why she had not responded earlier. Another respondent said she had received good health care, but was afraid because she was once a hospital worker! She has since changed her job, but sometimes still feels fearful, and goes to a private doctor who treats her at minimal cost.

Questions about the experience of care-giving elicited a range of responses. Several caregivers spoke about taking out their anger and frustration on their children. “I was mad at her for everything, when I first found out.” One recalled a time when she did not cook for her children because of “depression about the treatment from my man.” The children were sometimes given food by a neighbour, or the 11-year-old cooked, or they went to bed hungry.

Many spoke of depression. “Sometimes I feel like giving up, but I can’t, as I have my children to live for. I don’t know how I contracted the virus – my husband has never gotten ill, and he has been my only partner for 14 years.”

A number of the caregivers felt that children should only be told their HIV status when they were “big enough” or could “handle the consequences.” “Don’t tell them during exams,” said one. “One child knows and the others do not. I’m afraid that one day it will come back to haunt me – if he tells the others.” One woman planned to send her children abroad: “It is better for them to hear of my death than to see it.” Only one said, “Better to tell them than to let them find out.”

Only two of the caregivers had made firm plans for the custody of the children in their care, in the event of their own death or incapacity. Seven mentioned relatives who had been informally approached, or whom the caregiver hopes will take them. Two caregivers – including the institutional caregiver – said they believed institutions were not the best place for a child. “They need to feel like they are cared for in a family.”

Only one caregiver had drawn up a will, although two have made arrangements, such as changing the beneficiaries of their insurance policies. Four caregivers have discussed with their children the possibility of living with someone else, although it seems this was not in the context of the caregiver’s illness or death, but of finding a better life with relatives elsewhere. Two of the children are “excited” at the prospect of the move.

Finally, advice from the caregivers to others in the same situation:

- “Children can learn to love and trust someone even though it may not be their real parent. Parents can be comfortable with that, and not worry. It is also better to make some plans for their children, rather than leave them to the mercy of others.”
- “Forgive your parents and enjoy your life, but don’t let anyone take advantage of (that is, sexually abuse) you.”
- “Don’t take out your anger on your children. Even though I do it sometimes, I know it’s wrong.”
- “Fathers also need to carry the burden, and not leave it all to the mothers. Remember the mothers got it from them.”
- “Get education and a good job; do not depend on a man.”



# RECOMMENDATIONS

**E**xtended families tend to absorb orphaned and “shifted” children without drawing official attention to the fact, so this kind of foster-care is extremely difficult to measure.

In the context of HIV/AIDS, the number of OVC in any community will quietly increase until the absorptive capacity of families in that community is saturated, at which point various institutions and professionals will suddenly be called upon to act. This is a classic “pressure-cooker” scenario, where it is possible that no action will be taken until the problem explodes.

This survey suggests that pressure is building rapidly and, if left unattended, the OVC situation could explode to the long-term cost of Jamaica. The following steps are recommended to attend to the challenge before it becomes unmanageable. Since delays will make the ultimate solution more difficult and more expensive, and will result in the needless wastage of human potential, all of these actions should be regarded as extremely urgent.

## Actions

- 1. Drug therapies:** The best way to deal with orphaning is to avoid it, by keeping parents alive. Universal access to anti-retroviral therapies and to drugs that extend and improve the quality of life by treating opportunistic infections, such as diarrhoea, thrush and skin rashes, is strongly recommended.
- 2. Access to public services:** A major effort should be made to publicise all services that support caregivers in meeting their obligation to provide a secure environment, adequate nutrition, health care and education to the children in their care. Barriers that prevent people from using public services should be removed. Social workers and other intermediaries should be trained and deployed to facilitate access to these services.
- 3. Stigmatisation:** All workers (especially public servants) who come into contact with children should receive HIV/AIDS awareness and behaviour training.
- 4. Economic empowerment of caregivers:** Most problems relating to the care of children are directly related to household income. Income-generating activities, particularly within female-headed households with large numbers of children, should be investigated with a view to replicating and scaling up suitable models.
- 5. Psycho-social support/counselling:** Develop and implement a training programme for adults who work with children, such as teachers, nurses, child-care workers, clergy, caregivers, volunteers, etc, so that they can recognise and treat psycho-social distress in children.
- 6. Networking:** Opportunities must be created for the sharing and documenting of experience and ideas in relation to OVC; the inventory of institutions working for OVC should be kept up to date and circulated to those who need it; and a referral network should be established to facilitate collaboration in addressing the needs of individual and groups of children.
- 7. Planning for OVC:** Stakeholders should establish a Steering Committee, including representation from government, NGOs, faith-based organisations, people living with HIV/AIDS, donors, etc. to prepare a National Plan of Action for OVC in line with the declaration of commitment at the June 2001 UN General Assembly Special Session on HIV/AIDS. This Plan should be built on a human rights framework, and involve all stakeholders, both in its development and its implementation.



## RESEARCH

There is a need for more work, especially at the household level, to understand the scale and nature of the predicament facing OVC and their caregivers, and to pinpoint actions that will enable families and institutions to respond more effectively to their needs.

As far as possible, all data should be capable of disaggregating by sex and age of caregiver, sero-status of parents and whether they are still alive, ages of children in household, geographic area and socio-economic status. There may be benefits to asking caregivers and children the same questions, to test for similarities and differences in experience and perception.

For example it would be very useful to have more data on:

1. **Ratios of PLWA to dependent children:** How many children are dependent on adults who are HIV-positive? How many of these children are HIV-positive themselves?
2. **Number and relationship of children to caregivers:** If not the caregiver's birth-children, why were they separated from parents? If orphaned, what did parent(s) die from? If from AIDS, cross check with existing government data collection methods to confirm accuracy. How many men are performing care-giving roles, and what roles are they performing? How many caregivers/household heads are under the age of 18?
3. **Movement and affiliation:** How many times have children been "shifted" between caregivers? Who were the caregivers? What was the children's ages at time of shifting? Why were they shifted? Did their quality of life decline or improve? Were they moved to unfamiliar surroundings? Were they separated from siblings?
4. **Children's perceptions:** What do children think constitutes acceptable parenting (separation from parents, violent discipline, abuse, withholding rights such as food, schooling, etc.)? Do they plan to raise their own children the same way as, or differently from, the way they themselves are being raised?
5. **Costs of child-raising:** What does it cost to feed and clothe a child at home? To attend school? To use health services? To enjoy recreation? Are there other common expenditures that are considered essential (for example, insurance premiums and religious observance)?
6. **Barriers to health care and education services:** Are caregivers (and children) aware of services available to them? How do they perceive accessibility and cost? What is their experience of using the services? Are they required to disclose sero-status? Do they consider this disclosure to be confidential?
7. **Preparations made by HIV-positive caregivers for their children:** Have caregivers provided for inheritance, custody, material and psycho-social support? Have they disclosed their status to their children?
8. **Stigmatisation:** Have HIV-positive parents or parents of HIV-positive children disclosed their status to the community? If so, what was the result? How do unaffected people feel about those who are infected or affected - are children stigmatised simply by association?
9. **Alternative models of care:** What are the implications (cost and otherwise) of care in children's homes, places of safety, formal foster care and adoption? What are the implications of children's court proceedings to secure placement?





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# ANNEXURES

Literature Review

Workshop Report



# ORPHANS AND CHILDREN MADE VULNERABLE BY HIV/AIDS IN JAMAICA – A REVIEW OF LITERATURE

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## Definition of key terms: orphan, children orphaned by AIDS, and vulnerable children

The word 'orphan' is no longer limited to the classic dictionary definition of 'a child whose parents are deceased' as Non-Government Organisations (NGO's), governments, private and international agencies cannot seem to agree on a fixed definition. The documents reviewed indicate that one of the reasons for this inability to concur is based on the varied cultures and social structures of the different regions and countries. For example, in some countries an orphan is any child under the age of 18, who has lost either mother, father or both parents. The term 'lost' according to their definition means 'deceased.' On the other hand, some countries use a similar definition but perceive the word 'lost' to mean a missing or an absentee parent, not necessarily deceased.

In Jamaica, the percentage of single mother households and absentee fathers is high and thus the UNAIDS definition of an orphan 'as a child whose mother has died' may be an appropriate one to use in the Jamaican assessment. Such a definition, however, could lead to the unintended exclusion of children who are paternal orphans. Also, the distinction between maternal orphans and double orphans could be clouded by the above definition of 'orphan' and therefore some researchers recommend that separate data be collected for each group.

Another area of disagreement is the cut-off age for childhood. The traditional demographic cut-off is the 15th birthday but in many African and Caribbean countries the legal cut off age is 18 years old. Countries that adhere to the latter give these children the opportunity to be eligible for all child protection and socio-economic services, such as the completion of secondary schooling, for an additional three years.

Mr. Straton Nsanzabaganwa, The Director of Social Security and Vulnerable Groups, Rwanda, said 'Who are orphans and vulnerable children? Include street children, children in foster families, children in centres, children in child headed households, children with parents in prison, children in

exile, traumatized and handicapped children, children whose mothers have remarried, children in female-headed households, children with parents who are incapacitated due to HIV/AIDS, traumatism or absolute poverty.'<sup>1</sup>

The vulnerability of children orphaned by AIDS starts long before the death of the parent. Many of these children take on the role of 'parent' as they are forced to become the primary caregivers for the chronically ill parent. Many have to drop out of school because of discrimination and/or lack of income to provide uniforms, shoes and books. Many become malnourished, depressed and despondent. In addition, they have to go through the trauma of watching a parent die. One writer comments that 'Psychosocial distress is another dimension that impacts on children and families including anxiety, loss of parental love and nurture, depression, grief, and separation of siblings among economically strapped relatives.'<sup>2</sup> Researchers suggest that all of these factors increase the vulnerability of the child who has had to undergo the death of a parent/s to AIDS.

The view as to whether or not there should be a distinction between children orphaned by AIDS, orphans due to all causes, and vulnerable children in general, is common in the literature reviewed. Some writers prefer not to make a distinction because it can actually make the child's life more difficult either by drawing further attention to the stigma the child may be undergoing or because it has, in the past, caused resentment within communities who feel that other vulnerable children are being overlooked. However, there are advantages to making a distinction, if not blatantly in the field, then at least in keeping accurate data to assist in monitoring and evaluating the current programs and initiatives. This will ensure that each groups' needs are met by the most appropriate means possible.

In 2001 the number of children who are orphaned by AIDS in Jamaica was 125<sup>3</sup> while it is estimated that during that



1. "Situation of Orphans in Rwanda" Policy Workshop : Promoting Strategies for Community Care of Vulnerable Children, MINALOC-IRC, March 2001
2. Williamson, J, Chapter 3. Finding the way Forward: Principles and Strategies for Intervention.
3. National HIV/STD Prevention Control Program. Facts and Figures. Jamaica AIDS Report 2002
4. Statistics provided by Dr. Y. Gebre, Ministry of Health, "Workshop on Orphans and Children in Families Made Vulnerable by HIV/AIDS", Ocho Rios, Jamaica. (May 30 - June 1, 2001)

same period the number of vulnerable children was about 170,000.<sup>4</sup> Although the number of children who are orphaned by AIDS represents only a small percentage of the total number of vulnerable children, the literature suggests

it is important that a distinction be made as the stigma attached to HIV/AIDS could pose some unique problems with regards to the rights, housing, education and accessibility to health care, among other things.

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## The education system: passive, active, or judgmental?

The education system in Jamaica is overburdened and under financed. But in spite of limitations, attempts are being made to reduce the transmission of HIV/AIDS through the use of education. The Ministry of Education, Youth and Culture (MOEYC) is actively involved in the Jamaican HIV/AIDS/STI National Strategic Plan 2002- 2006. The primary foci of its work-plan are to evaluate and improve the HIV/AIDS/STI component of the Health and Family Life Education program run in schools, to help it to regain momentum, and to provide training and teaching tools to education officers, principals, teachers, guidance and peer counsellors.

Workshops have been planned to ensure this is accomplished. Strengthening the knowledge base of educators and their ability to impart information in an effective way should assist greatly in changing the stigma attached to HIV/AIDS, assist in preventing the spread of the virus and help to promote the rights of persons affected by HIV/AIDS. A link coordinator for this work-plan has been appointed with responsibility to monitor and evaluate the progress of all strategies and report to the MOEYC and the National AIDS Committee (NAC).

A review of a document entitled 'A Policy for Schools in a World with AIDS' commissioned by MOEYC raises some other important issues that relate directly to the rights of an HIV positive child to access education without fear of discrimination. Although the recommendations of the document are mostly relevant, some of them seem idealistic especially in an environment where there is fierce competition for available funds. The fundamental issues of the document can be linked to the Convention on the Rights of a Child (to which Jamaica is a signatory) which states that every child is entitled to have his or her rights respected, protected and fulfilled.

Currently, many Jamaicans do not feel that their rights are respected or even enforceable. The court system is perceived as slow and cumbersome. There is a wide disparity between legislation and reality in Jamaican society. In several controversial situations that have occurred in the recent past, the Government has not been perceived as strong activist for human rights. In the last two years, civil society has actively spoken out against the blatant violations of human rights in Jamaica and is now a force to be reckoned with by the government.<sup>5</sup> In this present culture, the Ministry of Education's commitment to ensure the rights of the child is a difficult task.

Further, social attitudes of intolerance and inequality carry over into the school system. Current research indicates that attitudes and values concerning children with HIV/AIDS are steeped in ignorance and irrational fears. Judgements are made on any child that is even suspected of being infected or affected by AIDS. The norm is for them to be scorned and if possible be removed from the mainstream educational system.<sup>6</sup> It is vital that there is a social transformation that reflects a respect for the rights of others. Children who may be infected with HIV have the potential to lead long and healthy lives. They have the right to an education as long as they do not pose a health risk to others and the Government has the overall responsibility to protect the rights of these children.

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5. Amnesty International Report on Jamaica. "Killings and Violence By Police. How Many More Victims?" 2001.

6. Senator Burchell Whiteman, Minister of Education, Youth and Culture, "Don't Isolate HIV/AIDS students" Jamaican Gleaner, February 19, 2001



## The child in distress - the needs of children orphaned by AIDS before and after the death of a parent

The current literature indicates that it is important for health and social workers to focus on the emotional and psychological needs of the child orphaned by AIDS. Mark Connolly of UNICEF writes that 'HIV/AIDS undermines and often destroys the fundamental relationships considered essential to healthy family life and child development. A child's progression through basic development stages is jeopardised if HIV-related illness reduces and then ends the parent's capacity to provide consistent love and care. Children suffer anxiety and fear during the years of parental illness, then grief and trauma when a parent dies.'<sup>7</sup> It is vital that any strategic plan includes the issues of future planning, ongoing counselling for the parent/s and their children, and bereavement counselling to enable the AIDS orphan/s to cope with their grief in the best possible way.

The available research suggests that parent/s with HIV/AIDS are hesitant to confront their upcoming death/s with their children because of several factors. Firstly, there is a fear of losing custody of the children once their health deteriorates and, secondly, there is a concern about the imposition of their children on other family members as a result of their death/s. The third reason is their unwillingness to face the fact that they will succumb to the virus and therefore need to plan for the future. Many children who are orphaned by AIDS are left in the dark as to why their parents died and also about their own HIV status. Serious emotional damage can be done to a child left in such a situation.

The literature recommends that early in the parent's illness ongoing counselling by health care professionals should be provided. This is to assist them to relieve stress and anxiety about the future by helping them to create memory books for their children. Counselling is also needed to help the parent decide upon legal issues such as guardianship, custody, and ensuring that as far as possible, siblings are not separated during acute bouts of illness or upon the death of the parent/s. In the United States, guardianship

laws have been introduced in six states which allows temporary custody to be given to a guardian if the parent is ill for an extended period of time. If the parent recovers the child will be returned.

On the other hand, in Africa and the Caribbean, the extended family normally takes on the role of caregiver at the death of the parent. Support groups like those run by Hope Worldwide at the Chiawelo Clinic in South Africa help parents to cope with the issues at hand. It is important that a legal framework is developed to ensure that the children are placed in suitable homes based on their parents wishes, and that they are monitored and counselled during that transition period of their lives.

It is also stated in the literature that emotional and psychological counselling should be ongoing for the parent/s, child, and the future caregivers, particularly for those children who are HIV-infected themselves. If the feelings of children affected by AIDS go unheard then the impact on their development, could be detrimental. 'Failure to do so can result in a "second generation" of problems, which may include alcohol and drug abuse, violent behaviour, suicidal tendencies, unwanted pregnancies, and sexually transmitted infections (including HIV infection).'<sup>8</sup> Children need an opportunity to voice their feelings, their fears and anger, and to deal with self-esteem issues. Counselling provides a forum for openness, which must be encouraged. Support groups run by trained counsellors and/or peer counsellors can assist in grief management and the long-term emotional support of these children. Presently the Jamaican HIV/AIDS/STI National Strategic Plan (2002-2006) makes no specific reference to these issues. Access to counselling is limited, due to budgetary constraints. Ongoing funding is needed to ensure that this extremely important aspect of HIV/AIDS care is not overlooked or marginalized.



7. Connolly, Mark. UNICEF "Principles to Guide Programming for Orphans and Other Children Affected by HIV/AIDS". (Draft)

8. Connolly, Mark. UNICEF "Principles to Guide Programming for Orphans and Other Children Affected by HIV/AIDS". (Draft)

# What's best? The role of the institution, community based organization, and the extended family in the life of children orphaned by AIDS

In 1989, the UN General Assembly adopted the International Convention on the Rights of the Child (CRC). The four main principles of the CRC are:

- 1) Non-discrimination
- 2) Best interest of the Child
- 3) The right to Survival and Development
- 4) Respect for the Views of the Child.

These four principles are supposed to govern policy makers in regards to children and yet in many countries the rights of the child, particularly a child affected by AIDS, has not been a priority for the governing powers.

A global view of the HIV/AIDS pandemic is important to understand when devising interventions for Jamaica. The statistics vary from region to region but it is obvious that it is a growing problem that will reach or has already reached overwhelming proportions in certain countries (for example in sub-Saharan Africa). The necessary policies and initiatives need to be devised now to help prevent the AIDS epidemic in Jamaica from getting out of control. The literature speaks to the fact that cultural, social, economic and political issues play an integral role in determining what programs will work in any given country. The severity of the pandemic also helps to determine what initiatives to use, depending on whether the social safety net of the extended family has been severely depleted, children are now being forced to raise younger siblings on their own, or whether the elderly have the overwhelming pressure of taking on that responsibility.

At the end of 1999 the adult HIV rate in the Caribbean was 2.1% ranking it as the highest in the Americas and second in the world (next to sub-Sahara Africa). Haiti has the most severe situation in the Caribbean. It is predicted that by the year 2010, 10% of Haitian children under the age of 15 will become orphans, with over 50% losing a parent to AIDS. In Haiti, one in every six orphan and vulnerable children (OVC) is in an institution but there is a reluctance by these institutions to take care of HIV positive children. The only

other viable options for these children are to live with extended families or on the streets. Many face violence and abuse and do not receive the necessary care or attention as a result of financial constraints and discrimination. The Haitian government's low political commitment to HIV/AIDS and its low commitment to the CAC in general, reflected in its lack of funding and coordination, have contributed to the high incidence of HIV/AIDS in that country.

In Trinidad, many OVC are still placed in institutions. Many of these children grow up without ever experiencing family life and have no place to go at the age of 18. There is presently only one institution that will house children who are HIV-positive. However, this particular home actually has a lower mortality rate than the rest of the country. It also provides a solution for children who otherwise would have been left in understaffed medical wards at hospitals.

Jamaica has a strong family safety net. It is commonplace for children to be raised by grandmothers and other relatives in the rural areas while their mothers work in the city. Most orphans have a family member to live with upon the death of their parent/s. OVC that have no family, or are abandoned, either end up on the streets or in an institution. Unlike Trinidad, children infected with HIV/AIDS in Jamaica are allowed in all government institutions. Policy recommendations for these homes have been developed to protect the human rights and safety of these children and staff of the children's homes.

From 1982 to the end of June 2001, 5,547 AIDS cases were reported in Jamaica, 2,402 of them being female cases. In 2001 alone, 428 new female cases were reported and 625 HIV positive women were pregnant. Although the number of children who are orphaned by AIDS was as low as 125 in the year 2001, it is obvious that this figure will grow as many of these mothers succumb to AIDS. The literature indicates that institutional care for these children should be



a last resort. Instead, the focus should be on strengthening the caring capabilities of families to adequately look after these children. Many low-income families have difficulty finding school fees, uniforms or other equipment and subsidies to assist them in the care of children who are orphaned by AIDS so as to alleviate the stress they undergo. Initiatives need to be taken by the state to strengthen the financial and economic support of caregivers as this will provide a two-fold solution to the problem: In the long run the financial burden on the state will be reduced and secondly the child will be raised in a family situation which is a healthier environment for their development.

Because of the vast number of orphans as a result of AIDS in countries like Uganda, Zimbabwe, and Zambia, community-based organizations (CBO's) have been formed to help deal with the crisis. In Jamaica, however, the plight

of children orphaned by AIDS is almost unknown, and therefore CBO's currently focus on issues that assist the community as a whole, be it schooling for the children, sports or maintaining peace. If the levels of infection continue, we can expect to see a sharp increase in the number of children who are orphaned by AIDS. It will then become necessary for CBO's to assume a much more active role in providing care. In this environment, success will be enhanced by the support of opinion leaders in the communities. This will be particularly useful to assist in combating ingrained negative stereotypes.

Ideally, the best situation for these children is to grow up in a loving, caring family situation with the help of community based initiatives, with the children's home being a last resort.

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## **An analysis of Jamaica's policy and legislative framework specifically with regards to OVC**

The government has to be actively involved in the fight against the spread of HIV/AIDS if Jamaica is to come close to beating this epidemic. They have to ensure that legislation, policies and programs are structured in a way to protect the fundamental rights of persons with HIV/AIDS. They need to secure funding to implement, monitor and maintain programs. Indeed, the Jamaican government, mainly through the Ministry of Health (MOH), has consistently attempted to do just that. In 1985 HIV/AIDS was declared a 'notifiable disease' under the Public Health Act. The HIV/STI Prevention and Control Program was established and has gone on to introduce over 17 major initiatives to help combat this potential epidemic. They have, however, up to this point, placed little emphasis on children orphaned by AIDS. Children born to HIV positive mothers are monitored for only the first eighteen months of their lives. The literature suggests that this policy needs reform to ensure that the needs of the child are effectively met in the event of the illness or death of the parent/s. The inaccessibility to anti-retroviral drugs because of cost has

led to an increase in the number of deaths among people living with HIV/AIDS in the low income bracket. This has in turn led to an increase in the number of orphans in low income communities.

A HIV/AIDS/STI National Strategic Plan has been structured for the next four years and one of its features is 'social policy reform to reduce vulnerability.' As a result, the Jamaican constitution is being reviewed with a view to reform any existing laws that may discriminate against or not adequately protect the rights of the person with HIV. Specific laws related to the rights of children were reviewed for the purpose of this document.

### **The Public Defender (Interim) Act**

This Act allows individuals to seek redress through the Public Defender for violations against them by any government agency, whether it be schools, medical facilities, or social services. He not only investigates complaints but also has the right to engage in legal proceedings before the Courts on the complainant's behalf. The Public Defender is a medium through which persons living with HIV/AIDS (PLWHA) could seek defence for any human rights violations or discrimination that they may face from the governing authorities. Minors are permitted to make complaints through parents/caretakers. This act therefore





provides an avenue for children infected or affected by AIDS to be heard in the light of any injustice or discrimination they may encounter through the public system. It must be noted that the Public Defender is a political appointment. The literature suggests that this could result in political partisanship or bias in his decision making role.

### **Adoption Act & Guardianship Act**

These Acts provide a thorough framework for the Courts to make decisions 'in the best interest of the child.' More and more, the Family Court is faced with children who are either infected or affected by HIV/AIDS. The lack of data on developmental and educational delays or changes in behaviour due to the death of a parent is a matter of concern. One recommendation suggested in the literature, is that the Court should ensure that caretakers are counselled properly on how to meet the emotional, educational, and health needs of these children and on coping strategies. The Court should ensure that this area is tracked and monitored by the Adoption Board.

In a review of the Act, it was suggested that it would be in the best interest of the child if the adoption process was not as long and tedious, to ensure that children are taken out of institutions and placed in family settings as quickly as possible. Currently there is no legal provision for the temporary placement of a child with a guardian during parental illness.

### **National Family Planning Act**

This Act is the primary tool of the government to implement family planning programs and policies to all strata of the society. The National Family Planning Board has been given wide powers to ensure the dissemination of sex education, planned parenting, HIV/AIDS/STI education, to all ages and groupings in Jamaica. It is responsible for coordinating research, collecting data and statistics, training health care personnel and operating family planning clinics. Its role in attempting to reduce the number of OVC cannot be overstated. The board is permitted to liaise with other ministries, such as with the Ministry of Education and to coordinate their efforts with regards to the school curriculum on family sex education issues.

### **National Insurance Act, Section 13: Orphans Benefit**

Caregivers of orphans under the age of 18 years are entitled to receive an Orphans' Pension subject to certain criteria: the mother must be dead, the father dead or unknown, and the child must have permanently resided with the mother prior to her death. In addition, the parent/s must have paid their National Insurance contributions for the caregiver to be entitled to this pension. Unfortunately, in Jamaica, many employers, and self employed persons (such as vendors) do not adhere to the laws regarding statutory payments. A gross salary is paid over to the employee (e.g. a domestic worker) and no deductions are paid over to the NIS Department. In the event of the death of a parent in that situation, the child and his caretaker would not be entitled to anything. In addition, no provision is made for persons who have been unemployed for an extended period of time due to chronic illness. These persons, most likely would be unable to make NIS payments, making their child's caregiver ineligible to receive this benefit upon the death of the parent.

### **Poor Relief Act**

This Act was instituted to provide for the poor and indigent in Jamaica. It provides funding for poor children to attend school, as well as medical assistance, basic food items, and shelter for those in desperate need. It could be a useful tool for those persons who are ill because of AIDS and who cannot provide adequately for their children's medical and schooling needs. However, reforms need to be made to ensure that there is no discrimination to PLWHA and that there is absolute confidentiality re their status if they are given financial assistance from the fund. The literature on this particular Act suggests that one reform could be to use poor relief funds to assist NGO's/CBO's with housing for an AIDS hospice to meet the ongoing needs of AIDS victims. Unfortunately, funds are very limited and in actuality, poor relief can do very little to meet the overwhelming needs of the poor and indigent in Jamaica.



## **The Juvenile Act**

The essence of this Act is to provide the Court with the necessary guidance on how juveniles should be treated by the Court and to protect the rights of children by ensuring that they are living in an environment free from any form of abuse and neglect. It also states that the age of criminal responsibility is age 12. The Court is given the right to intervene in situations where the child is without parental guidance, or to remove juveniles from situations where the parents have proven themselves to be unfit to care for these children. The Court has the right to place these children in institutions for their safety and protection. The literature suggests, however, that in Jamaica the lack of formalised sex education programs is high and therefore can actually increase a child's chances of contracting AIDS. It has therefore, been suggested that reforms should be made to ensure that sex education, HIV/AIDS/STI awareness and prevention is taught in these institutions. Data also suggests that since many of these children are sexually active from as early as ten years old, legislation needs to ensure that condoms are available for juveniles.

## **The Public Health Act and Education Regulations**

The Public Health Act lays down stipulations regarding safe public health procedures that have to be adhered to in any public place or institution. The Act implies, by its definition of 'communicable' diseases that HIV/AIDS would fall under this category. This clause needs further clarification as it is known that HIV/AIDS cannot be caught through casual contact ( like Chicken Pox ) and therefore, no discrimination should be shown to a PLWHA in a public setting. Within the educational system the regulations in section 31(1) states that 'students 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'. The legislation needs to clearly state what is a 'communicable disease' so as to ensure that children infected by AIDS will be protected from any form of discrimination or ban.

The rights of the child is an important issue for the Government as indicated by the appointment of an Ambassador for Children. In addition they have shown a willingness to reform legislation to protect the rights of children and have completely backed the National HIV/AIDS initiatives that have been formulated. With 68% of the 2002 budget supporting local and international debt financing, very little is left to meet the other needs of the country. Against the background, it is evident that although the government is willing to assist with reforming policy and legislation, it will be difficult for it to make any significant financial contributions to interventions that help the fight against the spread of AIDS. Many of the needs of children who are orphaned by AIDS will have to be met through international funding and creative community based activities.

## **The global picture - Jamaica's perspective**

A publication put out by UNAIDS entitled 'Children and Young People in a World of AIDS' summarized the global workplan against AIDS that was formulated at the United Nations General Assembly Special Session on HIV/AIDS in June 2001. A 'Declaration of Commitment to HIV/AIDS' was adopted to fight the HIV/AIDS epidemic by all member states with deadlines to achieve certain targets.

Although sub-Sahara Africa has the majority of children who are orphaned by AIDS currently, it is expected that Asia and the Caribbean will see a sizeable increase in children who are orphaned by AIDS over the next ten years. It is with this background that the member states of the United Nations have made a commitment to ensure that by the year 2003, countries should have developed national policies that should be up and running by the year 2005. Orphan programs should include 'counselling, protection from abuse, education and ways to prevent discrimination.'<sup>9</sup> By the year 2005, strategies are to be put in place to promote the advancement of women, empowering them to enjoy all human rights, as women globally, have been shown to be marginalized disproportionately by HIV/AIDS. Also by that year, 90% of the men and women between the age of 15 - 24 years are targeted to have access to age specific HIV/AIDS information and education and to services necessary to hone life skills so as to reduce their chance of



contracting the virus. If these goals are accomplished, they will play an integral role in the reduction of HIV/AIDS in Jamaica and the rest of the world.

An article in Family Health International, June 2001 entitled 'Care for Orphans, Children Affected by HIV/AIDS, and Other Vulnerable Children' comments on the fact that 'according to revised 2000 estimates there are 34.7 million children under age 15 in 34 countries who have lost mother, father or both parents to HIV/AIDS and other causes of death. By 2010 that number will rise to 44 million. Without AIDS the total number of children orphaned would have declined by 2010 to fewer than 15 million.' Reviewing global, regional and local documents have helped to put Jamaica's situation in the right perspective. John Williamson, Senior Technical Advisor for the Displaced Children and Orphan Fund (DCOF) of USAID, speaking on the African experience said 'There are no roadmaps to guide responses because we continually move into uncharted territory.' The plight of the AIDS orphan in Jamaica is 'uncharted territory' but fortunately the number of orphans is still fairly small. The literature available can serve as a compass to lead us to the interventions that will work in a developing country. It is hoped that by assessing the global picture we may be able to integrate and improve upon existing programs and

policies that are used elsewhere and learn from the mistakes that may have occurred as a result of the ever changing face of this pandemic.

One of the lessons learned from the African experience is that each country has its own unique problems and it is therefore important for one's local situation to be properly investigated to ensure that the initiatives taken fit the socio-economic and cultural background of the country. Strengthening partnerships between the Jamaican government, NGO's, CBO's, and the private sector is vital to ensuring that practical, viable, self supporting programs suited for the Jamaican environment are formulated. The communities need to get actively involved and vocal on what will work in their situation.

Jamaica along with all other CARICOM members should consider bulk purchasing of drugs and medical supplies to help cut costs. Technical assistance from international agencies like UNICEF, UNDP, and USAID should continue to be tapped into as an important resource. The OVC and AIDS orphan plight is a long term situation and therefore long term interventions have to be developed now to alleviate the suffering, stigma and problems that these children face daily.

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## Conclusion

A number of the documents included in this review did not deal with the Jamaican situation or directly with children who are orphaned by AIDS. However, they gave a global perspective to this topic and helped to provide vital information that can assist in formulating new policies in regard to the situation of children who are orphaned by AIDS in Jamaica. It is hoped that this literature review will help to bring a comprehensive view of the issues concerning children who are orphaned by AIDS across the world and act as a practical resource to help formulate policies and programs for the Jamaican situation.



# LITERATURE REVIEW

## International Documents

### 1. Care for orphans, children affected by HIV/AIDS, and other vulnerable children

*Family Health International HIV/AIDS Prevention and Care Department, IMPACT Project, June 2001*

**Geographic Area:** Global

**Key Words:** USAID, FHI, OVC, AIDS. IMPACT

**Location:** USAID

#### ABSTRACT

The HIV/AIDS pandemic will bring about massive social change because of the number of children affected by HIV/AIDS. It is estimated that by the year 2010, that 20 to 30 percent of all children under the age of 15 will be orphaned in 11 countries in sub-Saharan Africa. Several lessons have been learned to assist in the care and support of these children. The priorities suggested are, ensuring that government policies and laws prevent discrimination and protect the rights of the OVC affected by AIDS. Orphans and vulnerable children should have access to all forms of medical care. There should be socio-economic support to meet the basic needs of the family such as food, shelter, and education. Psychological support and the opportunity to receive an education are vital to ensure proper development of the OVC. It also states that there should be a human rights approach to programming linked to the tenets of the CRC, and finally, it is important to have community based programs. Source material for this article came mainly from the five basic strategies needed for interventions from 'Children on the Brink' by S. Hunter & J. Williamson and the UNICEF document 'Principles to guide programming for orphans and other vulnerable children.' (Draft 3, January 2001)

### 2. USAID efforts to address the needs of children affected by HIV/AIDS

**Geographic Area:** Global

**Key Words:** USAID, Reports, Children, AIDS,

**Location:** USAID

#### ABSTRACT

The work of the USAID with regards to children affected by AIDS around the world was detailed in this report. It comprehensively looked at the threat of HIV/AIDS to many regions of the world and how it has destroyed the social fabric and economic progress of many countries. The document states that over 70 million people have died from AIDS since the pandemic began, and it was estimated that there were over 36 million people living with HIV/AIDS. The number of children who are orphaned by AIDS was growing at a dramatic rate as a result of these figures. The impact of this pandemic on the vulnerability of these children is detailed in the document. They face the 'prolonged illness of one or both parents, as well as relatives, friends, neighbours; death of a parent/s; depletion of financial resources due to death, illness or support of increased dependents; stigma and discrimination associated with AIDS; loss of caring adults who can protect, teach, mentor and love children.' It was suggested that several issues needed to be considered with regards to the AIDS crisis. First of all, there must be 'urgency' to come up with solutions. Secondly, long term interventions needed to be developed to deal with the predicted long 'duration' of this pandemic on society. Thirdly, HIV/AIDS could no longer be dealt with as a medical crisis. Its 'complexity' impacted on all areas of society whether directly or indirectly. Finally the 'magnitude' of this pandemic requires that 'collaborative action is key to mobilizing resources in an effective manner at the international, regional, national and local levels.' USAID strategies focus on long term interventions by strengthening the community's ability to cope with the effects of the crisis. For the last 15 years, USAID has provided financial support and technical leadership to more than 40 different projects in 18 countries. They have spearheaded global



partnerships with organizations like UNICEF, the World Bank, UNAIDS. They have assisted in developing several successful community based interventions in some of the hardest hit countries by HIV/AIDS. They also have funded research projects in a number of African States that deal directly with improving the care of PLWHA in that region. The document stated USAID's commitment to information exchange among multilateral organizations, donors, and governments so as to strengthen the capacity of countries to cope with the effect of AIDS.

### 3. Partnerships to support orphans and vulnerable children

**Kathleen Henry**

**Geographic Area:** Global, Africa, Zambia

**Key Words:** USAID, FHI,, Building Partnerships, OVC, AIDS. IMPACT

**Location:** Building Partnerships, Vol. 2, No.1, June 2000

Family Health International, HIV/AIDS Prevention and Care Department, IMPACT Project, June 2000, USAID

#### ABSTRACT

This article analyses and examines the factors that will contribute to successful strategies to sustain communities ravaged by HIV/AIDS. It suggests that the most durable and long-lasting solutions for the needs of the OVC, will come from the partnerships forged between international organizations, governments, and communities. These partnerships will afford these children a 'second chance' in a social and economic environment that is crumbling before their very eyes. The writer, quoting from John Williamson, Senior Technical Advisor to the USAID states that the 'front line' in this battle, however, is the families and communities. Several community-based programs were mentioned in the article each attempting in their own way to 'strengthen the ability of families and communities to support and nurture' the orphans and vulnerable children in their communities. The Family AIDS Caring Trust (FACT) program in Zimbabwe's Manicaland Province implemented a Families, Orphans and Children under Stress (FOCUS) project which has successfully been able to mobilize volunteers from the community and offer support to OVC at the low cost of US\$9/family annually..

This program has proven to be an effective way to monitor the needs of orphans and therefore providing appropriate care. It has become obvious that socio-economic empowerment of the community is vital for them to be able to cope with the magnitude of the problem. The article also comments on the 'The Children in Distress Network,' otherwise known as the 'CINDI' project run by Zambia's Family Health Trust which provides funding and support to groups like the 'widow's club' (where widows volunteer to visit and maintain OVC). They also provide material assistance for child-headed households. They provide food, plots for gardens, school fees and even vocational training for the eldest child in the family. The article suggests that the advantage of the community getting involved in the care of its orphans is that they become an advocate for change not just at the local level but even at the national level. They can lobby successfully for policies that need to be reformed to ensure that the rights of women and children are better protected. 'Bridging the Gap' between need and response will be a challenge. The article suggests that expanding the size of programs is not necessarily the right solution. Instead sharing strategies and programs to be implemented by the communities themselves, may have a greater impact, as the feeling of ownership will be a big motivator in ensuring their success.

### 4. Principles to guide programming for orphans and other children affected by HIV/AIDS. (draft)

**Mark Connolly, UNICEF**

**Geographic Area:** Global

**Key Words:** Programming Principles, HIV, AIDS, Orphans, Children

**Location:** UNICEF

#### ABSTRACT

This document is a detailed and comprehensive analysis of the programming principles and recommendations that can be used as a basis to develop an expanded response for



orphans and other children affected by HIV/AIDS. The writer suggests that there is a 'human rights' approach to programming for OVC, guided by the principles of the Convention on the Rights of the Child. (CRC). It is necessary to ensure that actions are 'child centred, family and community focused, and human rights-based.' A situational analysis was done of the global impact of HIV/AIDS on children. Twelve programming principles are suggested to guide actions at local, national and global levels. These principles are as follows:

1. Strengthen the caring capacities of families through community based mechanisms.
2. Strengthen the economic coping capacities of families and communities.
3. Enhance the capacity of families and communities to respond to the psychological needs of orphans and vulnerable children, and their caregivers.
4. Foster linkages between HIV/AIDS prevention activities, home-based care, and efforts to support orphans and other vulnerable children.
5. Target the most vulnerable children and communities - not children who are orphaned by AIDS.
6. Give particular attention to how gender roles make a difference.
7. Involve children and adolescents as part of the solution.
8. Strengthen the role of schools and education systems.
9. Reduce stigma and discrimination.
10. Accelerate learning and information exchange
11. Strengthen partnerships at all levels and build coalitions among key stakeholders
12. Ensure that external support does not undermine community initiative and motivation.

In addition the document advised that an analysis of relevant national policies should be done to ensure that there is essential protection for OVC through the laws and policies of the country. These programs need to be monitored and evaluated both at the local and national level.

## **5. Planning for children whose parents are dying of HIV/AIDS**

**Committee on Pediatric AIDS 1998-1999, American Academy of Pediatricians**

**Geographic Area:** United States of America

**Key Words:** Pediatrics, Children, HIV, AIDS

**Location:** Pediatrics, Vol. 103, NO 2, February 1999

### **ABSTRACT:**

This article attempted to provide solutions for the problems associated with the impact on the parent/s who were diagnosed with HIV/AIDS and the role of health care professionals in this process. It was estimated that by the year 2000 there would be over 80,000 children who are orphaned by AIDS. The writers stated that 'future planning is a difficult and complex process that requires considerable time and effort and should be initiated in a sensitive manner early in the course of illness'. Several reasons were suggested as to why these parents may be hesitant to deal with this issue. Health professionals involved in the care of these parent/s or the children of these parents, needed to initiate counselling to deal with the issues of future planning, custody and guilt, and refer them to the relevant authorities that deal with any other social, financial and legal issues such as temporary guardianship and flexible policies by foster care agencies. This would ensure that after the parent is better from any acute illness, children could return to their care. It would also help to protect siblings from being split up during these bouts of illness or in the event of the death of the parent/s. The writers recommend that paediatricians and other health care professionals lobby the above issues to their local child welfare and state authorities.



## 6. AIDS-related parental death and its effect on orphaned children's self-esteem and sociability

*Kiirya, K. S.*

**Geographic Area:** Uganda

**Key Words:** AIDS; Mortality; Psychology; Death, Parents; Self Concept; Social Adjustment

**Location:** International Conference on AIDS, 1996, Jul 7 - 12; 11(2): 338 (abstract no:Th.D.4871.Pediatrics, Vol. 103, NO 2, February 1999)

### ABSTRACT

The study looked at whether AIDS-related orphanhood affected the child's self-esteem and sociability in school. This study was done in the Kampala District, Uganda. It compared 70 children who are orphaned by AIDS social behaviour against that of 70 non-orphan children within the same age group. The results suggested that children who are orphaned by AIDS are actually more sociable than non-orphans in athletic and non-athletic programs. A possible reason for this is that sociability is more linked to interest and ability. The self-esteem of children orphaned by AIDS, on the other hand, was much lower than the non-orphans as many of them perceived themselves in a negative manner. This study helped to reinforce the fact that children who have lost their parent/s to AIDS need psychological counselling to build up their perception of themselves and recommended that the issue of self-esteem in children orphaned by AIDS should be further investigated.

## 7. CEDRO Project, Lima Peru

**Displaced Children and Orphans Fund (DCOF) On-Site Review**

**Geographic Area:** Peru

**Evaluator:** Sharry Erzinger

**Key Words:** USAID; reports; evaluation

**Location:** Displaced Children and Orphans Fund, USAID, Peru

### ABSTRACT

This document reviewed three proposals received by the DCOF requesting funding for OVC projects for communities that were ravaged by a terrorist group between 1985 and 1994. Of specific interest was the Information and Education Centre for the Prevention of Drug Abuse (CEDRO) project in

Lima, Peru. Although this project is not linked to orphans affected by AIDS, it is worth considering as a possible alternative to the current institutions available for children. CEDRO has provided an effective option for street children by establishing 'Open Houses.' These houses allow complete freedom of movement (the children are not compelled to stay there) and at the same time provide vocational training to help them be financially prepared upon reaching the age of eighteen. It has a 40% success rate in reuniting and reintegrating street children back with their families.

## Regional Documents

### 8. Residential care for children with HIV/AIDS in Trinidad and Tobago

*Innette Marcia Cambridge*

**Geographic Area:** Trinidad

**Key Words:** Caribbean, Trinidad and Tobago, HIV/AIDS, children, residential care, demographics, social work services, child welfare.

**Location:** HIV/AIDS and Children in the English speaking Caribbean/Journal of HIV/AIDS Prevention & Education for Adolescents & Children, Vol. 4, numbers 2/3 2001, ed. Barbara a. Dicks, PhD

### ABSTRACT

This study focuses on the only institution in Trinidad and Tobago for children with HIV/AIDS. Background information about the AIDS epidemic in Trinidad includes data from the UNAIDS/WHO Epidemiological Fact Sheet for 1997 which states that the estimated number of children (under 15) who have lost a mother or both parents to AIDS was 760 and the number of orphans to date (1997) was 600. By now, this figure would have grown making the findings of this study even more alarming. In 1994, The Society of St. Vincent De Paul responded to this crisis of children who are orphaned by AIDS by starting a children's home for children who are orphaned by AIDS who were residing in hospitals. At the time, established Children's Homes did not accept any



children with communicable diseases. HIV/AIDS was categorized as such a disease. **Methodology:** The study took place between January and April 2000. It was divided into three parts. 1) a study of the gender and mortality rates of all the children that have ever resided at the home; 2) semi-structured questionnaire on 20 randomly selected children in the home. No questions were directed at the children, questionnaires were completed from file information and interviews with the caretakers close to the children; 3) interviews with senior staff at the home on the care of the children, resource allocation issues, and their concerns. An overview of HIV/AIDS in Trinidad, among persons under the age of 25 as well as an assessment of residential care as a response to the growing number of OVC in Trinidad was also provided. The study of the home looked at the demographic background of the children, such as gender ratios, mortality patterns of the children, age, race, health status and their parental situation. The study found that 85% of the children had HIV positive mothers, 65% of these mothers had developed AIDS and 40% of these mothers had died by the time of the study. Care ratio for the children is 1:8, plus the regular visit of a doctor, nurse and priest to the home. The home was funded by the parent institution, the national council, & community donations. There is a school on the compound that adheres to the state school curriculum. Three children of the sample went to school off the compound. Many of the community schools refused to register them because of their HIV status. The future for most of these children was unclear, some were expected to live until adulthood, only six would be able to live with relatives, none with parents. None of the children came to the Home through the Courts. Mortality rates at the home were lower than the national mortality rate. **Conclusion:** Residential care still has a role to play in meeting the needs of orphans infected with AIDS, who otherwise would have been left in understaffed hospitals. The child welfare policies of Trinidad need to be amended to ensure the protection of the rights of children who are orphaned by AIDS. HIV being categorized as a 'communicable disease' leads to segregation and the fundamental rights of the child being ignored. The literature

recommended that a permanent social worker be stationed at the home to meet the important need of counselling for the staff and children and to network with institutions for greatly needed assistance.

## 9. Knowledge, attitudes and sexual practice among the HIV infected women with repeated childbirths in Barbados.

*Alok Kumar, M. Anne St. John*

**Geographic Area:** Barbados

**Key Words:** HIV infected mothers, knowledge, attitude, practice, perinatal transmission.

**Location:** HIV/AIDS and Children in the English speaking Caribbean/Journal of HIV/AIDS Prevention & Education for Adolescents & Children, Vol. 4, numbers2/3 2001, ed. Barbara a. Dicks, PhD

### ABSTRACT

Twenty-seven HIV positive mothers with repeated childbirths were interviewed to assess their knowledge, attitudes and sexual practice. Just over 44% were younger than 25, over 70% only had primary education, and nearly 60% were unemployed while nearly 90% were unmarried. A third of these mothers had limited knowledge about Mother to Child Transmission (MTCT), the use of anti retroviral drugs such as AZT to prevent transmission to the babies, and the fact that these children would need to be monitored after birth. Most of these mothers did not plan the pregnancies, felt bad about being pregnant and had not made any plans for the care of these children in the future. In over 70% of these cases different fathers were involved, and the women were hesitant to inform the fathers' of their HIV status because of possible lose of financial support from these men. They also exhibited fear to be open with family members and friends. **Conclusion:** An aggressive HIV/AIDS prevention program needs to be maintained in the public health system. Ongoing counselling by health care professionals is needed for HIV positive women to help them to deal with guilt, openness, and safe sexual practices so as to reduce the spread of this disease. It is recommended that a larger study be done with regards to the social situations linked to MTCT.





## **10. Country plans, 'Accelerating The Response' session : Belize**

**Regional Workshop on Orphans and Children made Vulnerable by HIV/AIDS. (Ocho Rios, Jamaica 30 May - June 2000)**

**Geographic Area:** Belize

**Publication Type:** Workshop Documentation

**Location:** UNICEF

### **ABSTRACT**

Although there was no data to confirm the economic status of persons with HIV/ AIDS in Belize, most of the known cases seem to be from poor socio-economic conditions. It was estimated that there were over 360 OVC most of whom were cared for by extended families, some of whom were adolescents. However, up to that point the OVC issue was not part of the political platform. The PMTCT program protocols were being developed and it was recommended that it should include the tracking of children born to mothers who have HIV/AIDS. The stigma and discrimination attached to the virus continued to be of some concern as there is no legislation to protect the rights of persons with AIDS. Legislation needed to be reformed to ensure that there was no discrimination in schools and that OVC affected by AIDS could be easily integrated into the system. There was a great need for education on HIV/AIDS for governmental officials, teachers and the nation on a whole to ensure that PLWHA and children who are orphaned by AIDS got the appropriate assistance to ensure their rights and their survival.

## **11. Country plans, 'Accelerating The Response' session : Cuba**

**Regional Workshop on Orphans and Children made Vulnerable by HIV/AIDS. (Ocho Rios, Jamaica May 30 - June 1, 2000)**

**Geographic Area:** Cuba

**Publication Type:** Workshop Documentation

**Location:** UNICEF

### **ABSTRACT**

The success of the Cuban HIV/AIDS program was largely due to the fact that the government viewed HIV/AIDS as a priority of the state. Their political structure, (communism) ensured a much tighter control of HIV/AIDS positive parents who received specialized medical treatment and were provided with economic support. All pregnant women were tested and all HIV positive women received free ARV treatment, Caesarean sections, and ARV treatment to the newborn child. All HIV/AIDS victims received specialized treatment particularly the infected children and mothers. It was recommended that the political leadership include in their National Strategic Plan the specific needs of orphans and vulnerable children. Although financial, medical and educational support was provided by the government it is not quite clear what kind of emotional support and counselling was initiated for PLWHA and the OVC. This should be further investigated.

## **12. Country Plans, 'Accelerating the Response' Session & Haitian Delegation Presentation: Haiti**

**Regional Workshop on Orphans and Children made Vulnerable by HIV/AIDS. (Ocho Rios, Jamaica May 30 - June 1, 2000)**

**Geographic Area:** Haiti

**Publication Type:** Workshop Documentation

**Location:** UNICEF

### **ABSTRACT**

The situation in Haiti was of grave concern for several reasons. Firstly, the island of Haiti has had a history of political instability. Secondly, the high level of poverty and illiteracy limit the work needed to be done there to help slow down this epidemic. At the time, 5.4 to 7.7 percent of the population between the ages of 15 - 49 years was HIV positive. It was estimated that there was between 260,000 to 365,000 parents with AIDS. The annual HIV/AIDS related death was between 30,000 to 45,000. John Williamson and



Susan Hunter in 'Children on the Brink 2000' estimated that by the year 2005, approximately 11.5 % children in Haiti would be orphans. About 900,000 of the estimated 1.2 million OVC (25% of the under 15 population) lived in non-biological families, single parent households, institutions, or were on the streets. The aids orphan crisis in Haiti is second only to the situation in sub-Sahara, Africa.

The National HIV/AIDS Strategic Plan focused on HIV/AIDS as a medical issue and the social, economic, psychological and emotional needs of the PLWHA and the AIDS orphan were not really taken into account. It was suggested that children born to HIV positive mothers should be tracked for longer than 18 months. In addition, NGO's community work should include interventions for orphans and vulnerable children. The role of community based organizations in Haiti has been very limited and the stigma towards AIDS victims has been high. Many schools have refused children with AIDS. There has been a great need for the school curriculum to include the issue of stigma prevention and for the persons in that field including the PTAs to be trained and educated on HIV/AIDS awareness, prevention, and the rights of the child. Strengthening the role of the community via community leaders and counsellors was recommended. They needed to be mobilized and trained on HIV/AIDS and OVC to develop strategies and interventions on the community level to ensure that the housing, medical, educational and psychological needs of these children are met.

## Documents about Jamaica

### 13. Policy on HIV/AIDS in the Government and private children's homes

#### *Children Affected by AIDS (CABA)*

**Geographic Area:** Jamaica

**Key Words:** Policy, CABA, HIV, AIDS, Children's Homes,

Location: CABA, NAC

#### **ABSTRACT**

The need for clear policy guidelines regarding the safety and rights of children and employees of children's homes led to the development of this document by the CABA group. The document examined five issues, firstly, the testing of children and reporting. Under this policy, the document listed the only reasons why a child may be tested for HIV/AIDS. If the test must be performed, there must be counselling for the child prior to taking the test to assess the child's risk, to explain how the results of the test will have an impact on his/her life, and to give the child a forum to be open about his/her feelings. The counsellor must be the person to give the results of the test, again providing support and solutions to the child. All results are required to be reported to the Ministry of Health's Epidemiology Unit by the health practitioner that performs the test. Clear guidelines for confidentiality was the second issue discussed in this policy document. It emphasized that any breach of confidentiality would lead to termination of the employee/s involved. The third issue raised was that of caregiving. These guidelines stressed the importance of protecting the rights of the child in the caregiving process. Three main areas were considered in formulating this policy:

- a) Training the staff in the appropriate use of Universal Health Precautions.
- b) Rules for Daily Living to ensure that HIV positive children are not treated differently from the other children in the home simply because of their status.
- c) Caring for a sick child who is HIV positive require the same basic procedures to be followed if care was being provided to a child whose status was unknown.



The fourth policy issue explored employment. It is mandatory that all employees undergo at least eight hours of HIV/AIDS sensitivity and caregiving training with follow-up every six months. Every three months all employees of the home must attend a support group (15 persons/group) for feedback and direction. There are strict disciplinary actions for any employee who breaks the above policies. The rights of the employee with regards to confidentiality of his/her HIV status is to be respected. Policies are in place to ensure that such an employee can be protected against any form of discrimination. The final issue addressed in this document is the issue of fostering. All foster parents should be informed of the HIV status of any child they will foster. In addition they must also undergo HIV sensitivity as part of their foster parent training.

Input for these policies came from Superintendents of Homes, Children's Officers, Children's Home employees and NGO representatives. Setting clear policy guidelines will help to ensure a fair and standard approach for the care of HIV positive children in the Homes.

#### **14.A policy for schools in a world with AIDS. (developed for the Ministry of Education, Youth and Culture, Dec 2001)**

Ruth Jankee

**Geographic Area:** Jamaica

**Key Words:** Policy, Education, HIV, AIDS in Schools

**Location:** Ministry of Education, Youth and Culture (MOEYC)

#### **ABSTRACT**

The author was commissioned to develop a policy for schools that would protect the rights of children with AIDS. The impact of HIV/AIDS on the Jamaican population, including recommended revisions to the legal framework by the Attorney General as a result of issues raised by the AIDS epidemic is discussed first in the document, to set the stage for the rationale behind which the development of policies for schools is needed.

The data from the National AIDS Committee indicates that children are now at a greater risk, with adolescents having the highest number of new cases. Developing policies for

the educational system will ensure that those involved will be better equipped to meet the needs of children infected or affected by HIV/AIDS.

Highlights of the Attorney General's recommendations for new legislation were listed by the author. The policies that were detailed in the document flow from the legal framework mentioned above. They covered several important issues such as:

**Non-discrimination and Equality** – which dealt with the issue of ensuring that the fundamental human rights of students and teachers must be respected by all and therefore anyone even suspected of being HIV positive must be treated with respect and not be discriminated.

**HIV Testing, Admission and Appointment** – this stated that mandatory testing for HIV cannot be imposed on any teacher or student. No child or teacher shall be refused admission or be dismissed because of his or her HIV status.

**Attendance at an Institution by a Student with HIV/AIDS** – goes further to accentuate the point that the child with HIV should be free to attend classes as long as they are physically able.

**Disclosure and Confidentiality** – refers to the fact that the HIV status of a student or teacher, even if it is disclosed voluntarily by them, must be kept confidential. In the situation where the child's health may cause increased risk to those around, then the Principal can intervene.

**A Safe Environment and Prevention Measures related to Play and Sports** – looked at the issue of schools being properly stocked in medical items (such as gloves) and training in universal health precautions.

**Education on HIV/AIDS** – focused on not only age-appropriate education for students on issues such as, non-discrimination, HIV/AIDS transmission, and even on basic first-aid principles for each age group.

**Refusal to Study or Work with a Student or Educator with HIV/AIDS** – referred mainly to the role of the principal in ensuring that this form of discrimination is resolved by adhering to the Education Act, legislation and policies



stipulated in this document. **Implementation:** The author stated that implementation of the above action plan would be the responsibility of the MOEYC but recommended that the wider community be involved. It was recommended that a Health Advisory Committee be set up in each learning institution wherever possible. This committee would be comprised of representatives from the school, parents, students, medical or health care professionals. **Conclusion:** The role of educational institutions in providing knowledge has been proven internationally to reduce the impact of HIV/AIDS on a society. If effectively implemented, this document will provide necessary guidelines and policies to assist these institutions in dealing with the issue of HIV/AIDS.



# LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CARICOM	Caribbean Community and Common Market
CBO	Community Based Organization
CEDRO	Information and Education Centre for the Prevention of Drug Abuse
CINDI	Children in Distress
COPE	Community Based Orphan Support Project
CRC	Convention on the Rights of the Child
DCOF	Displaced Children and Orphans Fund
FACT	Family AIDS Caring Trust
FHI	Family Health International
FOCUS	Families, Orphans and Children under Stress
HIV	Human Immuno-Deficiency Virus
HFLE	Health and Family Life Education
MOEYC	Ministry of Education, Youth and Culture
MOH	Ministry of Health
MTCT	Mother to Child Transmission
NAC	National AIDS Committee
NGO	Non-Governmental Organization
OVC	Orphans and Other Children made Vulnerable by HIV/AIDS
PIOJ	Planning Institute of Jamaica
PLWHA	Persons Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
STD	Sexually Transmitted Disease
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development



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# Workshop on Orphans and Other Children Made Vulnerable by HIV/AIDS (OVC)

30-31 May, 2002

Altamont Court Hotel, Kingston, Jamaica

Sheila Evans

## Overview

As the HIV/AIDS pandemic continues to threaten the development of Jamaica, new issues press to the fore. One collection of issues that has been brewing is the effect of AIDS on children who are orphaned or made vulnerable when their parents or other members of their family are infected.

The National AIDS Committee (NAC), with the financial support of USAID and UNICEF, has now opened the door for discussion of these issues by commissioning a Rapid Assessment of what is happening in Jamaica relative to orphans and children made vulnerable by HIV/AIDS (OVC).

Immediately following the Rapid Assessment, the NAC and its global partners brought together the country's leading individuals and organisations in the fields of HIV/AIDS, children's health and advocacy, and family planning for a two-day workshop to share the data and begin the process of coming to grips with the multi-faceted problem of OVC. Representatives from parish and community organisations, as well as individuals living with AIDS, were among these experts.

The consultants who conducted the Rapid Assessment were the principal speakers for the workshop. The consultants were Mark Loudon, from South Africa, and Hope Ramsay, from Jamaica. They were given less than a month to gather their information, but this was sufficient to get a feel for the issues so that a dialogue could begin. Because of their respective experiences they also were able to put Jamaica's situation into the context of the worldwide pandemic and how other countries are responding to the challenge of OVC.

Participants also heard a report from Mark Connolly, from UNICEF Headquarters in New York, who specialises in issues of orphans and children. It was Mr. Connolly's findings that prompted this workshop. His research was shared in a UNICEF workshop held in Ocho Rios in May 2001 and gave the impetus to begin work on the issue of OVC in Jamaica.

The fourth speaker for the day was Dr. Deanna Ashley, Director of the Health Promotion Division, Ministry of Health. Dr. Ashley gave a brief overview of the Ministry's National Strategic Plan on HIV/AIDS and how the issues of OVC are addressed in the plan.

The workshop's first day included 100 participants including the Japanese Ambassador to Jamaica, Mr. Isao Otsuka, and the Chair of the United Nations Integrated Theme Group on HIV/AIDS for Jamaica, Dr. Manuel Pena, who also is the Representative of the Pan American and World Health Organisation in Jamaica.

Following the consultants' presentations, participants began formulating strategies for moving forward.

The effectiveness of the Rapid Assessment and presentations was evidenced by the almost unanimous complaint by participants (as shown by evaluation forms), that they did not have sufficient time to come to meaningful strategies for dealing with all the issues.

The NAC had intended the workshop to be the beginning of the discussion, not the completion of the process, so they saw this criticism as a mandate to maintain the rapid pace at which the issues were now starting to be addressed.

A group of 20 workshop participants met for a second day on the issues of OVC. The group included representatives of PLWAs, funding agencies, the health ministry, parish-level organisations, health professionals, and the consultants.





## Rapid Assessment Report

Mark Loudon, UNICEF consultant, opened his remarks by telling the participants that the problem of OVC is “worse than you think it is; but you can do more about it than you think you can.”

**It is not sick babies we are taking about, but children who are growing up without their parents.**

He clarified that the day's work would not be about sick babies, but about children whose parents are infected with HIV. These are children who are profoundly affected by

the disease, and who are vulnerable to being orphaned, traumatized, malnourished, abused and even infected with HIV themselves.

The magnitude of the problem is huge, he explained. AIDS is creating orphans and leaving children vulnerable like nothing seen before in history. The orphan issue is not a minor side-effect of the AIDS pandemic; it is the most significant long-term consequence of the disease. One day HIV will be something we read about in history books, but the effects of the virus on the socialisation of children, on the mental and physical well-being of children as they become parents themselves, will be with us for generations.

He said these effects will show up in such things as high levels of unemployment, poverty and crime, anti-social behaviour, and even higher levels of household violence, as children who have grown up without the nurturing and guidance of their parents become adults themselves.

**OVC issues can only be dealt with effectively if they are done in partnerships.**

This is not a phenomenon limited to sub-Saharan Africa, although the problems there are many times greater. This is a real danger for Jamaica – and one that will grow exponentially as the effects of AIDS unfold. Now is the time for meaningful interventions, not only for those who are most at risk of infection, but also for those who are already affected because one or both parents are HIV-positive.

Mr. Loudon gave an idea of the extent of the OVC problem in Jamaica today. He noted that the prevalence of HIV is

estimated by the Ministry of Health to be 1.5% of the population, which would translate to some 20,000 people. With the population of persons in the 15-49 age group being 1.4 million, it means that between 10,000-20,000 children are at risk of losing one or both parents to AIDS.

The difficulties these OVC face because of AIDS are remarkably similar to the difficulties faced by children who are orphaned or made

vulnerable by other factors such as violence, poverty, sickness, automobile accidents, and natural disasters. Those orphaned by AIDS may suffer stigmatisation in ways other children do not, but the majority of their needs are the same – where will they live? What will they eat? Who will care for them? How will they get their basic needs met? Who will love them?

Mr. Loudon posed the question to the group: Are we here to deal with AIDS or here to deal with vulnerable children? By the end of the two days, the consensus was that AIDS may have brought these people together, but protecting and helping children was what they were committing to do.

The consultant told the participants that Jamaica has some impressive strengths. The social safety net provided by the nation's families, government and civil society give this country the capacity to provide for these children. However, many of these services were not reaching those who needed them, and it was time to take a closer look and make improvements to safeguard the lives, minds and spirits of these children as an investment in the country's future.

**There are an estimated 10,000-20,000 children in Jamaica today who are 'earmarked to be orphaned' by AIDS.**

**AIDS may have brought these people together, but protecting and helping children was what they were committing to do.**



Families that once were willing to take in children are being stretched too far. They can't make it, financially or physically. They need help. But, Mr. Loudon said, a remarkably small amount of moral, technical and economic support can make a huge difference.

In addition, children are wonderfully resilient and respond well to such things as counselling. They cannot do it alone, however.

In fact, given the number of children and the scope of the problem, no one can do it alone. There is no government agency, no NGO, no company we can turn to and say, "This is your job; it's your problem to deal with." It goes across all sectors, and can only be dealt with effectively if we work in partnerships.

As Jamaica begins the work of addressing OVC issues, there are some key elements of success that Mr. Loudon shared:

- There must be a recognition that this is a serious problem with profound implications for the country;
- There must be active participation by all players;
- Make sure nothing gets in the way; and
- Work quickly and work together. In this arena, delays are measured not only in dollars, but in wasted lives.

Hope Ramsay, the local consultant, expanded on some of the points made by Mr. Loudon, and applied them directly to Jamaica. She talked directly to Jamaican children and their caregivers and discovered the depth of vulnerability AIDS has forced on many of Jamaica's children.

She found, among other things, that HIV mothers in Jamaica have an average of four children who will need care after she dies.

Fathers do not usually take over the care of children when the mother dies. Rather, it is usually a grandmother or aunt, who may already have taken in other children who have come to her because of economic need, migration, or death from some other cause.

**Usually, a grandmother or aunt takes over the care of OVC. This household may already have taken in other children because of economic need, migration, or death from some other cause.**

Stigma makes the AIDS experience worse, effectively keeping people from accessing help. Stigma sometimes comes from care providers – the very people who should be providing comfort and assistance.

Children respond to counselling, mentoring, etc. from such people as school counsellors, nurses, ministers, neighbours, etc. Social services need to be more user friendly so that people will use them.

Mrs. Ramsay's presentation concluded with a list of the major findings of the Rapid Assessment, which included:

- More children are in trouble, as is evident from school absenteeism and rising levels of street children, crime, abuse, suicide, drug abuse, early pregnancies, depression and other factors
- Many Jamaicans are willing to foster children who are not related to them – especially if the caregivers are helped to become financially independent
- Social services should be made more accessible and 'user friendly'. This would save money, and improve lives, in the long term.
- A participatory situation analysis could bring together all role-players to pool their insights and ideas, and to develop a National Plan of Action and establish a coordinating structure.

The consultants recommended that a steering committee should be established as a matter of urgency to take the OVC issue forward.

Mrs Ramsay's presentation was followed by questions and an interactive session, where participants offered their insights.



## Participant Input

Some of the points made by the participants include:

- We need to be careful when working for children made vulnerable by AIDS that we don't inadvertently create new discriminations and stigmatisations.
- Teen pregnancy is going up; HIV prevalence is going up; the number of street children, children who are exposed to HIV infection, etc. We need to be able to test these children. Can we do it without parental consent? The answer, given by an attorney in the group, was that if there is a known parent or guardian, that adult must give consent first. If there is no known responsible adult, the child must be made a ward of the court which must approve the testing.
- Mental health issues may be the most critical health issues of this decade. This workshop is on target for finding new techniques and avenues to provide these services to people most in need.
- Is more research planned? Yes. Regional and area basic statistics need to be gathered, as well as more in-depth looks at the issues children and their caregivers are facing.
- There must be a mechanism for including grass roots people in the strategic planning. These are the people who are closest to these children.
- Some schools have expressed concerns about HIV-positive children in day care, in schools. They must be reminded that everyone needs to be trained in universal precautions. Under most circumstances, no one needs to know a child comes from an HIV household or is HIV-positive.
- This workshop is a sounding board of planning people and agencies to begin the awareness of the scale and scope of the issues and to begin to formulate a response.
- Those doing planning need to be sensitive to the diversity of the people of Jamaica and use the term "faith-based organisations" in place of "churches" which is specifically Christian.
- There needs to be a targeted effort to include mental health professionals in this effort.
- Blue Cross, Jamaica National Bank and the Gleaner Company are setting up wellness clubs in schools. Maybe they can be part of the OVC effort.
- The Ministry of Education is formulating a curriculum on HIV for use in schools, but caregivers need training themselves.
- There need to be continuing workshops for health care providers. Some of the worst stigmatisation comes from that sector. There also needs to be training for school counsellors and nurses.
- There was a discussion of mandatory sterilization for infected women, to reduce the number of children being orphaned. The consensus was that the group would not like to see such treatments made mandatory.
- The four pilot parishes identified by UNICEF for developing and supporting caring environments for OVC should be expanded to seven to include those parishes that are hardest hit by HIV/AIDS. Most are in the western portion of the island.
- Some parents who are HIV infected deliberately infect their child or children. Shouldn't this child get the best care possible? What do you do about a parent who would do such a thing?

An attorney answered that the law already provides for criminal charges to be brought against anyone who acts with the intention of harming another. If the child should die, it would be a charge of murder. One major problem is that people do not want to disclose that they are associated with HIV/AIDS. So the trouble is in proving intention.

The question of the child getting the best care possible, all children should get the best care. Differentiating among children based on how they became infected will lead to many problems.



- We need to make more of an effort to combine family planning and HIV awareness.
- Ignorance is what is perpetuating AIDS, and the stigma associated with it.
- If we develop a steering committee to deal with OVC issues, make sure it works with other HIV steering committees and other committees dealing with children and related issues.
- Different stakeholders are at different levels of knowledge and understanding on various aspects of the issues. We need to constantly be educating ourselves and one another.

## Goals, Principles and Strategies to Strengthen Collaboration

Mark Connolly provided more back-up information on the issue of OVC.

- Orphans are not the only children affected by AIDS. For every child orphaned, there is one or more living in vulnerable households, usually caring for a sick parent.
- Without even looking at children who themselves are infected with HIV, AIDS has threatened children's health in many ways, from nutritional problems to lack of attendance at health clinics, to transactional sex, and the list goes on.
- The United Nations General Assembly Special Session on HIV/AIDS last year approved a Declaration of Commitment to give special help to OVC, especially those associated with AIDS. Jamaica has signed it, so this is our green light to begin the effort.
- Jamaica is not only at risk, relative to HIV and OVC, it is on the brink of a full-scale crisis.

Mr. Connolly charged the group to

- challenge yourselves;

- come up with a shared vision of the situation; and
- collectively determine what needs to be done.

Come up with your own personal plan of action. That makes putting together a national plan a lot easier.

He said communities are at the front lines, and they are already doing many of the right things for their children. They need to be strengthened, however. We need to strengthen them, not undermine them.

He noted that keeping parents alive longer is one key response. It is the best, most cost-effective solution to the problem of vulnerable children.

We must involve children and adolescents as part of the solution, he advised. This is one of the most important elements, and one we often talk about, but rarely actually put into action.

Another way to move the response forward is to involve women's groups. Look at how much time women spend on children's issues and you will see the logic of including them.

There are mixed reviews of micro-enterprise programmes. Mr. Connolly believes they can be used effectively to offer economic independence to families made vulnerable by AIDS.

However, the most effective way to mobilise the community in the long-term and the most impressive and effective mechanism available to us, is to increase the involvement of people living with HIV/AIDS and their families in our efforts. Another important community to embrace is grandparents.

Mr. Connolly gave this list of problems that most OVC face:

- pervasive stigmatisation;
- economic hardship;
- taking on adult responsibilities, especially the oldest child;
- being forced to leave school;
- losing their inheritance;
- forced into hostile, strange environments.



Finally, Mr. Connolly gave 12 principles to guide programmes for children:

1. Strengthen the protection and care of orphans and other vulnerable children within their extended families and communities;
2. Strengthen the economic coping capacities of families and communities;
3. Enhance the capacity of families and communities to respond to the psychosocial needs of orphans, vulnerable children and their caregivers;
4. Link HIV/AIDS prevention activities, care and support for people living with HIV/AIDS and efforts to support orphans and other vulnerable children;
5. Focus on the most vulnerable children and communities, not only those orphaned by AIDS;
6. Give particular attention to the roles of boys and girls, men and women, and address gender discrimination;
7. Ensure the full involvement of young people as part of the solution;
8. Strengthen schools and ensure access to education;
9. Reduce stigma and discrimination;
10. Accelerate learning and information exchange;
11. Strengthen partners and partnerships at all levels and build coalitions among key stakeholders;
12. Ensure that external support strengthens and does not undermine community initiative and motivation.

## Moving Forward Exercise

Workshop participants were formed into five groups of 10 to 12 members each. They selected a rapporteur and facilitator from among themselves and spent the next 45 minutes drafting five strategies for moving forward from this point. A spokesperson from each group then shared its strategies with the entire workshop.

Since this exercise set the stage for the second day's work, it will be incorporated in the report of the second day.

## National Strategic Plan on HIV/AIDS

Dr. Deanna Ashley presented the Ministry of Health's National Strategic Plan on HIV/AIDS, as it relates to OVC. She noted that AIDS is the second leading cause of death for children 4 years old and younger. She also noted that people in Jamaica aged 15 to 49 are the hardest hit – those in the prime reproductive years.

She said there is a high level of commitment from the Ministry to respond to AIDS issues, and that there is already an improvement seen in STI and HIV infection rates, as well as a high level of awareness regarding HIV prevention, including an increase in the use of condoms.

While there is no direct reference to OVC in the plan, the mother to child transmission programmes and behaviour change programmes will allow for OVC projects. There is also a new push to increase voluntary counselling and testing that should be helpful. She said the Ministry is strengthening the laboratory side of testing so that people will not be put off by the long waits now associated with HIV testing.

## More Input

- Participants shared real-life stories of people trying to get or to offer help, and finding barriers. There also were a few success stories of programmes that really worked to help vulnerable families.
- One participant said one way to help reduce stigmatisation is to increase voluntary testing. People who are tested tend to identify with having AIDS. They become more empathetic, at least for a while. If we make testing easier, faster and more confidential, more people will want to get tested, and there could be a beneficial effect regarding stigmatisation.
- We need to build fundraising capacity at the grass roots level, so community-based organisations can develop proposals for funding agencies.



- We need more workshops like this one, to share and exchange information. Information and education cannot be overemphasised. People must have access to information to make good choices.
- The issues being discussed at this workshop are the same that are being talked about in the PLWA support groups. Officials need to come to the PLWAs for their input; and the PLWAs need to become more proactive. It is not enough to come together only for meetings like this, or when there is a crisis. We need to find real solutions.
- There should be financial incentives for people to adopt OVC. There is no shortage of people willing to take children, especially if income generation helps them afford the added responsibilities.
- Any person living with AIDS can be included in the social safety net programmes and receive help, but it may require them to disclose their HIV status.
- The concerns of OVC cannot be separated from women and girl-child issues. Women and girls will need to be given special attention in these programmes.

## Day 2

The workshop resumed on 31 May, chaired by Monica Dias from UNICEF. Participants numbered about 20, all of whom had taken part in the previous day's workshop. The group consisted of representatives of PLWAs, funding agencies, Ministry of Health, parish-level organisations, health professionals, and the consultants.

Verity Rushton, NAC co-ordinator, announced that RJR News had aired an extensive interview and call-in programme on the OVC issue the previous night. The programme appeared to attract a good deal of interest.

She also explained that, although the OVC work in Jamaica started a year ago, many people at this year's workshop were still at the very early stages of understanding. This means that, while we want to move forward quickly, we do

not want to undercut our stakeholders. This is all part of a process, and a process needs to take some time.

One of the participants noted that Dr. Ashley's report the previous day had not included any direct reference to OVC as part of the National Strategic Plan and wondered how that could be changed. In the discussion that followed, it was clear that the National Strategic Plan is a five year plan, and is unlikely to have opportunities to change it, especially during its first year. Others said the plan was broad enough to accommodate children's issues in line items that may be listed as institutional strengthening, behaviour change and other general titles. Ms. Rushton said there is one line item in the Plan that is specific to OVC, but there is no detail in it which leaves opportunities for developing programmes.

Continuing a concern from the previous day, one participant reiterated the need to work on orphan issues from the child's perspective, not an AIDS perspective. One major concern is adding to the children's problems by calling them out as "special" orphans. This would likely lead to new forms of discrimination and stigmatisation.

This discussion brought the group to the point where they were forced to decide what issue they were really dealing with:

- orphans and other vulnerable children, or
- orphans and children made vulnerable by AIDS.

After some discussion, the decision was made to deal with the broader, more inclusive issue. The children's connection to HIV/AIDS cannot be lost, but it can also not become the primary focus for several reasons:

**The decision was made to deal with all orphans and vulnerable children, not only those resulting from AIDS.**

- It will likely have a limited amount of support outside of AIDS agencies;
- It will be in competition with other orphan programmes for money, time commitments, etc.;
- It will introduce new types of discrimination; and
- It will duplicate the efforts that need to be made for other vulnerable children.



In addition, the consultants noted that the closer you get to reality, the less you deal with the illness and the more you deal with things like economics, health care, food, housing, etc.

One consultant noted that trusted leaders must be involved in OVC efforts at all levels. This will become an attractive issue for people who want to be associated with good programmes, but have no deep commitment to making change. If people see those charismatic, but untrustworthy people leading this effort, it will be a serious stumbling block to helping children.

A way to avoid this is to enlist the faith-based organisations, PLWAs and women's groups to take major roles. These are people who are seen as more trustworthy.

## The way forward, part 2

On the workshop's first day, participants formulated a number of strategies that could be implemented to begin addressing OVC issues. Mrs. Ramsay read out a detailed report on the proceedings from the first day, including a list of 10 action ideas which had emerged from the group discussions. Mark Loudon distilled these further into five areas of common concern:

1. Supporting caregivers – supporting income generation activities to help parents to look after their own children and to encourage others to take in children who need a home; strengthening and improving the formal and informal systems of fostering and otherwise caring for OVC; training to improve parenting skills of infected parents and new caregivers; etc.
2. Ensuring access to existing social services – making people aware of the services which exist and how to access them; finding ways to make services available without demanding disclosure of sero status; helping make services available while maintaining the dignity of those who need the help; removing barriers to getting help to those who need it; building the capacity of organisations that can act as intermediaries to help people access services, etc.

Discussion: There are many services, but people cannot or will not access them because they must disclose their sero status or otherwise humiliate themselves.

Service providers often do not have to add new programmes, but can see their existing programmes through the “OVC glass.”

If a child is made a ward of the court and placed in foster care, the government will give some money for support of that child. The amount is small, so it is not a real incentive that might lead to “baby farming” situations. No one would foster a child for the money, because it is such a small amount and the care given to the children is closely monitored.

Even within the Children's Services Division, informal fostering within the family is preferred to formal fostering through a Children's Court. However, we need to give more support to those who voluntarily take on these informal arrangements. Parents may form their own co-operatives or other support systems to help one another and possibly qualify for financial assistance. These will probably be more successful than new bureaucratic procedures.

The question was raised if a PLWA could formally foster or adopt a child. No one in the room knew what the official response would be.

3. Providing psycho-social support to OVC and caregivers, including training those who can offer counselling, support, mentoring, etc. This includes teachers, health professionals, religious leaders, relatives, and others; make existing services known and accessible, etc.

Discussion: Children are raising children, stress levels are reaching the breaking point in many households; abuses take place when children are not wanted in a household; siblings are often separated. Just because you are an adult or a family member, does not mean you are automatically a good parent. Parenting skills training is needed by many caregivers.



4. Reducing stigma – including continuing education of people at all levels on HIV/AIDS, including young children; strengthening advocacy efforts; pushing government agencies to develop guidelines and policies for public servants, including disciplinary measures for breaching these policies; working with the media to continue giving anti-discrimination messages, etc.

Discussion: When there is a problem, many PLWAs will not file a complaint, since it may mean disclosing their sero status or otherwise making their children and themselves more vulnerable. There was a suggestion that a watchdog individual or organisation be developed. PLWAs will probably be the best candidates for this position.

Must be careful about punishing people for not doing what we think they should do. The more workable approach, especially in business or government, is to help them develop a structured set of guidelines, with disciplinary measures incorporated into them.

5. Information sharing and coordination of action – bringing together people who are interested in or concerned about children's/OVC issues; developing a directory of services and making sure those people who need it – like PLWA and parenting groups – have access to it; establishing a referral system, etc.

## General discussion:

We need to know how the systems work now before we can make suggestions about making them better. This is something which should be done at the Parish level; looking in depth at the experience of children, caregivers, service providers and others.

We really need to get the people who are already involved in children's issues to be aware of how AIDS will be impacting their jobs, their operations. The involvement of AIDS organisations may be received as a welcome relief once these groups already have some idea of the magnitude of the impending crisis.

There needs to be general strengthening of the capacity of NGOs and CBOs with such basic things as telephones, office space, computers, etc. to facilitate their involvement in the effort.

It is too early to begin a formal process of participatory situational analysis, structured response, etc. The work must begin on the ground and build to a point where the political leaders will take an interest. The door was opened when the Prime Minister signed the UNGASS Declaration of Commitment for Children in 2001, but now we need to take the reins and put things in place we believe are in the best interests of children.

## Leading Roles

The discussion turned to who should be the lead agency, organisation or individual in each of these five areas? But as the discussion evolved, it was agreed that:

- 1. The major work needs to be done at the parish level.**
- 2. The role of Government ministry chiefs, initially, is to allow their parish-level staff to become involved.**

There was a consensus to focus efforts initially in the four parishes identified by UNICEF as parishes where pilot OVC programmes will be funded.

The other major decision reached at the conclusion of the workshop was that the OVC effort must be led by an organisation that is recognised as a child-oriented agency, rather than an AIDS agency.

The participants identified two organisations that would be excellent candidates for this leadership role: the Jamaica Coalition on the Rights of the Child (JCRC) and the Coalition

**The OVC effort must be led by an organisation that is recognised as a child-oriented agency, rather than an AIDS agency.**

for Better Parenting (CBP). Representatives from both groups will have a good background on the issues and passions expressed on the workshop's first day, since they both had representatives present.





Both organisations are already hard at work on children’s advocacy issues and may already have programmes in place that will facilitate this new focus. The NAC and UNICEF will approach these organisations immediately regarding this leadership role.

The day 2 participants believed there will need to be workshops at the parish level to explain the issues, garner support, and begin the work. These will be later in the summer, once the report is finalised and the ministry cooperation is obtained. In each of the five focus areas, the participants named at least some of the agencies and organisations that should be included at the parish level.

Since the parish organisers will know the key players, a complete list will be developed by them, but as a start:

1. Parenting – Coalition for Better Parenting, Children’s Services Department, faith-based organisations and umbrella bodies such as the Jamaica Christian Coalition.
2. Social services – all line ministries but health, education, National Insurance Service and Children’s Services Department especially; NGOs and CBOs; faith-based organisations.
3. Psycho-social support – Child Guidance Clinic, health professionals – especially in mental health – teachers, religious leaders.
4. Stigma reduction – human rights organisations, media alliance, journalists, Artistes Against AIDS, MOH’s behaviour change officers.
5. Information sharing – local newspapers, cable stations and radio stations; youth groups; police.

Participants reminded themselves continually that PLWAs, care givers, relatives, children and young people must be included at every step and given leadership roles whenever possible.

**Caregivers, relatives, children and young people must be included at every step and given leadership roles whenever possible.**

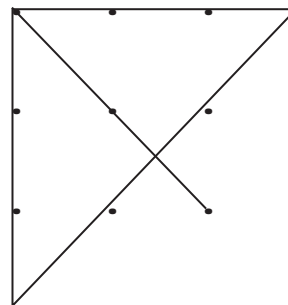
## Barriers among the faithful

In discussing “next steps,” each participant was asked what he or she saw their own agency doing, and immediately barriers to progress began appearing. Work plans were already set, funds were limited, staff were non-existent.

Mark stopped the proceedings to do a mental exercise in which participants were asked to draw four continuous straight lines to connect three sets of three parallel dots



The answer is that it can not be done if you stick to the traditional thinking, the standard way of looking at the relationship between the dots and the lines. You must go “outside the box” and draw the lines like this:



Or find some other creative solution. If you want something badly enough, you will find a way to make it happen.



## Time line

The time line for taking the next steps from this workshop:

4 June, 2002	Rapid Assessment and workshop report complete – ready for distribution for peer review
3 – 7 June 2002	NAC and UNICEF meet with children's agencies to secure lead in OVC effort
14 June, 2002	Peer review complete, suggestions incorporated
24 June, 2002	Reports posted to NAC web site; go to printing
1 July, 2002	Distribution of reports.
24 June – 5 July 2002	NAC and UNICEF visit Government ministries to secure support for parish level staff members to participate in OVC workshops and efforts

People attending the second day of the workshop will be invited to join a steering committee once a suitable organisation has been found to lead the initiative. The first meeting of the steering committee should be after the first round of workshops at Parish level, to review progress.

## Conclusion

The participants did a “check out” exercise in which they each expressed what they thought they had received from the two days of meetings. A final thought was expressed by one of the participants:

**You don't have to die of AIDS for it to have a profound effect on your life.**





