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THE PROTAGONIST OF STIGMA AND DISCRIMINATION IN INCREASING THE VULNERABILITY OF CHILDREN INFECTED WITH AND AFFECTED BY HIV/AIDS

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Abstract

India, which has the largest number of AIDS orphans comparing to any country in the world, is facing accelerating threat from HIV. HIV/AIDS greatly impacts the social fabric of Indian society, especially through the escalating AIDS related crises such as the unprecedented number of orphans being left with little or no adult care and protection. Richter quotes from an article written by Jonathan Mann where he states that discrimination has a powerful and insidious impact on the dignity and self-respect of the person being discriminated. Mann saw dignity as flowing from two sources: an internal one (the way an individual sees her/himself) and an external one (the way other people see that particular individual). Mann argued that when a person's dignity is repetitively compromised by external sources the person's internal source of dignity would also be undermined. This in turn impacts on that person's self-image, self-confidence and wellbeing and thus ultimately reduces a person's capacity to deal with their HIV/AIDS status. He argued that AIDS discrimination might be just as damaging as HIV: "Violations of dignity have such significant, pervasive, and long-lasting effects that injuries to individual and collective identity may represent a thus far unrecognized pathogenic force of destructive capacity towards well-being at least equal to the capacity of viruses or bacteria". This research paper aims to identify: The nature and extent of discrimination against children and youth infected with and affected by HIV/AIDS, the responses to stigma and discrimination, including legal and programmatic responses in South Africa and other African countries, to counteract stigma and discrimination and the lessons we have learned about stigma and discrimination. A series of interviews with selected key role players working in the field of children, HIV/AIDS and/or human rights in Coimbatore District. The findings shows that discrimination on the basis of stigmatic nature of AIDS was prevailing and disseminate and aggregate the epidemic

Key words: *Children living with HIV/AIDS, stigma, violation of human rights and social inequality*

Introduction

We are now twenty-eight years into the epidemic and the Human Immune-deficiency Virus (HIV) remains a complex and incurable disease which continues to devastate the lives of millions of individuals worldwide, and affect communities and nations. HIV can be deemed as one of the greatest threats to human development. The issue of HIV-related stigma and discrimination remains a serious obstacle to the HIV response. The message consistently reported in the body of literature reviewed indicates, HIV-related stigma and discrimination are substantive impediments to successful responses to the epidemic (UNAIDS, 2005a.) According to Peter Piot, UNAIDS Executive Director, since the beginning of the epidemic, stigma, discrimination, and gender inequality have been identified as major obstacles to effective responses to HIV" (UNAIDS, 2007, p, 1). These "obstacles" have undermined the success of HIV-related interventions in many countries throughout the world and Guyana is no exception. The Stigma and discrimination on the basis of HIV status or AIDS is a trend that has been associated with HIV/AIDS since the early days of the epidemic. As early as 1988, Herek and Glunt argued that people living with HIV and AIDS, and their support networks were experiencing a particular and more intense type of discrimination and prejudice as that of people with other medical conditions. It is frequently argued that stigma and discrimination against

children and youth infected with and affected by HIV/AIDS is a characteristic of the HIV/AIDS epidemic in many countries, particularly in the developing world. There are a number of different definitions of stigma. Burris has defined stigma not as a status, but as a social relation between a stigmatized person and a "normal" person based on a shared belief that some part of the stigmatized person's identity is "spoiled". Stigma can also be seen as the imposition of a special, discrediting and unwanted mark on a person or a specific category of persons in such a way that in their interactions with others they are looked at as fundamentally and "shamefully different" by themselves and others.

The mark of stigma is usually non-material, but in certain instances, the differentiation intention and process have gone as far as translating into material things (e.g. mutilations to the human body, tattoos, brands etc.). In these cases, stigmatized persons are not only looked at as different, they appear unmistakably different, and that is, their difference shows.

Stigma may remain at the level of subjective perception. However, research has shown that in most cases, stigma manifests itself in various ways, when society behaves and acts in a certain way towards those stigmatized (known as enacted or objective stigma).

Manifestations of stigma include:

- Communications: words, images, popular discourse
- Social relations (including within institutions and within families and communities)
- Laws and policies;
- Self-inflicted stigma, the experience of those at risk of stigma; and
- Prejudice, avoidance, ostracism, hostility, violence, etc.

Children and Youth infected with and affected by HIV/AIDS

Richter argues that fear; ignorance and an inability to accept any deviance from the 'norm' constitute the main reasons for prejudice or stigma against people living with HIV/AIDS.

She puts forward four origins of stigma against people living with HIV/AIDS:

- Moral attitudes and systems of belief, as sex and morality are closely linked in our society; thus AIDS is seen as a punishment for immoral behaviour that one should dissociate oneself from;
- Ignorance and a lack of knowledge has led to fear and irrational behaviour;
- Self-interest; this includes a desire to create a chasm between healthy and 'unhealthy' people so as to reduce the possibility of personal vulnerability to HIV; and
- Media images of defenselessness, and a dichotomy between those who are innocent (for example, children infected through vertical transmission from mother to child) and those guilty (for example, those infected through sexual intercourse).

Children and youth infected with and affected by HIV/AIDS are even more vulnerable than adults as they face the possibility of stigma relating to their own status as well as stigma flowing from their parent or caregiver's status. This stigma often continues even after the death of their caregiver, when they are rejected or treated with scorn by the extended family and the community. It forms part of wider denial of the HIV/AIDS epidemic. Children and youth infected with and affected by HIV/AIDS too often form a constant reminder of the death of a parent or sibling: something that our community does not want to face and confront.

Discrimination

Discrimination ensues when a distinction is made that result in a person being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group. The legal definition of discrimination flows from the right to equality. Our law recognizes that every person is entitled to be treated equally. Therefore unequal treatment is in certain instances unlawful, as it is a form of unfair discrimination. The law refers to both formal and substantive equality. Formal equality amounts to sameness of treatment, whilst substantive equality amounts to ensuring that there is an equal outcome. For example formal equality means that all children must have access to the education system, whilst substantive equality means that we recognize that some children (such as disabled children) may have special needs and will thus require a special form of education if there is to be an equal outcome. Our Constitution recognizes the rights to both formal and substantive equality.

Link between Stigma and Discrimination

Discrimination entails a person acting on a pre-existing sentiment or stigma, which results in a person being treated unfairly. Stigma and discrimination therefore form a continuum of harmful thoughts and behavour that is based on prejudice. When the discrimination is unfair and not justifiable then the action may be unlawful and the stigmatized person could use legal remedies to resolve the matter.

Diagram 1: Source: Preliminary Assumptions on the Nature and Extent of Discrimination against PWA.

Link between Stigma, Discrimination and Vulnerability

Clacherty describes the theory of vulnerability of children and youth in terms of the concepts of risks which a child is exposed to, and the resilience of a child based on the balance between the stresses and risks, and the various protective factors in a child's life. As we will see from our research findings, stigma and accompanying discrimination form a social risk for children infected and affected by HIV/AIDS. Burris54 describes a social risk in health behaviour as:

"The danger that individuals will be socially or economically penalized should they become identified with an expensive, disfavored or feared medical condition. It has two distinct components: (a) attitudes and behaviour that cause or threaten social harm, and (b) the perceptions and the threat among those who are in some way tied to the trait or disease".

Additionally, many research will show that the impact of stigma and discrimination is extremely damaging for children and youth infected with and affected by HIV/AIDS, in that it diminishes their resilience by impacting on the various protective factors in a child's life, and thus increasing their vulnerability. Donald, Lazarus and Lolwane identify three key protective factors that promote resilience in a child's life:

1. Personal or individual characteristics of a child;
2. Characteristics of a child's family; and
3. Characteristics of formal and informal social support networks into which a child may be connected.

These three key protective factors can also be related to key rights of the child, as defined by our Constitution and international instruments such as the United Nations Convention of the Rights of the Child.

Research has supports this and has shown the following effects of stigma and discrimination amongst affected children and youth:

- It causes great emotional pain, feelings of powerlessness and impacts on their perception of self and self-worth;
- It creates secrecy around HIV and AIDS, and fear of disclosure of HIV status;
- It acts as an impediment to children and youth accessing services which are rightfully theirs, such as health care and education, which further impacts on the physical and mental well-being of the children;
- It limits the right of children and youth infected with and affected by HIV/AIDS to parental care;
- It impacts on the right of children and youth infected with and affected by HIV/AIDS to appropriate alternative care and support, in the absence of parental care;
- It has a detrimental effect on the physical well-being of children and youth, due to the lack of appropriate care; and
- It increases circumstances of poverty and vulnerability to exploitation amongst children and youth infected with and affected by HIV/AIDS

Materials and methods

The Purpose of the Research

This research paper aims to identify:

The nature and extent of discrimination against children and youth infected with and affected by HIV/AIDS;

- The responses to stigma and discrimination, including legal and programmatic responses in South Africa and other African countries, to counteract stigma and discrimination;
- The lessons we have learned about stigma and discrimination;
- Our understanding of stigma and discrimination; and
- Recommendations for priority interventions.

Methodology

The research paper has used 2 different methodologies to obtain information around stigma and discrimination against children and youth infected with and affected by HIV/AIDS:

- A **Desk Review** of relevant literature, law (including national and international human rights law, statutes, common law and court cases) and programmatic responses regarding HIV/AIDS and discrimination and stigma.
- A series of **Interviews** with selected key role players working in the field of children, HIV/AIDS and/or human rights;

Major findings

Several key role players interviewed noted that children who are either known to be living with HIV , or who are perceived to be living with HIV:

Stigma and Discrimination within the family

A woman living with HIV whose young child also lives with HIV reports that:

> *"The children do not find enough love at home. Everyone in the family removes themselves because the mother has got the sickness. When a child touches something they give it to her because they think that they'll get the disease from the child and they also tell the children as much"*

A teenage girl living with HIV had the following to say:

> *"The treatment from them was terrible after this. They never wanted to touch anything that I touched. I was not allowed to cook anymore and they started locking things up. A plate, a cup, saucer and spoon were always lying around and I guess that was meant for me to use. They made it very difficult to me to continue living at home. I think my sisters or someone at home told the neighbours. I noticed one day when I went to pick up a key from a neighbour it was just put on the cupboard. I was told to take it – they would not give it to me. I think this was the final straw. I decided I can't continue living like this and that's why I came to hostel."*

Children infected with or affected by HIV/AIDS who are accepted into extended family networks often receive sub-standard care, work harder and are given the least priority in terms of access to family resources.

An orphaned boy who was taken in by his aunt's reports:

> *"Sometimes they are treated badly. They are made to work more than other children in the families that they stay with. They fetch water whereas other children are just sitting, they cut wood. They work more than the others".*

Stigma and Discrimination within the community

Children whose parents are ill with AIDS or who have died of AIDS experience related stigma and discrimination. They report being marginalised and isolated from other children, being teased and gossiped about, being presumed to also be HIV positive, and not receiving care.

An eleven-year-old boy , whose mother lives with HIV/AIDS, told the following story:

> *"This is the church and the child's mother has got AIDS. When he goes to church other children laugh at him. So he sees it better not to go to church because they'll laugh at him. His mother's weight is getting down. He is sad."*

An orphaned boy reported:

> *"They laugh at us. There is nothing that you can say. Because your parents died from AIDS you have it too."*

Stigma and Discrimination in Schools

A teenager told of the social ostracisation at school:

> *"Even in school they treated me badly. My skin was bad-looking; it had funny things on it. They told themselves that I've got AIDS and they ran away from me. Even my friend told me she won't eat with me again. One told me right in my face that I've got AIDS and I should stop going to school and stay at home. I would feel terrible. Cry deep down. I would sit alone and cry alone. People would be staring at you saying nothing, even those who used to be happy when they see you were not anymore".*

A teenager living with HIV/AIDS said:

> *"Ha! I'll have to be forced to go to school. On my own I'll never go. I won't feel comfortable at all. It would be like others know already. I am afraid. They will gossip about me, others will laugh at me secretly. I am afraid."*

Discrimination and Denial of Access to Health Care Services

Children and youth infected with and affected by HIV/AIDS are frequently denied access to health care services, or denied basic medical treatment that is available to other patients.

A teenager living with HIV/AIDS says:

> *"They don't take us seriously. Say you go to the clinic because you've got a headache they tell you they don't have headache pills. Even if it is, you can see it there."*

Children and youth infected with and affected by HIV/AIDS also report various infringements of their right to dignity, in their access to basic health care services.

Teenagers living with HIV/AIDS in Orange Farm reported:

> *"People treat us badly, even the nurses themselves. They don't treat us like people who know about this sickness. The way they treat you is like they say you deserve it eve the way they say it. They make it a point that you are shamed by your illness".*

Discussion

We can see how the above-mentioned examples indicate both stigma and discrimination against children infected with and affected by HIV/AIDS. The social attitudes towards the children in the examples show that the children are viewed as "shamefully different" and are stigmatised due to their known or perceived HIV status, or due to their association with HIV and AIDS. The apparent community value system and discourse shows a persistent unwillingness of many people to let them be identified in any way with any persons infected or affected by the epidemic. The stigma also leads to discriminatory actions, where these children are treated differently. The different treatment in many of these examples is clearly stated to be on the basis of HIV and AIDS, or can be assumed to be on the basis of HIV and AIDS. However, in the cases where children brought into extended families are made to work harder and have least access to resources, it is difficult to determine whether the discriminatory treatment is necessarily on the basis of HIV and AIDS, or on the basis of the fact that the children are 'adopted'.

The examples show instances where children and youth infected with and affected by HIV/AIDS receive less love, care and support from their immediate and extended families, peers, and the community at large, as well as being made to work harder and given least access to family resources. Furthermore, in terms of the yardstick of the impact such discrimination has on children, the impact is such as to make the discrimination unfair. The discrimination impacts on the children and youth's feelings of dignity and self-worth. Additionally it results in the loss of parental care, extended family care or appropriate alternative care in the community, as well as the loss of the related economic, social and emotional support that accompanies such care, which increases their vulnerability and their susceptibility to homelessness and economic exploitation.93 It impacts on their willingness and desire to access services which are rightfully theirs, such as basic education.

Furthermore, it is likely that a court would find that the unfair discrimination is unjustifiable, given that there are no reasonable and justifiable grounds for the discrimination. Many of the instances of unfair discrimination seen within the family and community are based on isolating and refraining from even physical contact with children and youth infected with and affected by HIV/AIDS due to an assumption that children from an infected household are likewise infected with HIV, and a fear of HIV transmission. The stigmatization leads to various forms of discriminatory treatment, which in most cases occurs quite clearly on the basis of HIV and AIDS. In some of the examples, where for instance children and youth infected with and affected by HIV/AIDS are denied access to services, such as health care and welfare services, it is not always possible to determine whether the denial of access to services is due to discrimination based on HIV or AIDS or due to a generalized lack of resources and the inefficiency of the social services system.

In order to determine whether the different treatment against children and youth infected with and affected by HIV/AIDS is unfair discrimination, we need to consider the impact this treatment has on children. The examples above show that as a result of this discrimination, children are rejected by peers and

role-models (such as educators) in the community, which impacts on their dignity and feelings of self-worth. Furthermore, the discrimination impacts severely on their ability to access rightful services such as basic education, parental care, appropriate alternative care in the absence of parental care, health care and social services. Given the impact on the rights of children and youth, the behaviour evidenced above clearly indicates examples of unfair discrimination against children and youth.

RECOMMENDATIONS

Law Reform Recommendations

While our law clearly provides protection for children and youth infected with and affected by HIV/AIDS from unfair discrimination on the basis of HIV status, our research has shown that this protection is not specific enough to assist children in ensuring the right to nondiscrimination.

The research shows the need to strengthen our anti-discrimination and other protective laws. Some preliminary recommendations for doing so include:

- The inclusion of HIV and AIDS as a specific ground for non-discrimination in the Equality Act; and
- The development of specific laws and policies protecting the rights of children and youth infected with and affected by HIV/AIDS to equality and protection from unfair discrimination, particularly in the health and welfare sector.

Social Programmes

Our research shows the need to ensure that national programmes aimed at dealing with community myths, prejudices and attitudes towards HIV and AIDS need to be expanded, improved and sustained. In particular, such programmes need to focus on attitudes and perceptions that lead to stigma and discrimination against children and youth infected with and affected by HIV and AIDS.

- The introduction of social programmes to reduce fear;
- Transforming the public perception of HIV/AIDS through providing information and challenging myths; and
- Encouraging high profile community leaders to be open about HIV and AIDS
- Continued and improved high level commitment to openness around HIV and AIDS, and a commitment to dealing with the epidemic;
- National awareness and media campaigns targeting stigma and discrimination against children and youth infected with and affected by HIV/AIDS;
- Providing forums for children and youth infected with and affected by HIV/AIDS to openly discuss their problems and concerns; and
- Establishing community associations to train young people as peer educators and counsellors to provide social support in key sectors, to children and youth infected with and affected by HIV/AIDS;

Access to Health Services

- Increased treatment options for children and youth infected with and affected by HIV/AIDS;
- Improved access to voluntary testing and counselling services that take into account the needs of children and youth infected with and affected by HIV/AIDS;
- Ensuring that children and youth have access to child- and youth-friendly health care services that promote their dignity and self-respect.

Conclusion

We trust that this project which has attempted to identify both the nature, extent and impact of stigma and discrimination against children and youth infected with and affected by HIV/AIDS, and responses to dealing with HIV-related stigma and discrimination will serve various purposes, including:

1. Highlighting the nature and extent of the problem; and raise awareness of the impact such stigma and discrimination has on children and youth and their development; and
2. Serve as a useful tool in encouraging an enhanced response to the problem; encouraging state departments and NGOs to review their current response; and finally, to the developing a holistic response to the causes and effects of stigma and discrimination based on HIV status. In conclusion, we recognize that this is simply the first step in a long journey:

"We have set out on a quest for true humanity, and somewhere on the distant horizon we can see the glittering prize"

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