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

RESEARCH REPORT

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Principal researchers
Ann Strode
Kitty Barrett Grant

Supporting researchers
Clacherty & Associates

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Save the Children (UK)
PO Box 40623
Arcadia 0007
South Africa
Tel: 012 341 1889
Fax: 012 341 1383

The role of stigma and discrimination in increasing the vulnerability of
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Whilst every effort has been made to ensure the accuracy of the information contained in the report,
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Foreword

Save the Children (UK) has been promoting children's rights around the world for more than 80 years. At present it is active in more than 100 countries, working in partnership with governments, NGOs communities, families and children to improve health, education and welfare services. Its experience throughout Africa indicates that, today, the greatest threat to children's rights and welfare is undoubtedly HIV/AIDS. In South Africa alone, the pandemic is likely to deprive at least 1 million children of parental care by the year 2005 and will impact negatively on every area of life, eroding the significant gains made by South African society over the last few years. It is unlikely that any family or community will remain untouched as HIV/AIDS depletes the natural pool of workers and carers and strains family and community support systems to breaking point. Its adverse effects threaten not just the health and welfare of AIDS orphans but the rights of all South African children to education, care, health, shelter, play, family support and love.

HIV/AIDS's social effects are as dangerous and debilitating as its physical effects. Until the stigma and discrimination suffered by people living with AIDS and their families is addressed, the pandemic will continue to grow. Prejudice and fear prevents people seeking proper care. For those infected with HIV/AIDS, there is little incentive to be open about their condition if it results in isolation and hostility. Ignorance, prejudice and fear help HIV/AIDS to spread. Openness, acceptance and support are essential for its containment.

This report clearly illustrates the powerful and negative effects of stigma on those affected by HIV/AIDS. The stories from children are particularly powerful. They remind us all of the human tragedies that lie behind the statistics. HIV/AIDS touches us all in some way – through family, friends, or communities. Addressing the HIV/AIDS pandemic requires a strong and coordinated response from all sectors of society - government, NGOs, churches, communities and children, as well as the international community. But this response has to incorporate changes in attitude and behaviour at the personal level, if they are to be successful.

I would like to thank the researchers for their work in this area and for demonstrating so clearly the devastating effects of stigma and discrimination on children and families. I hope that this report will assist in some way to overcome the prejudice that still unfortunately prevails in relation to HIV/AIDS and so improve the lives of many already disadvantaged children and families in South Africa.

Kevin Byrne

Director
Save the Children (UK)
South Africa Programme

INTRODUCTION

1.1 The Problem

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[1] argued that people living with HIV and AIDS, and their support networks were experiencing a particular and more intense type of discrimination and prejudice than that of people with other medical conditions. The Panos Institute of London term this discrimination the "third epidemic"[2] in their research into this subject. [3]

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.[4]

However, at this stage very little concrete information exists as to the exact nature and extent of stigma and discrimination against children and youth infected with or affected by HIV/AIDS in South Africa.

There is a good deal of anecdotal information from service providers, and the occasional high profile case of stigma and discrimination (such as that of Nkosi Johnson, who was refused admission to a school on the basis of his HIV status), which makes news headlines. However, for the most part, the stigma and discrimination faced by children, youth and their guardians goes unreported.

Additionally, there is little understanding of how stigma and discrimination actually affects children, youth and their guardians, how it impacts on their lives, and how it impacts on their access to basic rights such as health care.

We need to fully understand the nature and extent of this discrimination, its impact and effect on the rights of children and youth, and what has been done to counteract this phenomenon. Only when we do will we be in a position to identify where we've gone wrong, and what we still need to do in order to address and reduce stigma and discrimination against children and youth infected with and affected by HIV/AIDS.

1.2 The Purpose of the Research

In order to help us to answer some of these questions, and to assist us in developing our programmatic responses, 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;
- The gaps in our understanding of stigma and discrimination; and
- Recommendations for priority interventions.

1.3 Methodology

The research paper has used 3 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. This included a close examination of the AIDS Law Project's paper on *Preliminary Assumptions on the Nature and Extent of Discrimination against PWA in South Africa* which was completed during July 2001[5];
- A series of **Interviews** with selected key role players working in the field of children, HIV/AIDS and/or human rights;
- A series of **Participatory Workshops** conducted by Clacherty and Associates[6], with children, youth and adults infected with and affected by HIV/AIDS.

It should be noted that the findings in the report by Clacherty and Associates entitled '*The Role of Stigma and Discrimination in increasing the Vulnerability of Children and Youth affected by HIV/AIDS'* have been fully integrated into this report. Examples of the material collected in the report have also been used to elaborate and clarify points made. It is available as a separate report detailing their findings and research methodology.

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[1] Herek, GM and Glunt, EK (1988) *"An epidemic of stigma: Public reactions to AIDS"* American Psychologist, 43(11), p886-91

[2] The first epidemic being the transmission of HIV in homosexual men and intravenous drug users and the second epidemic being the heterosexual transmission of HIV.

[3] Lachman SJ *Heterosexual HIV/AIDS as a Global Problem : A Guide for Medical Practitioners and Health Care Workers* (Fifth Ed) 1995 at 53

[4] Richter M *Preliminary Assumptions on the Nature and Extent of Discrimination against PWA in South Africa* Research conducted for the AIDS Law Project, 2001, at 11

[5] sRichter M, *Preliminary Assumptions on the Nature and Extent of Discrimination against PWA in South Africa* Research conducted for the AIDS Law Project, 2001

[6] *The Role of Stigma and Discrimination in increasing the Vulnerability of Children and Youth Affected by HIV/AIDS* Research conducted for Save the Children (UK), 2001.

DEVELOPING A COMMON UNDERSTANDING OF THE TERMS STIGMA AND DISCRIMINATION

DEVELOPING A COMMON UNDERSTANDING OF THE TERMS STIGMA AND DISCRIMINATION

Save the Children

2.1 Defining Stigma

There are a number of different definitions of stigma. Burris[7] 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.[8] The mark of difference is imposed on people who have or are believed to have a distinctive status or a "deviance"

Brown defines prejudice or stigma more in terms of social attitudes and resultant behaviour:

> *"the holding of derogatory social attitudes or cognitive beliefs, the expression of negative affect, or display of hostile or discriminatory behaviour towards members of a group on account of their membership of that group."*[9]

2.1.1 Manifestations of Stigma

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, that is, their difference shows. For example during the Nazi's reign in Germany they required all Jews to wear a yellow star on the outside of their clothes as a way of ensuring that they stood out as being 'shamefully different'.

Sometimes, confinement in specially designated areas is also used as a material way to visualize the difference and to draw a boundary that separates the stigmatized person from other human beings. An example of this may be the quarantining of lepers.

Stigma may remain at the level of subjective perception. However, research has shown that in most cases, stigma manifests itself in various ways[10], 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.

Discrimination is one of the key manifestations of stigma.

2.1.2 Why Children and Youth infected with and affected by HIV/AIDS are Stigmatized

Richter[11] 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[12]:

- 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 lead 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.

2.1.3 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 behaviour 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 PWAs* at p 12.

2.2 Defining Discrimination

Discrimination ensues when a distinction is made that results in a person being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group.

Once a person's prejudiced thoughts lead them to doing something, or to omitting to do something that either harms or denies services or entitlements to another person, the act that harms is a discriminatory act. For example, a person may fear a child or youth infected or affected by HIV/AIDS and may perceive them as blameworthy or inferior, and for this reason may be extremely indifferent to their needs. These thoughts and perceptions constitute stigma. If this same individual then decides to exclude a stigmatized child from the local Sunday school, it is at this point that they have discriminated against the child.

The legal definition of discrimination flows from the right to equality. Our law recognizes that every person is entitled to be treated equally[13]. 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.[14] Our Constitution recognizes the rights to both formal and substantive equality.

2.2.1 Legal Rights to Equality and Non-Discrimination

Constitutional Provisions

Section 9 of the Constitution states:

"s9(1) Everyone is equal before the law and has the right to equal protection and benefit of the law.

(2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.

(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, martial status, ethnic or social origin, colour, sexual orientation, age disability, religion, conscience, belief, culture, language and birth.

(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination."

There are a number of significant principles that are established in this section:

- Only 'unfair discrimination' is prohibited; in other words it is accepted that there may be some forms of differentiation or discrimination which are fair;
- Both the state (s9(3)) and any person (s9(4)) are prohibited from unfairly discriminating against any person. This means not only may the government not pass any law or engage in any conduct which unfairly discriminates against any person, but nor may any other individual. Therefore if an employer, a social club or a private school unfairly discriminates against a child or youth, legal action may be taken against them;
- Seventeen grounds upon which a person may not unfairly discriminate are listed. "HIV/AIDS" is not a listed ground for non-discrimination. However, our courts have already indicated that a person may be unfairly discriminated against on the basis of HIV status, notwithstanding the fact that HIV status or AIDS are unlisted grounds for non-discrimination[15]

The Court's Interpretation of the Constitutional Provisions on Equality

Our courts have used the equality jurisprudence from Canada to help them develop our definition and concepts of equality. The Canadian courts have defined discrimination as:

> *"A distinction whether intentional or not but based on grounds relating to personal characteristics of the individual or group, which has the effect of imposing burdens, obligations or disadvantages on such individuals or groups which are not imposed on others, or which withholds or limits access to opportunities and benefits availible to other members of society."*[16]

Our courts have stated that the rationale for protecting the right to equality is that every person has an inherent right to dignity. For example in *President of the Republic of South Africa v Hugo*[17] discrimination was defined as follows:

> *"At the heart of the prohibition of unfair discrimination lies a recognition that the purpose of our new constitutional and democratic order is the establishment of a society in which all human beings will be accorded equal dignity and worth regardless of their membership of a particular group."*[18]

Thus in summary the Constitutional Court defines unfair discrimination as:

> *"treating persons differently in a way which impairs their fundamental dignity as human beings, who are inherently equal in dignity."*[19]

In determining whether conduct or a law is discriminatory, our courts use a three-stage approach that was first set out in *Harksen v Lane*.[20] This requires the following process to be followed:

(a) *Inquiry into whether the law or conduct creates a differentiation between individuals or groups?*[21]

If there is such a differentiation, then does it have a rational connection to a legitimate government purpose? This requires two levels of scrutiny, first one must determine whether there is in fact a differentiation being made and secondly one must look at the purpose of the differentiation. For example to create separate schools for disabled children is a form of differentiation. However one must then ask if this has a rational and legitimate government purpose, such as to ensure that disabled children are provided with an education that meets their special needs.

(b) *Inquiry into whether the differentiation amounts to unfair discrimination.*[22] This is also a two-stage analysis.

The first question is whether the differentiation amounts to discrimination. If it is alleged that the differentiation is discrimination on the basis of a ground specified in the s9 of the Constitution[23] such as "disability" or "race" then it is accepted that discrimination has been established. If it is alleged that the differentiation is based on a ground not specified in the Constitution such as "HIV status"[24] then the applicants will have to show the court that although it is an unspecified ground, the law or conduct discriminates against individuals or groups due to certain characteristics or attributes which they share, and this in turn impairs their fundamental human dignity or affects them adversely.

If it is shown that discrimination exists, then the second question follows, in terms of which it must be asked whether such discrimination is unfair. If it is alleged that the discrimination is on a ground specified in the Constitution (for example "disability") then it is presumed that it is unfair. If discrimination is alleged on a ground not specified in the Constitution then it must be established that this is unfair. The test for determining unfairness focuses primarily on the impact the discrimination has on individuals or groups. It takes the following factors into account:

- The position of the applicants in society; for example, whether they been victims of past patterns of discrimination;
- The nature of the discrimination and its purpose; and
- The extent to which the applicants have had their rights infringed and their fundamental dignity has been impaired due to the particular law or conduct.[25]

(c) *The final stage of the inquiry is asking if the unfair discrimination is justified.*[26]

If the law or conduct is found to discriminate unfairly then the court must use the limitations clause in s36 to determine whether the right was limited by a law of

general application for reasons that can be considered reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom. For example if a physically disabled child is excluded from mainstream education and it is found to be a form of unfair discrimination then one must still finally asked whether such an exclusion is justified due, for example, to the costs of accommodating such a child within a mainstream school.

Equality Legislation

The Constitution places a duty on the state to enact legislation preventing and prohibiting unfair discrimination[27]. As a result, the Promotion of Equality and Prevention of Unfair Discrimination Act ("Equality Act") was passed in February 2000. Although it has been promulgated, the Act has not been operationalised and it is uncertain when this will take place as the Department of Justice does not currently have a budget for its implementation.[28] This Act aims at amongst others:

- Giving effect to the letter and spirit of the Constitutional principles relating to equality;
- Providing measures for determining unfair discrimination; and
- Setting out remedies for the victims of unfair discrimination.

Chapter Two of the Equality Act states that neither the state nor any person may unfairly discriminate against another person[29]. It defines discrimination as:

> *"any act or omission, including a policy, law, rule, practice, condition or situation which directly or indirectly-*
> *(a) imposes burdens, obligations or disadvantage on; or*
> *(b) withholds benefits, opportunities or advantages from any person on one or more of the prohibited grounds."*[30]

It goes on to detail what types of conduct are forms of unfair discrimination, on the basis of race, gender and disability.[31] Like the Constitution, the Act lists seventeen grounds on which unfair discrimination is prohibited. The Act adds that there may also be discrimination on a ground not listed if it is:

> *"s1(b) ….any other ground where discrimination based on that other ground-*
> *(i) causes or perpetuates systemic disadvantage;*
> *(ii) undermines human dignity; or*
> *(iii) adversely affects the equal enjoyment of a person's rights and freedoms in a serious manner that is comparable to discrimination on a ground in paragraph (a)."*

'HIV status' is not listed as a prohibited ground of discrimination. However, as seen from the broad definition of unfair discrimination, this does not preclude a court from finding that a person can be unfairly discriminated against on the basis of HIV status. Furthermore, s34 of the Equality Act states that in the light of the overwhelming evidence of discrimination based on HIV status, special consideration should be given to including 'HIV status' within the definition of 'prohibited grounds' in the future.[32] To date the Equality Review Committee have not met and so it is still uncertain as to whether HIV status will be included as a separate ground within the Act. Albertyn et al argue that HIV could be equally protected either through the creation of a new ground or by its being recognized as a disability.[33]

In making the determination as to whether conduct is fair or unfair discrimination the Equality Act sets out a two stage process which is slightly different from the one currently used by the Constitutional Court. It is unclear at this stage exactly how these two different approaches will affect our equality jurisprudence. The Equality Act's test is as follows[34]:

(a) Is there discrimination?[35]

Sections 7 to 12 identify a number of forms of Unfair Discrimination. These include for example:

- the system of preventing women from inheriting family property;[36]
- failing to eliminate obstacles that unfairly limit or restrict persons with disabilities from enjoying equal opportunities;[37] and
- publishing information with the intention of discriminating against a person.[38]

This is not a closed list of the forms of discrimination, as there is a general prohibition on unfair discrimination in s6. Therefore s7 –12 simply form a guide to assist the court in determining whether the conduct complained of is discriminatory.

(b) Is the discrimination unfair?

S14 sets out the criteria that the court must take into account when determining whether the discrimination complained of is unfair. This is done in three stages:

(1) Identifying the context.[39] This stage requires a judicial officer to determine what surrounding circumstances are relevant to the inquiry[40];

(2) An examination of nine relevant factors[41] including the nature and extent of the discrimination; whether it impairs a person's dignity; whether it has a legitimate purpose and whether there are other means of achieving the same end result. These criteria require the adjudicator to look at both the impact the discrimination has, and to assess why the discrimination occurred, so as to determine whether it was legitimate; and

(3) whether when weighing up the nature and extent of the discrimination against the justification given for it, the discrimination is reasonable and justifiable.[42] For example if the reason given for barring physically disabled children from a sports school is that they do not have the capacity to play sport the court will have to interrogate this and make a finding as to whether it is justifiable to deny children who may be able to participate in sport in a different way, from attending such a school.

The primary mechanism for enforcing the rights set out in the Act is through the Equality Courts[43]. These are courts that are to be set up within the magistrates' courts to inquire into whether unfair discrimination has taken place[44]. On making a finding of unfair discrimination they have a number of innovative remedies available to them including:

- the payment of damages, including damages for emotional suffering as a result of unfair discrimination;
- an order prohibiting the unfair discrimination;
- an order requiring the implementation of special measures to address the unfair discrimination;
- an order that an 'unconditional apology be made';
- an order requiring the perpetrator of the unfair discrimination to be subject to an audit of their policies and practices relating to the discrimination; and
- recommendation to the appropriate authority to suspend or revoke the license of such a person.[45]

2.2.2 Prohibition on Unfair Discrimination against Children and Youth Infected with and Affected by HIV/AIDS

Children and youth are protected against unfair discrimination both by the Constitution and the Equality Act, as set out above; therefore neither the state nor any person may unfairly discriminate against children and youth.

The Constitutional Court has only had to deal with one case relating to unfair discrimination on the basis of HIV status. In this case, *Hoffman v South African Airways*,[46] the court found that SAA had unfairly discriminated against Mr Hoffman in rejecting his application for employment because he was HIV positive, and that this was a violation of the equality clause.[47] However they did not make a finding on whether this unfair discrimination was on the ground of 'disability' or 'HIV status'. Therefore, whilst it is clear that the court will find discrimination on the basis of HIV status unfair, it is not certain whether this is because they regard HIV status as a 'disability', or as a separate ground to be protected from unfair discrimination.

With regard to the discrimination faced by people living with HIV or AIDS the court noted:

> *"People who are living with HIV constitute a minority. Society has responded to their plight with intense prejudice. They have been subject to systemic disadvantage and discrimination. They have been stigmatized and marginalized. …… Society's response has forced many of them not to reveal their HIV status for fear of prejudice. This in turn has deprived many of them of the help they would otherwise have received. People living with HIV or AIDS are one of the most vulnerable groups in our society."*

The court case indicates that the protection against unfair discrimination extends to protection from discrimination on the basis of HIV status for all people, including children and youth, infected with and affected by HIV/AIDS.

Legal protection for children and youth against unfair discrimination on the basis of HIV status also exists within a number of other pieces of legislation such as:

- Section 6 of the Employment Equity Act No 55 of 1998 and the Code of Good Practice on Key Aspects of HIV/AIDS and Employment[48] prohibit unfair discrimination on the basis of "HIV status" within the workplace;
- The South African Schools Act, Act 84 of 1996 which provides in s 5(1) that a school may not unfairly discriminate against learners in its admission policies and section 9 which protects against expulsions for arbitrary or discriminatory reasons;
- The National Policy on HIV/AIDS for Learners and Educators[49] which prohibits unfair discrimination against learners and educators in schools;
- The Medical Schemes Act No131 of 1998 which prohibits medical schemes from excluding persons on the basis of their past or present 'health status'[50] and provides that the Minister of Health may proscribe a minimum level of benefits which medical aids must then provide to all members;[51] and
- The Draft National Health Bill[52], June 2000, provides in s7 that all users of the health care system have the right to be treated with respect; it is argued that as to be treated with respect is a form of protecting a person's dignity and would include the right not to be discriminated against.

2.3 Working Definitions of Stigma and Discrimination for the Purposes of this Research Paper

In the light of the above definitions, this research paper is based on the following premises:

(1) Stigma against children and youth infected with and affected by HIV/AIDS occurs when children and youth who are either:

- HIV positive or have AIDS;
- Perceived to be HIV positive or to have AIDS; or
- Are associated in some way with HIV/AIDS

are viewed by society and themselves as "shamefully different" or "spoiled" in some way.

This stigmatization is evident in, amongst other things, the perceptions, beliefs, values and discourse of society towards children and youth infected with and affected by HIV/AIDS.

(2) Discrimination is one of the manifestations of this stigma. Unfair discrimination is defined as the situation where children and youth infected with and affected by HIV/AIDS are treated differently as a result of HIV or AIDS, in a way that impairs their fundamental dignity as human beings. More specifically, unfair discrimination against children and youth infected with and affected by HIV/AIDS occurs where they:

- Are treated by the state, or any person or organisation, law or policy as differ ent in some way;
- The differentiation against children and youth infected with and affected by HIV/AIDS is unfair, in terms of its infringement of their dignity and its adverse impact on such children; and
- The unfair discrimination against children and youth infected with and affected by HIV/AIDS is not justifiable in an open and democratic society based on human dignity, equality and freedom.

For example, stigmatization against children and youth infected with or affected by HIV/AIDS occurs when a child whose parents died of AIDS is shunned by the community, and is subjected to negative perceptions and attitudes. Discrimination occurs, for example, when a child who is living with HIV, is turned away from school because of his or her HIV status.

2.4 Link between Stigma, Discrimination and Vulnerability

Clacherty[53] 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. Burris[54] 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, our report 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[55] identify three key protective factors that promote resilience in a child's life:

- Personal or individual characteristics of a child;
- Characteristics of a child's family; and
- 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.

In terms of personal and individual characteristics that can protect children, children have personality rights, which include the right to equality, dignity, privacy and bodily integrity.[56] They also have the right to development including rights to education and to mental and physical well being.[57]

In terms of protection that can be provided by a child's family, every child has the right to parental care, or appropriate alternative care[58] , with all that this entails. Children also have a right of access to formal services that exist, in terms of our Constitution, such as the right to basic health care services and the right to social services when their parents or family cannot provide for such needs.[59]

Finally it is argued that we can protect children by ensuring that effective legal support networks exist which could assist them to enforce their rights; these would include in the first instance parents, guardians or family members who could assist children who do not have legal capacity to undertake legal action on their own, to protect and enforce their rights. Secondly, they could include statutory bodies such as the South African Human Rights Commission, the National Youth Commission, and the Commission on Gender Equality. Support networks could also include NGOs providing legal services, the Legal Aid Board and lawyers in private practice providing *pro deo*[60] services.

The report therefore focuses on the nature and extent of stigma and discrimination against children and youth, the impact such discrimination has on the rights of children, and the ways in which this increases the vulnerability of children and youth infected with and affected by HIV/AIDS; and furthermore how the law and other programmes could be used to promote resilience within children to deal with unfair discrimination.

2.5 Enforcing Rights to Equality

At present, there are two ways in which to protect rights to equality:

- Using the rights and remedies as detailed within legislation such as the Employment Equity Act or the Equality Act; and
- Using section 9 of the Constitution.

In terms of the legal principle of avoiding a constitutional issue, a litigant is required to use the remedies provided in other legislation or the common law, if they exist, before using the rights within the Constitution, to resolve a dispute[61] .

This would mean that in future the Equality Act would become the primary mechanism for dealing with unfair discrimination. Albertyn et al suggest that as the Equality Courts will be based in magistrate's courts, they will be extremely accessible, cheap, and informal and

will be able to develop creative remedies. However the Constitutional Court will still have to deal with cases involving not simply an act, but legislation that infringes a constitutional right[62]. For example if a child was excluded from a children's home on the basis of their HIV status they would use the remedies set out in the Equality legislation to enforce their rights to equality. If however the government passed a law stating that HIV positive youth would not be entitled to financial aid to study at a tertiary level, then this law could be challenged in the Constitutional Court on the basis that it is unconstitutional.

Applying this to children and youth infected with and affected by HIV/AIDS, if a child living with HIV or AIDS was, for example, refused access to medical treatment at a local hospital, this could challenged on the basis of unfair discrimination. The following process is set out for using the Equality Courts:

(1) Approach the clerk of the Equality Court and complete the necessary forms.[63] (It is currently uncertain as to exactly how an application to the court will be made, as this will be detailed within the regulations which are yet to be published);

(2) Inform the other party (that is, the discriminator) of the claim;[64]

(3) The magistrate will refer the matter to the appropriate forum for adjudication (for example, to the Constitutional Court or the Human Rights Commission or the Equality Court itself).[65]

(4) A hearing is held. (The exact form the hearing will take will only be detailed in the regulations.)

(5) The presiding officer makes a finding and grants a remedy.[66]

At this point it does not appear that the 'victim of discrimination' would need an attorney in the Equality Court, as the application process and the proceedings within the Court will be informal.

If a complainant used section 9 of the Constitution to enforce their rights, they would have to:

(1) Consult an attorney for advice on whether the discrimination was a 'constitutional matter'[67] and accordingly whether section 9 of the Constitution could be used;

(2) If advised that it was a constitutional matter, draft papers setting out that a differentiation occurred based on 'HIV status' or 'disability' and this was unfair and not justified in an open and democratic society;

(3) Lodge such papers either with the constitutional court[68] or the High Court[69]; and

(4) Attend the hearing and ask for an appropriate order regarding the discrimination eg a declaration that the law is unconstitutional.

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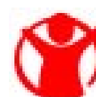
[7] Burris S "*Studying the Legal Management of HIV-Related Stigma"* American Behavioural Scientist, Vol 42 No 7, April 1999 at p.1231

[8] Nabagala, Scovia Kasolo from Uganda; a participant in the stigma and discrimination listserv discussion group organized by SAfAIDS at http:www.hdnet.org

[9] Brown R *Prejudice – its Social Psychology* 1995 Oxford Blackwell at 8, as quoted in Richter M *Preliminary Assumptions on the Nature and Extent of Discrimination against PWAs,* Research conducted for the AIDS Law Project, 2001.

[10] Herek GM, Mitnick L, Burris S, Chesney M, Devine P, Thompson Fullilove M, Fullilove R, Chao Gunter H, Levi J, Michaels S, Novick A, Pryor J, Snyder M, Sweeney T *Workshop Report: AIDS and Stigma: A Conceptual Framework and Research Agenda* AIDS & Public Policy Journal, Spring 1998 at 36-47
[11] Richter M *Preliminary Assumptions on the Nature and Extent of Discrimination against PWA in South Africa,* Research conducted for the AIDS Law Project, 2001 at 11
[12] *Ibid* footnote 5 at p.14 - 18
[13] The Constitution of the Republic of South Africa Act No 108 of 1996, s9
[14] De Waal J, Currie I and Erasmus G *The Bill of Rights Handbook* (4rd ed) Juta 2000 at p.184
[15] *Hoffman v SAA* 2001 (1) SA 1 (CC)
[16] *R v Turpin* (1989) 1 SCR 1296 at 1332
[17] 1997 (4) SA 1 (CC)
[18] 1997 (4) SA 1 (CC) at para 41
[19] *Prinsloo v van der Linde and Another* 1997 (3) SA 1012 at 1026 F – G
[20] 1998 (1) SA 300 (CC)
[21] *Ibid* at 320 A - C
[22] *Ibid* at 323 C – 325 E
[23] Act 108 of 1996
[24] The Constitutional Court is yet to make a ruling on whether unfair discrimination based on HIV status should be regarded as being protected by "disability" (a specified ground) or whether it ought to be recognized on its own as an unspecified ground.
[25] Harksen's case at para 52
[26] *ibid* at para 53
[27] See s 9(4) of Act 108 of 1996
[28] Personal communication with Ms Liesl Gernholtz of the AIDS Law Project on the 10 August 2001
[29] s6
[30] s1(viii) of Act 4 of 2000
[31] *Ibid* see s 7,8 and 9
[32] The Equality Committee set up in terms of the Equality Act is enjoined to consider this within one year of the commencement of this section of the Act – that is, by September 2001. To date, however, there has been no public announcement of the outcome of any investigation into this issue by the Equality Review Committee.
[33] Albertyn et al (eds) *Introduction to the Promotion of Equality and Prevention of Unfair Discrimination Act, 4 of 2000* Witwatersrand University Press 2001 at 86
[34] A number of academic writers have criticized the test, see Albertyn *et al ibid* where they argue that this section should be re-drafted. In the light of this it is possible that the test will change in some way within the next 2 years
[35] s 14(2) and (3)
[36] s 8(c)
[37] s 9(c)
[38] s 12(b)
[39] s 14(2)(a)
[40] Albertyn et al (eds) *Introduction to the Promotion of Equality and Prevention of Unfair Discrimination Act, 4 of 2000* Witwatersrand University Press 2001 at 42
[41] s 14(2)(b) and (3)
[42] S 14(2) and (3). Albertyn et al (see footnote 33) argue that it is not completely clear how the court will apply the test as they will have to weigh up factors which include whether the discrimination is justifiable twice in terms of the test set out in s 14(2) and (3)
[43] These courts are not yet operational (September 2001).
[44] s 21(1)
[45] s 21(2), (3), (4) and (5)
[46] 2001 (1) SA 1
[47] *Ibid* at para 29
[48] GN R1298, GG 21815 of 1 Dec 2000
[49] GN 1926, GG 20372 of 10 August 1999
[50] s 29(1)(n)
[51] s29(1)(o). Currently, the regulations require medical aids to provide members living with HIV/AIDS with treatment for opportunistic infections, as well as hospitalization.
[52] The Health Bill is not yet law, but when it is promulgated will replace the existing Health Act No 63 of 1977
[53] Clacherty and Associates "*The role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS"* Research conducted for Save the Children (UK), 2001 at 21-23.
[54] Burris S *"Legal Management of HIV-Related Stigma"* AIDS Behavioural Scientist at 1231
[55] Quoted by Clacherty and Associates in "*The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS*" Research conducted for Save the Children (UK), 2001 at 21.
[56] S 9, 10, 14 and 12 of Act 108 of 1996
[57] *Ibid* at s 29 and 28(1)(d)
[58] *Ibid* at s 28(1)(b)
[59] Bekink et al 'Constitutional Protection of Children' in Davel CJ (ed) *Introduction to Child Law in South Africa*, Juta, 2000 at 174
[60] Legal service which are provided without charge
[61] *S v Mhlangu* 1995 (3) SA 867 (CC) at para.59



[62] Albertyn et al (eds) *Introduction to the Promotion of Equality and Prevention of Unfair Discrimination Act, 4 of 2000* Witwatersrand University Press 2001 at 31

[63] s 20(2)

[64] The Act doesn't provide for this, but the details of how this must be done will be set out in the regulations to the Act.

[65] s23(3)(a)

[66] See Section 2.2.1 for details of the possible remedies

[67] s 167(7) of Act 108 of 1996

[68] *Ibid*

[69] s 169 of the Constitution

THE NATURE OF STIGMA AND DISCRIMINATION AGAINST CHILDREN AND YOUTH INFECTED WITH AND AFFECTED BY HIV/AIDS

Save the Children

Most research has focused on discrimination faced by adult persons infected with or affected by HIV/AIDS. For example in a Preliminary Research Report prepared by the drafters of The Promotion of Equality and Prevention of Unfair Discrimination Act[70], they described this discrimination as follows:

> *"People who have been diagnosed as HIV positive, or who have AIDS, are being discriminated against very severely in a range of contexts and environments, from employment, and various economic spheres, to sports and aspects of community service all of which have a severe impact on their social lives and social image. Much of this discrimination is in fact unjustified and unfair. It results in such persons having to resort to secrecy, social withdrawal and lies. There can be little doubt that discrimination on these grounds has to be addressed."*[71]

Our research shows that children and youth experience 2 main forms of stigma and discrimination on the basis of HIV/AIDS:

- General stigmatization and isolation by families, communities and institutions within communities; and
- Discrimination by service providers in accessing rights and services.

3.1 General Stigmatization and Isolation by Families and Communities

Several key role players interviewed noted that children who are either known to be living with HIV[72], or who are perceived to be living with HIV (for instance, when a parent is known to have died of AIDS or when a child is being cared for in an organization such as Cotlands Baby Sanctuary)[73], or who begin to exhibit well known symptoms of HIV (such as weight loss or thrush)[74], are stigmatized and isolated by their communities. This was confirmed by the research undertaken by Clackerty and Associates.[75].

3.1.1 Stigma and Discrimination within the family

Research indicated the following forms of stigma and discrimination within the family:

(1) Children are stigmatised and isolated within their own immediate families.

For example, parents and caregivers whose children receive health care at Cotlands Baby Sanctuary are reported to visit infrequently, due to the stigma attached to HIV and AIDS.[76]

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".*[77]

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

> *"I've told them at home. 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 my 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 here."*[78]

(2) Extended families stigmatize and isolate children and their parents who are infected with or affected by HIV/AIDS.[79]

> *"If relatives get to know about it they'll never treat your child well. I am talking about what I know. My other sister has got it [HIV/AIDS] too. When we go to my aunt's place my aunt literally guards what our children are doing. She also tells her children not to use the same glasses. You can see from this that she doesn't want our children. Since she knows what they have she doesn't accept them any more." (Women living with HIV whose young child is also living with HIV.)*
>
> *"My other child, he was staying at my aunt's place, was sick the other day. He had stomachache. They made him sleep on the stoep of the house. He was also told not to cough in front of the other children. When we got there to fetch him I was told not to bring him there anymore. They know very well this child is not infected." (Woman living with HIV, East Rand.)*

(3) Children infected with or affected by HIV/AIDS often experience difficulties finding foster or adoptive parents even within the extended family[80].

(4) 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.[81]

An orphaned boy who was taken in by his aunt's family in Ingwavuma 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".*

A girl orphan in Ingwavuma states that:

> *"I fetch water from the river – I am the only one who takes care of the maize field, the only one who is expected to do work around the house".*

3.1.2 Stigma and Discrimination within the community

(1) 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.[82]

A woman living with HIV in Bloemfontein said:

"Some children call to our kids, "I'll give you your thin mother". This happens to my child when he is playing with his friends especially if the hospice car comes by. They would say 'Your mother rides in a car that is ridden by people who have AIDS which means she has got AIDS too'.

An eleven-year-old boy from the East Rand, 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 from Ingwavuma reported:

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

A man from Bloemfontein living with HIV/AIDS reported:

"The community discriminates against children even before we die. Because people know what we have even before we die they don't even consider helping our children when we die. It is better if you die because of any other disease because people somehow are prepared to help. It is difficult for people to take care of your child even though they know that he or she doesn't have it [HIV/AIDS]."

(2) Childcare organizations often experience difficulties finding foster or adoptive parents for affected children within the community.[83]

(3) Children who present with symptomatic illnesses are often isolated by community members, rather than cared for[84]; this includes isolation by other children and youth;[85]

A teenager from Ingwavuma 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".

(4) Parents often do not wish children living with HIV to attend the same pre-schools and schools as their own children.

In a case which Bloemfontien Hospice dealt with, parents of other children at a crèche wanted to remove their children from the crèche when it became known that one of the children was living with HIV[86]. Likewise in the case of Nkosi Johnson, 50% of parents did not wish him to attend their child's primary school.[87]

(5) The loss of business through being associated with a child who was perceived to be HIV positive.[88] a clear example of this type of community stigmatization and discrimination was given by Thandanani of Pietermaritzburg. They reported:

> *"The Natal Witness ran an article on a 'gogo' in Mpopemeni[89] who was looking after 18 children who had been abandoned in her care due to the impact of HIV/AIDS on her extended family. Following the article the family were threatened with violence and shunned by the community. They were told that they were bringing the area into disrepute as now everyone would think that the area was full of AIDS and no industries would come and create jobs for the community. Some community members also accused them of trying to get more social welfare benefits than they were entitled to and saw them as trying to exploit the situation."[90]*

3.1.3 Analysis of attitudes and behaviour in terms of working definitions of Stigma and Discrimination

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 themselves 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,[91] 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'.[92]

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. Clacherty and Associates[94] note that:

> *"the discrimination against children affected by HIV/AIDS parents is most often related to a lack of understanding about how the disease is transmitted; people believe it is transmitted by sharing plates and cups and sharing a bed or a home with a person who is infected and this is why they marginalise people who are infected…Related to this point is the second issue; people believe that children whose parents are ill or have died are a danger and could transmit the disease to others"*

Isolating and discriminating children and youth infected with and affected by HIV/AIDS due to a fear of HIV transmission is not reasonable, nor can it be seen as justifiable, given our medical knowledge of HIV transmission.

Other forms of discrimination in the examples quoted above do not appear to have any rational reason or justification. They may simply be based on the stigmatization around HIV and AIDS, and assumptions such as the fact that the disease is linked to sexual promiscuity and sin. Clacherty and Associates note the following responses in interviews with groups of random selected adults in the East Rand and in Bloemfontien: [95]

> *"If it was a mistake or any other way than sexual it would be easy to accept. It would be easy to accept if a person gets AIDS while helping someone else. It is different if a person gets it through promiscuity. AIDS is the consequence of what she was doing."*
>
> *"I can forgive a person if a person had an open wound and put himself in danger without knowing. At least that's forgivable"*
>
> *"Now it seems the first response when a person has got AIDS is that you've been sleeping around"*
>
> *"If people could just get it out of their minds that it is the sinner's diseases."*

It is unclear as to why the community value system against sexually active persons who become infected with HIV should also extend to affected children and youth, and perhaps is some indication of the pervasiveness of the stigma and prejudice associated with HIV and AIDS.

As with unfair discrimination based on unrealistic fears of HIV transmission, unfair discrimination based on prejudice and existing stigma is likewise unjustifiable and would not pass muster with a court of law. In a recent Constitutional Court case on HIV discrimination[96] , Judge Ngcobo held that:

> *"Prejudice can never justify unfair discrimination. This country has recently emerged from institutionalized prejudice. Our law reports are replete with cases in which prejudice was taken into consideration in denying the rights that we now take for granted. Our constitutional democracy has ushered in a new era – it is an era characterized by respect for human dignity and for all human beings. In this era, prejudice and stereotyping have no place. Indeed, if as a nation we are to achieve the goal of equality that we have fashioned in our new Constitution we must never tolerate prejudice, either directly or indirectly."*

3.2 Discrimination by Service Providers in accessing Rights and Services

In many cases, children and youth are discriminated against in that they are stigmatized and treated differently in a way that is unfairly discriminatory, by service providers, when they access basic services, as a result of HIV/AIDS. This form of discrimination is also a social risk that makes children vulnerable to being excluded from accessing the services required to meet their health, welfare and education needs.

3.2.1 Stigma and Discrimination in Schools

(1) Children and youth infected and affected by HIV/AIDS experience isolation and rejection by their peers and parents[97] of other children at schools.

For example, a 7 year old girl in Port Shepstone who was known to be living with HIV as a result of a court case against the perpetrator who sexually abused her, told of severe ostracisation and rejection by her school peers as a result of her HIV status, to the point where she no longer wished to attend school.[98]

Nkosi Johnson reported that a boy at school:

> *"will greet me but if I go near him he moves away. If I go to touch other boys he says 'Don't go near him, don't touch him!'"*[99]

(2) Children and youth infected and affected by HIV/AIDS report discriminatory treatment from educators themselves.

An 8 year old girl in Mpumalanga who was perceived to be living with HIV (her mother was known to have died of AIDS) had open sores on her head. Educators at her school sprayed her head with fly repellant and sent her home, telling her only to return to school once the sores had healed[100].

A girl from the East Rand whose mother is living with HIV/AIDS described the fear of disclosure of HIV status by educators:

> *"Teachers can tell the others at the assembly and other children will laugh and others will start playing cruelly with you and tease you that your mother has got AIDS."*[101]

(3) Children and youth infected and affected by HIV/AIDS are at times denied access to schooling.

For example in the case of Nkosi Johnson, at the age of 7 years old, he was refused admission to a local primary school because his mother told the school that he was living with HIV.[102]

(4) Children and youth infected and affected by HIV/AIDS are also reported to refuse to continue schooling, or to be removed from school by their parents, as a result of the stigma and discriminatory treatment they receive or even simply as a result of the fact that they are living with HIV/AIDS.

A teenager living with HIV/AIDS from Orange Farm 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."*[103]

Mercy Makhalemele speaks of the fact that, due to the severe discrimination her son suffered at school:

> *"Thabang never wanted to go to school again so he actually stayed back a year."*[104]

The AIDS Legal Network in KwaZulu Natal dealt with a case where a 16-year-old girl was removed by her parents from a private school when the girl's doctor unlawfully told them that their daughter was living with HIV/AIDS[105].

3.2.2 Discrimination in Pre-Schools and Creches

(1) Children living with HIV, or perceived to be living with HIV, are denied access to pre-schools and crèches[106]

In a recent case that was publicized on Carte Blanche, a mother of a 2-year-old foster child living with HIV was outraged when her child was refused entry into a Montessori Pre- and Primary School on the basis of the child's HIV status.[107]

(2) Children living with HIV, or perceived to be living with HIV are more often asked to remain home when they have minor ailments.

For example, a child from Cotlands (who was not in fact living with HIV but perhaps perceived to be so because of the association with the organisation) is frequently sent home with minor ailments and the social worker concerned reports that efforts are being made to exclude the child from the school.[108]

(3) Children living with HIV or perceived to be living with HIV are handled with caution.

For example, Bloemfontein Hospice reported a case of discrimination against a child who was perceived to be HIV positive and began to show symptoms of HIV infection. Caregivers at the crèche insisted on wearing gloves when changing the child's nappy, although this was not done with any other children. They also began to discuss the child's HIV status amongst each other, so that it became widely known even to parents of other children at the crèche.[109]

(4) Parents of other children at a pre-school or crèche are reported to complain about the presence of children infected or affected by HIV/AIDS in pre-schools and crèches.

3.2.3 Discrimination in terms of Denial of Parental Care and Appropriate Alternative Care

(1) Children infected with and affected by HIV/AIDS have reportedly been removed from parents living with HIV/AIDS, based on an assumption that the parents are unable to provide appropriate care.

Our research indicated cases where a parent (particularly a mother) is living with HIV, and the children are removed from the parent and placed into alternative care, even in instances where the parental care is still adequate.[110] The AIDS Law Project dealt with a case where a social worker had two children removed from a mother who was living with HIV, by order of court, although the mother was subsequently shown to be well and the children were not in need of care. The AIDS Law Project intervened and had the children's court order reversed.[111]

(2) Children and youth infected with and affected by HIV/AIDS are reported to be abandoned, particularly by fathers, in instances where the mother is known to be living with HIV/AIDS.

According to the Child Health Policy Unit, a study by the Red Cross showed that 14 out of 16 fathers abandoned the family where the mother declared her HIV status. Likewise, Grootte Schuur report that around 60% of fathers abandon women who disclose their HIV status.[112]

(3) Children orphaned by HIV/AIDS are often denied access to appropriate alternative care such as foster or adoptive parenting, or children's homes.[113]

(4) Children orphaned by HIV/AIDS reportedly receive different and frequently substandard levels of care when in alternative care such as foster and adoptive families, and children's homes.

An example of this is the fact that staffs in children's homes are reported to discriminate against children with HIV, to the point where some refuse to work with these children,[114] and others are reported to give sub-standard care and mistreatment to children living with HIV. Valencia Mofokeng, a women living openly with HIV, tells the following story:

"The first time I disclosed, I was staying in Lenasia and I was working a Children's Home as a child-care worker. There were two children there who where HIV positive but the staff were not treating them correctly, it was not like the other kids. They used to swear at them and sometimes they didn't even wash their clothes."[115]

3.2.4 Discrimination and Denial of Access to Health Care Services

Clacherty and Associates, in *The Role of Stigma and Discrimination in increasing the Vulnerability of Children and Youth affected by HIV/AIDS*, note that one of the main themes that emerged from their participatory workshops was the discrimination PLWAs experienced in hospitals and clinics[116]. The most common nature of this discrimination is as follows:

(1) 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.[117]

The Children's Rights Center in Durban reported[118] that they had experience of HIV positive children being denied care as health care institutions had informal policies of not treating "babies with full-blown AIDS". This was confirmed by the experiences of Thandanani[119] in Pietermaritzburg who noted that their volunteers reported nursing staff would refuse to care for what they termed "Thandanani babies" ie those that were suspected of being HIV positive. This refusal to care for HIV positive babies meant that such children where not fed, bathed or had their nappies changed unless the Thandanani staff were present.[120]

A woman living with HIV/AIDS in the East Rand reported that:

"When you go to the clinic with a baby most of the nurses encourage us to tell the doctors that the child is HIV positive but once you say so they ask you what do you expect them to do then. So they do not even treat what the child is presenting with the minute you disclose the child's status. And nurses and especially doctors they say to you, 'You know what your child has and yet you bring him. You know that your child will never live, 'negkhe a pile'".[121]

A teenager living with HIV/AIDS in Orange Farm 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 Panado and you can see it there."[122]

(2) 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.[123]

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. They 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".

3.2.5 Discrimination and Denial of Access to Social Services

(1) Children and youth infected with and affected by HIV/AIDS are reported to experience discrimination on the basis of their actual or perceived HIV status.[124]

For example the Children's Rights Center in Durban recalled a case where a 13 year old was the head of household and the social workers refused to assist her with her application for a birth certificate and identity document which she needed to access the child support grant for her siblings because of her association with HIV, that is, she was perceived to be an 'AIDS orphan'.[125]

(2) Children and youth infected with and affected by HIV/AIDS find it difficult to access existing social services, or find the existing social services inadequate to meet their growing needs.[126]

Adults living with AIDS on the East Rand reported their difficulties accessing grants:

> *"I get the child support grant but it is not enough for us to find enough to eat. I only work one day a week. I do my best, I try as a mother but my problem is I get tired."*
>
> *"There is so much mis-information, we just don't know how to get it".*

They also described how their children over 6 years suffered because they did not have access to the grant for children over this age.

3.2.6 Analysis of Attitudes and Behaviour in terms of working definitions of Stigma and Discrimination

The examples above again show that children and youth infected with and affected by HIV/AIDS are stigmatized as a result of the HIV status, perceived HIV status, or association with HIV and AIDS. The mistreatment and infringements of the dignity of children and youth, by various service providers in the education, health care and welfare setting indicates a belief that these children are in some way "spoiled" and "different".

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.[127] 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.

Finally, we need to consider whether the unfair discrimination is in any way reasonable and justifiable in an open and democratic society based on human dignity, freedom and equality. This entails looking at issues such as the purpose of the discrimination, and whether it serves a legitimate purpose that could not be dealt with in a less restrictive way.

In many instances, we can assume that the purpose of the unfair discrimination against children and youth infected with and affected by HIV/AIDS is a misguided attempt to protect others from becoming infected with HIV. For example, in the pre-school and school setting, the fear of HIV transmission is frequently cited as a reason for unfair discrimination.[128] This fear may also be the cause of mistreatment and neglect reported in residential care facilities and in the health care setting.

Unfair discrimination on this basis is not reasonable or justifiable, given that HIV is a sexually transmitted disease and is not transmitted through casual contact. In the case of *Hoffmann v South African Airways*[129] the court stressed that:

> *"Fear and ignorance can never justify the denial to all people who are HIV positive of the fundamental right to be judged on their merits. Our treatment of people who are HIV positive must be based on reasoned and medically sound judgements".*

The Department of Education's *National Policy on HIV/AIDS for Learners and Educators in Public Schools, and Students and Educators in Further Education and Training Institutions* recommends that universal infection control procedures should be implemented in all schools to minimize the risk, if any, of HIV transmission[130]. The use of universal infection control procedures is therefore seen as a reasonable, lawful as well as less restrictive response to managing the risk of HIV transmission in the educational setting, as opposed to marginalizing, isolating and denying entry to children and youth infected with and affected by HIV/AIDS.

Where children and youth infected with and affected by HIV/AIDS are denied access to services, such as health care and welfare services, it is more difficult to determine whether this constitutes unfair discrimination. In instances where this occurs as a result of government policy (for example, where a child's right to basic health care is limited by government policy, due to resource constraints), it is the policy itself, rather than the health care or welfare service provider, which needs closer examination. The state is constitutionally obliged to provide certain services[131]. Where government services are limited, this is generally on the basis of resource constraints and distribution of resources, and a court of law would need to carefully examine government policy in this regard, in accordance with the rights of children and youth, and the limitation clause, in order to determine whether particular policies are justifiable limitations based on the given reasons.[132] However it appears that in many of the examples cited above (for example, the refusal to treat "AIDS babies" or provide basic medical care to youth living with HIV/AIDS), there is evidence of service providers making decisions based on their own prejudices and frustrations, rather than on the basis of legitimate government policy or legislation. Unfair discrimination that denies services and entitlements to children and youth infected with and affected by HIV/AIDS on this basis, is unreasonable and unjustifiable.

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[70] *Discussion Document 3: Preliminary Research Reports and Proposals regarding a framework on Equality Legislation for South Africa July 1998* Equality Legislation Drafting Unit at 25
[71] *Preliminary Research Report and Proposal regarding a Framework on Equality Legislation for South Africa*, developed by the Department of Justice Equality Drafting Unit, 1998
[72] Interview with Musa Njoko, Interviewer for SABC Positivity TV Show, 29 January 2001;
[73] Interview with Lyndsay Barr, social worker, Cotlands Baby Sanctuary, 22 January 2001.
[74] Interview with Musa Njoko, Interviewer for SABC Positivity TV Show, 29 January 2001.

[75] Clacherty and Associates "*The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS"* Research conducted for Save the Children (UK), 2001 at 25 - 37

[76] Interview with Lyndsay Barr, social worker, Cotlands Baby Sanctuary, 22 January 2001; Interview with Musa Njoko, Interviewer for SABC Positively TV Show, 29 January 2001; Interview with Sonja Giese, Co-ordinator, Child Health Policy Unit, 29 January 2001; Interview with Jennifer Joni, Attorney, AIDS Law Project, 22 January 2001.

[77] Clacherty and Associates "*The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS"* Research conducted for Save the Children (UK), 2001 at 26.

[78] *Ibid* at 28.

[79] *Ibid* at 26.

[80] Interview with Nolundi Ndungane, social work lecturer, University of the Transkei, 31 January 2001 and Gerrit Te Haar, Chairperson, God's Golden Acre, KwaZulu Natal, 26 January 2001

[81] Clacherty and Associates "*The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS"* Research conducted for Save the Children (UK), 2001 at 25.

[82] *Ibid* at 30-34; Interview with Gerrit Te Haar, Chairperson, God's Golden Acre in KwaZulu Natal , 26 January 2001. Mr Te Haar argued that the language used often discriminated against those affected by HIV. He felt that the term "AIDS orphan" as it was used in the community was stigmatizing as it seemed to indicate that children orphaned by AIDS were different from other orphans.

[83] Interview with Lyndsay Barr, social worker, Cotlands Baby Sanctuary, 22 January 2001; Interview with George Swarts, Orphan Co-ordinator, Bloemfontein Hospice, 29 January 2001.

[84] Interview with Musa Njoko, Interviewer for SABC Positivity Show, 29 January 2001. Interview with Sonja Giese, Co-ordinator, Child Health Policy Unit, 29 January 2001.

[85] Interview with Gerrit Te Haar, Chairperson, God's Golden Acre, KwaZulu Natal, 26 January 2001

[86] Interview with George Swarts, Orphan Co-ordinator, Bloemfontein Hospice, 29 January 2001. In a case which Bloemfontien Hospice dealt with, parents of other children at a crèche wanted to remove their children from the crèche when it became known that one of the children was living with HIV.

[87] Interview with Jennifer Joni, Attorney, AIDS Law Project, 22 January 2001.

[88] Interview with Ncumisa Nongongo, National Training Co-ordinator, AIDS Legal Network, 19 January 2001 who spoke of a hawker who lost his business when his daughter was photographed being held by an American HIV/AIDS advisor to President Bill Clinton.

[89] A township outside of Howick in the Natal Midlands.

[90] Interview with Linda Aadnesgaard, Director, Thandanani, 19 January 2001

[91] In the case of children in need of care, it is less difficult to determine whether this is necessarily on the basis of HIV and AIDS, or simply an indication of the difficulties experienced by communities in taking on the responsibility of caring for other children and youth.

[92] Research indicates that generally, orphaned children fare worse than natural children, particularly in poorer households. "Pre-school children show greater physical consequences of their changing status than their older siblings and experience greater degrees of malnutrition, ill health and higher mortality rates than their non-orphaned peers" Barrett K, McKerrow N, Strode A "*Consultative Paper on Children Infected and Affected by HIV/ADIS"* Research conducted for the South African Law Commission Project Committee on the Review of the Child Care Act, January 1999, at 10-11.

[93] The impact of stigma and discrimination is discussed in more detail in section 5, below.

[94] *The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS* Research conducted for Save the Children (UK), 2001 at 63.

[95] *Ibid* at 65.

[96] *Hoffman V South African Airways* 2001 (1) SA 1 (CC). SAA argued that one of the justifications for refusing to employ cabin attendants living with HIV was that competitors employed a similar practice, and that SAA would be disadvantaged against its competitors if it did not employ the same discriminatory practices.

[97] In the case of Nkosi Johnson, the school canvassed the opinion of parents to determine whether to admit Nkosi Johnson to the school. The parents were divided on the issue, with 50% of them wishing to refuse admission to a child known to be living with HIV. Interview with Jennifer Joni, Attorney, AIDS Law Project, 22 January 2001.

[98] Interview with Musa Njoko, Interviewer for SABC Positivity Show, 29 January 2001.

[99] Department of Health *Living Openly: HIV Positive South Africans tell their stories* February 2000 at 15.

[100] Interview with Musa Njoko, Interviewer for SABC Positivity TV show, 29 January 2001. Another child whose mother is openly living with HIV and works as an AIDS activist experienced discrimination and stigmatization from other children, prompted by educators themselves, who told them "Don't touch this child, his mother has AIDS". Department of Health *Living Openly: HIV Positive South Africans tell their Stories* Feb 2000 at 3.

[101] Clacherty and Associates "*The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS"* Research conducted for Save the Children (UK), 2001 at 37.

[102] Interview with Jennifer Joni, Attorney, AIDS Law Project, 22 January 2001. The case was brought to the attention of the AIDS Law Project, who intervened on behalf of Nkosi Johnson. However, it is important to note that this incident of discrimination occurred before the enactment of the Department of Education's National Policy on HIV/AIDS for Schools. Our research did not highlight any further instances of outright denial of education to children, but rather differential treatment and discrimination against children living with HIV in schools.

[103] Clacherty and Associates "*The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS"* Research conducted for Save the Children (UK), 2001 at 38.

[104] Department of Health: *Living Openly: HIV Positive South Africans tell their stories*, Feb 2000 at 3.

[105] Interview with Ms Ncumisa Nongongo, National Training Co-ordinator, AIDS Legal Network, 19 January

2001

[106] Interview with Ncumisa Nongogo, National Training Co-ordinator, AIDS Legal Network, 19 January 2001. Barrett K, McKerrow N, Strode A *"Consultative Paper on Children Infected and Affected by HIV/AIDS"* Research conducted for the South African Law Commission Project Committee on the Review of the Child Care Act, January 1999 at 26.

[107] Communication with Ms Pereira, 31 January 2001. In a letter to the schools, Ms Pereira notes that: "In my initial telephonic discussion with Lesley a couple of weeks ago, I was told that there would be no problem in accepting Tholakele and that there was place in the Toddlers group for her. It was also mentioned by Lesley that Tholakele would be the first HIV positive child in the school and so far the only Black child in her group. The sudden change in attitude on our arrival to view the school this morning was a shock; this as a result of a discussion between all the teachers at the school." The same child has since been denied access to 2 more pre-schools, according to an Interview with Jennifer Joni, Attorney, AIDS Law Project, 20 October 2001.

[108] Interview with Lyndsay Barr, social worker, Cotlands Baby Sanctuary, 22 Jan 2001.

[109] Interview with George Swarts, Orphan Co-ordinator, Bloemfontein Hospice, 29 January 2001.

[110] Interview with Sonja Giese, Co-ordinator, Child Health Policy Unit, 29 January 20 01.

[111] Interview with Jennifer Joni, Attorney, AIDS Law Project, 22 January 2001.

[112] Interview with Sonja Giese, Co-ordinator, Child Health Policy Unit, 29 January 2001.

[113] Barrett K, McKerrow N, Strode A *"Consultative Paper on Children Infected and Affected by HIV/AIDS"* Research conducted for the South African Law Commission Project Committee on the Review of the Child Care Act, January 1999 at 24-27. The practice of conducting HIV testing on children in need of care and protection before placement is reported to lead to discrimination against these children.

[114] Interview with Sonja Giese, Co-ordinator, Child Health Policy Unit, 29 January 2001.

[115] Department of Health *Living Openly: HIV Positive South Africans tell their stories* , Feb 2000at 53.

[116] Research conducted for Save the Children (UK), 2001, at 39

[117] Interview with Sonja Giese, Co-ordinator, Child Health Policy Unit, 29 January 2001.

[118] Interview with Cati Vawda, Co-ordinator, Children's Rights Center, Durban, 24 January 2001

[119] Interview with Linda Aadnesgaard, Director, Thandanani, 19 January 2001

[120] *Ibid*. An extreme example of the type of discrimination that children with HIV faced as opposed to other children in the hospital is that one volunteer reported that when she bathed a baby over the weekend it was so hungry and thirsty it started to lap the bath water into its mouth.

[121] Clacherty and Associates *"The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS"* Research conducted for Save the Children (UK), 2001 at 41.

[122] *Ibid* at 40.

[123] *Ibid* at 40.

[124] Interview with Cati Vawda, Co-ordinator, Children's Rights Center, 24 January 2001, Interview with Linda Aadnesgaard, Director, Thandanani, 19 January 2001.

[125] Interview with Cati Vawda, Co-ordinator, Children's Rights Centre, 24 January 2001.

[126] Clacherty and Associates "*The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS"* Research conducted for Save the Children (UK), 2001 at 48.

[127] The impact of stigma and discrimination is dealt with more fully in section 5, below.

[128] Interview with Ncumisa Nongogo, National Training Co-ordinator, AIDS Legal Network, 19 January 2001; Clacherty and Associates *The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS* Research conducted for Save the Children (UK), 2001 at 37-39, 63-64.

[129] 2001 (1) SA 1 (CC)

[130] Notice 1926 of 1999, Govt Gazette 20372, 10 August 1999. Section 2 of the policy is based on various premises, including the premise that "HIV cannot be transmitted through day-to-day social contact… The risk of transmission of HIV in the day-to-day school setting or institution environment in the context of physical injuries, can be effectively eliminated by following standard infection-control procedures or precautionary measures (also known as universal precautions) and good hygiene practices under all circumstances".

[131] For example, the Constitution of the Republic of South Africa Act No 108 of 1996, section 28(1)(c) states that every child has the right to basic nutrition, basic health care services and social services.

[132] An example of a potentially unfairly discriminatory government policy is that of the failure by government to provide anti-retroviral treatment to prevent mother-to-child transmission. At the time of writing, the Treatment Action Campaign were threatening legal action against the Department of Health's failure to provide Nevirapine in public hospitals for pregnant women living with HIV, in order to prevent HIV transmission to their babies.

THE EXTENT OF STIGMA AND DISCRIMINATION AGAINST CHILDREN AND YOUTH INFECTED WITH AND AFFECTED BY HIV/AIDS

It has been very difficult within this current research project to establish the extent of discrimination and stigma against children and youth infected with and affected by HIV/AIDS as:

- No original research exists on this subject; and
- We could only find anecdotal information supporting a view that discrimination was wide spread.

In the only survey we could find which attempted to interview a wide spectrum of South Africans on their views regarding human rights, it was reported by respondents that they felt that discrimination against people living with HIV or AIDS was rife and that there was a real stigma attached to being HIV positive. Furthermore, 88% of them felt that people with HIV or AIDS should be protected from discrimination.[133]

[133] Pigou P, Greenstein R and Valji N, *Assessing Knowledge of Human Rights among the General Population and Selected Target Groups*, CASE, 1998.

TRENDS IN STIGMA AND DISCRIMINATION AGAINST CHILDREN AND YOUTH

There was an indication given that stigmatization by communities as a whole appears to be decreasing, although nevertheless prevalent. Cotlands Baby Sanctuary, for instance, report that a few years ago fewer children resident at the organisation for health care services were visited by family, due to the stigma attached to HIV and AIDS. Also, very few of the parents were willing to disclose the child's HIV status to other family members. However, there is an increased trend towards parents and immediate family members visiting these children, and of family members being aware of the child's HIV status.[134]

Most persons interviewed noted a change in the form of stigma and discrimination against children and youth. They characterized these changes as:

- A lessening in discrimination with more community members being open about their HIV status;[135]
- A change in the way in which schools approached HIV positive children;[136] and
- A move to more subtle forms of discrimination; for example discriminating against children living in poverty who are frequently in that position due to the impact of HIV or AIDS on their lives.[137]

Interview respondents were also unanimous in their acceptance that girl children faced more stigma and discrimination than boys. In particularly they reported:

- HIV is seen as a "female problem";[138]
- Home based care and looking after siblings fell to girl children;[139] and
- Girls are seen as responsible for controlling male sexuality.[140]

One interview respondent noted that she had not experienced any difference in the discrimination between rural and urban areas;[141] whilst Ms Nongongo of the AIDS Legal Network commented that it was difficult to know what was happening in rural areas, as most legal and para-legal services were in town and rural people had difficulty accessing these services. This position was confirmed by the Clacherty and Associates research report[142], which found greater secrecy attached to HIV in the workshops held in Ingwavuma. Clacherty and Associates argue that this was possibly due to the lack of open discussion on sex and death, the physical isolation of the area form services, and the deep poverty.

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[134] Interview with Lyndsay Barr, social worker, Cotlands Baby Sanctuary, 22 January 2001.
[135] Interview with Cati Vawda, Co-ordinator, Children's Rights Center, 24 January 2001, Nolundi Ndundane, Lecturer, University of the Transkei, 31 January 2001, Linda Aardensgaard, Director, Thandanani, 19 January 2001 and Gerrit Te Haar, Chairperson, God's Golden Acre,26 January 2001
[136] Interview with Ms Ncumisa Nongongo, National Training Co-ordinator, AIDS Legal Network, 19 January 2001. She reported that her organisation saw less discrimination in schools since the introduction of the aforementioned HIV/AIDS Policy.
[137] Clacherty and Associates *The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS* Research conducted for Save the Children (UK), 2001 at 41
[138] Interview with Cati Vawda, Co-ordinator, Children's Rights Center, 24 January 2001
[139] *Ibid*. Interview with Nolundi Ndundane, Lecturer, University of the Transkei, 31 January 2001; Interview with Ncumisa Nongongo, National Training Co-ordinator, AIDS Legal Network, 19 January 2001; Interview with Linda Aadnesgaard, Director, Thandanani, 19 January 2001
[140] Interview with Gerrit Te Haar, Chairperson, God's Golden Acre, 26 January 2001.
[141] Interview with Linda Aadnesgaard, Director, Thandanani, 19 January 2001.
[142] *The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS* Research conducted for Save the Children (UK), 2001 at 66-67.

THE IMPACT OF STIGMA AND DISCRIMINATION ON CHILDREN AND YOUTH INFECTED WITH AND AFFECTED BY HIV/AIDS

6.1 The Impact of Stigma and Discrimination

Richter[143] 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).[144] 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 well being 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 unrecognised pathogenic force of destructive capacity towards well-being at least equal to the capacity of viruses or bacteria".*[145]

Our 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.[146]

A child participating in the Clacherty research reported the impact of discrimination on them as follows:

> *"This is school. They are laughing at her outside of the class. They are laughing at the fact that her mother has AIDS. She is angry and going away. She feels angry and she also feels like beating them but she knows they will report her at the office. So it is better for her to walk away. She cannot report it to the teacher because she is not in the class and the girl is too angry and doesn't have time to do this. She is even afraid to go and report this. She is afraid the teachers will tell all the other children at assembly."*[147]

6.2 The Link between Stigma, Discrimination and Vulnerability

Our research shows that stigma and discrimination clearly pose a significant risk of social harm for children and youth infected with and affected by HIV/AIDS, leading to social and economic disadvantage for such children.

Furthermore, as we can see above, stigma and discrimination significantly reduces key protective factors promoting resilience, in the lives of these children and youth.

Clacherty and Associates describe important personal or individual characteristics which promote resilience in children, such as communication and problem solving skills; a positive self-concept and feeling of self-worth; and a strong internal locus of control linked to a sense of hope and future directed goals. [148] Our research shows that stigma and discrimination have a severe impact on the feelings of self-worth of children and youth infected with and affected by HIV/AIDS, as well as on their feelings of power and control over their environment.

Family characteristics such as a caring, stable and supportive family, a relationship with one stable caregiver, adults that encourage competence and adults that share a strong, coherent and consistent set of values are furthermore said to be an important protective factor promoting resilience amongst children.[149] For many children and youth infected with and affected by HIV/AIDS, our research shows that stigma and discrimination leads to a loss of parental care or appropriate alternative care, and sub-standard care. This further impacts on the resilience of these children and youth.

Finally, Clacherty and Associates[150] stress that social support networks such as positive peer networks, role models beyond the family, especially educators, and extended family and community contacts promote resilience in children who are exposed to social risks. Stigma and discrimination against children and youth infected with and affected by HIV/AIDS results in a loss of peer network support and corresponding feelings of social acceptance and value, due to marginalisation and isolation of these children and youth. Our research has also shown that role models such as educators are frequently responsible for the stigma and discrimination against children and youth infected with and affected by HIV/AIDS. Stigma and discrimination also impacts on children and youth's ability to access an extended family and community support network in order to assist them to cope with difficult life situations.

Additionally, our research shows that stigma and discrimination also leads to children and youth infected with and affected by HIV/AIDS being denied or being discouraged from accessing basic services, such as health care and welfare services. This has a severe impact on the physical and mental well being of such children, further impacting on their resilience.

Taking these various factors into account, it is clear that stigma and discrimination leads to extreme vulnerability in children, in terms of both the risks it poses for such children and the reduction of protective factors promoting resilience in such children.

6.3 The Impact of Stigma and Discrimination on Programme Development

The reported impact of stigma and discrimination will certainly create barriers to access to HIV-related projects and programmes for children and youth infected with and affected by HIV/AIDS, for the following reasons:

- ❑ Children and youth targeted for participation in such programmes will be feeling vulnerable, powerless and will have low self-esteem;
- ❑ The high levels of secrecy and fear of disclosure around HIV and AIDS may discourage children from openly participating in HIV related programmes, and may also limit service providers in accessing children and youth in need of care and support; and

- The negative experiences of many children and youth in terms of accessing services may discourage children and youth infected with and affected by HIV/AIDS from participation.

[143] *Preliminary Assumptions on the Nature and Extent of Discrimination Against PWA in South Africa,* Research conducted for the AIDS Law Project, 2001 at p12 - 13

[144] Mann, J. *"Dignity and Health: the UDHR's Revolutionary First Article*" Health and Human Rights, vol. 3, no.2 at 32

[145] Mann, J. *"AIDS and Human Rights: Where do we go from here?"* Health and Human Rights, Vol.3 No.1, at 148.

[146] Clacherty and Associates *The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS* Research conducted for Save the Children (UK), 2001 at 42; Interview with Cati Vawda, Co-ordinator of the Children's Rights Center, 24 January 2001 where she reported that due to a hospital's refusal to treat a baby with AIDS the child had died. Nolundi Ndundane, Lecturer, University of the Transkei, 31 January 2001; Interview with Linda Aadnesgaard, Director of Thandanani, 19 January 2001.

[146] Interview with Linda Aadnesgaard, Director of Thandanani, 19 January 2001

[147] Clacherty and Associates *The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS* Research conducted for Save the Children (UK), 2001at 38.

[148] *The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS* Research conducted for Save the Children (UK), 2001 at 22.

[149] *Ibid* at 22.

[150] *Ibid* at 22-23.

FRAMEWORK FOR RESPONDING TO STIGMA AND DISCRIMINATION

FRAMEWORK FOR RESPONDING TO STIGMA AND DISCRIMINATION

7.1 Introduction

An ideal framework for responding to stigma and discrimination against children and youth infected with and affected by HIV/AIDS should be one that is able to respond comprehensively to all the various forms of stigma and discrimination against children and youth, as set out in terms of this research. This response needs to address both the underlying causes of stigma as well as its effects:

- The fact that stigma and discrimination is manifested in various forms such as attitudes and perceptions, as well as behaviours, laws and policies;
- The fact that stigma and discrimination occurs at the family and community level, as well as the level of service providers, institutions and government departments;
- The fact that stigma and discrimination occurs in various different forms and for varying reasons; and
- The impact that stigma and discrimination has on children and youth.

For this reason, responses to stigma and discrimination against children and youth infected with and affected by HIV/AIDS should include:

- A legal and human rights response, based on law review and reform, increasing awareness of legal rights, as well as increasing and improving access to legal remedies; and
- A broader programmatic response dealing with various other aspects relating to stigma and discrimination, such as community perceptions and awareness, knowledge of HIV transmission and knowledge of rights, access to health care services, programmes to address vulnerability etc.

7.2 Legal and Human Rights Based Response to Stigma and Discrimination

Several years of experience in the HIV/AIDS epidemic have shown that an essential component of preventing HIV transmission, protecting people from stigma and discrimination and reducing the impact of the epidemic, is the p*romotion and protection of human rights*. The UNAIDS Guidelines on HIV/AIDS and Human Rights[151] state that:

> *"One essential thing learned in the HIV/AIDS epidemic is that universally recognised human rights standards should guide policy-makers in formulating the direction and content of HIV-related policy and should be an integral part of all aspects of the national and local response to HIV/AIDS."*

In many countries the initial government reaction to the HIV epidemic was to attempt to curb it by using draconian public health measures. These included the use of isolation, quarantine, mandatory testing and disclosure of a person's HIV status.[152] In response to this, activists, lawyers, counsellors and people living with HIV and AIDS rallied for a human rights approach to the epidemic. This was premised upon the notion that the only way to reduce the growth and impact of the epidemic was to encourage every individual to take responsibility for their own health. This would allow people living with HIV and AIDS to come forward for voluntary testing, treatment and care, thus creating an environment where affected people could, without fear of reprisal or discrimination, participate in the community and in voluntary behaviour change.[153]

> *"The protection and promotion of human rights are necessary both to protect the inherent dignity of persons affected by HIV/AIDS and to achieve the public health goals of reducing vulnerability to HIV infection, lessening the adverse impact of HIV/AIDS on those affected, and empowering individuals and communities to respond to HIV/AIDS."* [154]

In practice it has been shown that non-discrimination is not only a human rights imperative but also a technically sound strategy for ensuring that persons with HIV are not driven underground, where they are inaccessible to education programmes and health care treatment, and unavailable as bearers of AIDS prevention messages. Upholding human rights principles therefore assists public health efforts to protect the health of the whole community by promoting the individual behaviour change necessary for a reduction in HIV infection rates.[155]

The link that has been established between human rights abuses in the form of discrimination, and the vulnerability of children and youth infected with and affected by HIV/AIDS,[156] points to the role of the law in bringing about the changes necessary to protect children and youth. Internationally since the 20 century law has always been one of the principle mechanisms of protecting basic human rights.

In this regard it has been argued that law has both a direct and indirect role.[157] The direct role of law is seen as being the introduction of specific legal protection to outlaw stigma and discrimination against children and youth infected with and affected by HIV/AIDS; whilst the indirect role of law is based on the idea that the law can be an instrument of social and behavioural change.

With regard to the direct role of the law, the Joint United Nations Project on HIV/AIDS (UNAIDS) *HIV/AIDS and Human Rights International Guidelines* state that:

> *"States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors, that will ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation and provide for speedy and effective administrative and civil remedies"*[158]

In particular, in relation to children, the guidelines detail the following necessary steps:

- ❑ Anti-discrimination and protective laws should be enacted to reduce human rights violations against children in the context of HIV/AIDS so as to reduce the vulnerability of children to HIV infection and to the impact of HIV/AIDS;
- ❑ Such laws should provide for children's access to HIV-related information, education and means of prevention inside and outside school;
- ❑ Such laws should govern children's access to voluntary testing with consent by the child or by the parent or appointed guardian, as appropriate;
- ❑ Such laws should protect children against mandatory testing, particularly if orphaned by HIV/AIDS;
- ❑ Such laws should provide for other protections in the context of orphans, including inheritance and/or support;
- ❑ Such laws should also protect children against sexual abuse, provide for their rehabilitation if abused, and ensure that they are considered victims of wrongful behaviour, not subject to penalties themselves; and
- ❑ Protection in the context of disability laws should also be extended to children.

The UNAIDS *Handbook for Legislators on HIV/AIDS, Law and Human Rights*[159] recommends that states enact anti-discrimination legislation, in order to protect children and young people infected with and affected by HIV/AIDS.

They further recommend that the rights to non-discrimination and privacy are important in decisions regarding custody, fostering and adoption, and that the best interests of the child should be paramount in such cases, but should not be used as a pretext for mandatory testing. HIV status should be confidential, but if the HIV status of the child or parent is known, it should be treated like other analogous medical conditions.[160]

With regard to legal support services, the UNAIDS *International Guidelines*[161] furthermore provide as follows:

- States should implement and support legal support services that will educate people affected by HIV/AIDS about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of Ministries of Justice, ombudspersons, health complaints units and human rights commissions;
- Such services should also address the issue of reducing the vulnerability to infection within and the impact of HIV/AIDS on vulnerable groups (including children and youth). The location and format of the information provided via such services should render it accessible to members of these groups.

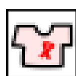
The indirect role of law is undoubtedly complex and controversial; however it is argued that it can be successful. For example if rights of access to treatment were created, it is argued that this would have the social effect of encouraging more people to be open about their HIV status as they come forward for care and support from the state. In this way the law indirectly changes attitudes towards both the disease (its incurable and a death sentence) and to those infected or affected (they are blameworthy).

With regard to the indirect role of law the United Nations Development Programme on HIV and Development have recommended that 3 key strategies be looked at:

- The inter-connection between law and economic dependency; often laws to land ownership, marriage, access to credit and social services etc act as barriers which prevent children and particularly youth from being economically independent;
- How law can be used to enhance the status of children and youth, in so doing the law provides the necessary support and re-enforcement for other social efforts to change cultural practices; and
- Using the law to express an appropriate policy response to activities such as commercial sex work can act as a means of protecting youth engaging in such activities instead of criminalizing their conduct and thus making them even less accessible to social support services.[162]

7.3 Other Programmatic Responses

The UNAIDS *International Guidelines*[163] recognize that a legal and human rights response to HIV and AIDS must also, by definition, encompass a broader programmatic response, in order to promote a supportive and enabling environment for children and youth by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.



The Guidelines recommend:

The UNAIDS *International Guidelines* also set out guidelines for states in order to promote a supportive and enabling environment[164] . They recommend, *inter alia*:

- States should support the establishment and sustainability of community associations to undertake peer education, empowerment programmes, positive behaviour change and social support.
- States should ensure that all women and girls of child-bearing age have access to accurate, comprehensive information and counselling about the prevention of HIV transmission, as well as access to the available resources to minimize that risk.
- States should ensure the access of children and adolescents to adequate health information and education, including information relation to HIV/AIDS prevention and care. States should ensure that children and youth have adequate access to confidential, sexual and reproductive health services, including HIV/AIDS information, counselling, testing and prevention measures such as condoms, and to social support services if affected by HIV/AIDS;
- States should ensure that child care agencies, including adoption and foster care homes, are trained with regard to HIV-related children's issues in order to be able to take into account the special needs of HIV-affected children and protect them from mandatory testing, discrimination and abandonment.
- States should support the implementation of specially designed and targeted HIV prevention and care programmes for marginalised groups.[165]
- States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatization, through media groups, NGOs, educational institutions; training programmes for service providers and community leaders.[166]

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151 UNAIDS/United Nations High Commissioner/Centre for Human Rights, *HIV/AIDS and Human Rights International Guidelines*, Second International Consultation on HIV/AIDS and Human Rights, Geneva, 1996 at p 4

152 Strode A *"The role of law in creating an environment which protects and promotes the rights of children with HIV or AIDS"* presented at the *Caring for Children Infected and Affected by HIV/AIDS Conference*, Johannesburg on the 12 September 1997 at p.2

153 *Ibid.*

154 UNAIDS/United Nations High Commissioner/Centre for Human Rights, *HIV/AIDS and Human Rights International Guidelines*, Second International Consultation on HIV/AIDS and Human Rights, Geneva, 1996 at p.4

155 UNDP HIV and Development Programme *The Role of the Law, Ethics and Discrimination*, Issues Paper No.11, New York, 1993, p.3-5.

156 See the section on Impact of Stigma and Discrimination, above.

157 Hamblin J and Reid E, *Women, The HIV Epidemic Human Rights: A Tragic Imperative*, United Nations Development Project, 1993 at p 14 - 16

158 UNAIDS *HIV/AIDS and Human Rights International Guidelines* ,Geneva, 1996, Guideline 5.

159 Geneva, 1999.

160 UNAIDS *Handbook for Legislators on HIV/AIDS, Law and Human Rights* , 1999.

161 *HIV/AIDS and Human Rights International Guidelines*, Geneva, 1996, Guideline 7

162 These recommendations have been adapted from general guidelines regarding the use of the direct and the indirect role of law to protect women issued by the UNDP in 1993.

163 UNAIDS/United Nations High Commissioner/Centre for Human Rights, *HIV/AIDS and Human Rights International Guideline*, Second International Consultation on HIV/AIDS and Human Rights, Geneva, 1996

164 *Ibid*. Guideline 8

165 *Ibid* Guideline 8

166 *Ibid* Guideline 9

EXISTING RESPONSES TO STIGMA AND DISCRIMINATION

EXISTING RESPONSES
TO STIGMA AND
DISCRIMINATION

8.1 Legal and Human Rights Responses

8.1.1 An Enabling Legal Environment

The South African government has not responded to the HIV/AIDS epidemic by introducing coercive measures against PLWAs. However AIDS service organizations and NGO's report receiving numerous complaints of violations of rights and extensive discrimination and stigma.[167]

> *"That there has been discrimination and stigma against persons with AIDS and HIV, on an enormous and debilitating scale, is beyond question. The death by stabbing and stoning of Gugu Dlamini, not twenty kilometers from here, in December 1998, provides a brutal testament of such hatred and ignorance."*[168]

Despite the almost universal ratification of the United Nations Convention on the Rights of the Child, children and youth infected with and affected by HIV/AIDS continue to suffer serious discrimination, exploitation and abuse in most countries.[169] The position of widespread discrimination and stigma in South Africa was confirmed by the National Review of all HIV/AIDS programmes undertaken by the Department of Health in 1997.[170]

In South Africa since 1994 most fundamental human rights have been entrenched in first our Interim Constitution and then our final Constitution. This has given legal protection to human rights based approaches to dealing with the epidemic.

The most important forms of legal protection for children and youth infected with and affected by HIV/AIDS against stigma and discrimination are those laws that set out the child's basic rights to non-discrimination, and to access certain services. These provisions are, for the most part, found in documents such as the Constitution and the United Nations Convention on the Rights of the Child. Several service providers point out the inadequacy of these provisions, in that they are broad principles, and do not relate specifically to HIV[171] .

Research indicates a need for more specific HIV-related policy and legislation, such as the National Policy on HIV/AIDS for Schools, to assist service providers in accessing the rights of children infected with and affected by HIV/AIDS.

International Law Obligations

South Africa has ratified a number of international conventions that protect the rights of children and youth. These place positive duties on the government to ensure that our law and social programmes meet the standards set out in such conventions. Additionally, our Constitution in section 39(1)(b) and (c) provides that the courts must use foreign law and public international law when interpreting the Bill of Rights.[172] This means that when the courts interpret provisions such as a child's right to family care[173] they must see how such rights have been interpreted in international law and in other countries.[174]

The most important of the conventions are those relating to the international bill of rights, the Universal Declaration of Human Rights and the conventions focusing on the rights of children, namely; the United Nations Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child.

The International Bill of Rights

There are 3 international covenants making up the International Bill of Rights:

- The International Covenant on Economic, Cultural and Social Rights (provides for, for example, the right to social security and adequate standard of living);
- International Covenant on Civil and Political Rights ((provides for, for example, equal rights between the sexes and no cruel and unusual punishment);and
- the Operational Protocol to the International Convention on Civil and Political Rights (this is an implementation document which provides specific guidance to states on how to fulfil the rights within the Covenant).

South Africa has ratified all of these Conventions and most of the rights are protected by our Constitution. These conventions set out a wide range of civil, political and socio-economic rights that ought to be protected by a ratifying state. They do not place a special focus on children or on discrimination based on health status.

Universal Declaration of Human Rights

This Declaration is the most extensive international document setting out fundamental human rights. It is not a legally binding document but all the countries ratifying it agree to promote universal respect and observance of human rights. It is widely used as a yardstick against which a country's compliance with human rights can be measured.

The United Nations Convention on the Rights of the Child (CRC)

This is the most important international instrument on the rights of children and youth. South Africa ratified the CRC on the 16 June 1995. The CRC is based on what are called the four basic pillars of children's rights:

- right to non-discrimination;
- right to survival and development;
- right to have the principle of the best interests of the child applied in all circumstances; and
- right to participation by the child.[175]

The CRC does not specifically refer to HIV or AIDS but its provisions are broad enough to protect children and youth infected with and affected by HIV/AIDS. Furthermore the UN Commission on Human Rights has recently passed a resolution stating that the term "other status" in international non-discrimination provisions should be interpreted to cover health status including HIV/AIDS.[176]

Article 2 of the CRC protects children from unfair discrimination (as is done by our Constitution). Other protective provisions include Article 3 which states that the interests of the child are paramount; Article 16 which protects the right to privacy; Article 18 which provides that states must provide parents or legal guardians with assistance in the performing of their child rearing responsibilities and Article 19 which protects children from abuse. Furthermore, Article 24 provides that each child has the right to "the enjoyment of the highest attainable standard of health"; Article 26 states that every child has the right to benefit from social security; Article 28 refers to a child's right to education, and Article 29 prohibits child labour.

In order to fully implement this Convention in South Africa the government has set up a National Programme of Action (NPA). This body's implementation plan was adopted by Cabinet in April 1996.[177] A Steering Committee co-ordinating the work around the NPA meets monthly.

The African Charter on the Rights and Welfare of the Child

The African Charter on the Rights and Welfare of the Child is an African Charter based on a number of international instruments. It was developed in response to a concern by many African countries that issues affecting African children were not fully covered within the CRC. This included a view that a Charter was needed which recognized:

- Customary practices such as female genital mutilation were a major threat to the rights of children;
- Socio-economic conditions such as illiteracy and their impact on rights; and
- The role of the extended family in raising children.[178]

South Africa ratified this Convention on the 7 January 2000. Viljoen argues that the Charter has three key anchoring principles:

- Non-discrimination;
- Best interests of the child; and
- The primacy of the Charter over harmful cultural practices[179] and customs.[180]

The Charter also protects the survival and development rights of children.[181]

The Constitution of the Republic of South Africa Act No 108 of 1996

The Constitution is the supreme law in South Africa. All laws must comply with its provisions. The equality clause in section 9 of the Constitution provides protection against unfair discrimination; in particular S 9 (1) – (4) provides that both the state and no person may unfairly discriminate against another person on one or more listed grounds. Some relevant grounds include those of "disability", "gender", "age" and "birth".

Furthermore the Constitution recognizes that children are a vulnerable group that needs special protection. For this reason, Section 28 of the Bill of Rights contains a specific children's rights clause, which sets out the special rights of all children.

In terms of this section 28(1)(d) protects against abuse by stating that every child has the right to be protected from maltreatment, neglect, abuse or degradation.

Section 28(1)(e) protects children from exploitative labour practices and in s28(1)(f) children are required to be protected from working or performing services that are inappropriate for their age or detrimental to their health.

Section 28(2) promotes the best interests of the child**.** It says that all actions concerning a child must be taken with due regard to that child's "best interests".

Other Laws Protecting Children from Discrimination

A number of other laws specifically protect children and youth from unfair discrimination[182], as set out in section 2.2.1 above.

8.1.2 Provision of Legal Services by the State

The Constitution provides that any person involved in a criminal case is entitled to a lawyer at state expense if without such a lawyer a "substantial injustice" would occur in the matter. Simarily any child involved in civil proceedings has a right to have access to a legal practitioner, provided by the state, if it is needed to prevent "substantial injustice".[183]

It appears that these rights extent to children who wish to bring civil claims against persons who unfairly discriminated against them. In practice the Legal Aid Board is under enormous financial pressure and legal aid for civil cases is granted but only in certain cases.[184]

8.1.3 Legal and Human Rights Services provided by NGOs

A number of national NGOs provide legal services directly to indigent children affected by HIV/AIDS. All of these NGOs provide these services free of charge. The largest of these are:

AIDS Law Project

The ALP is a NGO based at the Centre for Applied Legal Studies at the University of Witwatersrand. It was the first NGO established to respond to the legal and human rights issues relating to HIV.[185] They aim to:

- Use litigation to protect and establish rights of persons affected by HIV/AIDS;
- Offer free legal advice that will empower people living with HIV/AIDS to seek legal remedies in response to acts of discrimination;
- Carry out research on HIV/AIDS and legal rights; and
- Produce media that creates an awareness of the legal rights of people living with HIV and AIDS.[186]

Currently the ALP focuses much of its attention on a national programme with the Treatment Action Campaign to advocate for the provision of anti-retroviral treatment for HIV. Although they will assist children and youth infected with and affected by HIV/AIDS where ever possible, they do not have a specific programme dealing with the rights of children at the present time. At present, however, the ALP is considering taking on the case of a child who has been denied access to a various pre-schools on the basis of her HIV status, in order to challenge the constitutionality of this action.[187]

AIDS Legal Network (ALN)

The ALN is a national network of organizations committed to protecting and promoting the rights of all persons affected by HIV/AIDS. The ALN currently runs three programmes; first is a national para-legal training programme based in East London, the second is a national treatment programme based in Cape Town and the third a gender project based in KwaZulu-Natal.

The ALN do not have a specific programme dealing with children and are not currently lobbying around any children's issues. Furthermore they do not directly provide legal services but they will advise persons who approach them and refer them to all NGOs or law clinics.

Black Sash Advice Offices

The Black Sash aims to:

> *"enable all to recognize and exercise their human rights …. And to create a society which has effective laws and delivery systems, including comprehensive social security provision for those most in need."*[188]

The Black Sash has advice offices in Cape Town, Johannesburg, Knysna, Pietermaritzburg, Durban, Grahamstown and Port Elizabeth. They focus on assisting indigent persons access social security grants.[189]

Campus Law Clinics

Every South African university has a campus law clinic which provides legal services to indigent persons. The clinics in Pietermaritzburg, Durban, Johannesburg and the Western Cape have all taken up specific HIV/AIDS issues in the past.

Children's Rights Centre

The Children's Rights Centre is based in Durban, KwaZulu-Natal. It aims at providing training, information, advice, materials and organizational support to all organizations and individuals who promote the rights of children.[190]

Lawyers for Human Rights (LHR)
LHR is a national NGO whose vision is amongst others to be a leading human rights watchdog and to contribute towards the full implementation of socio-economic rights. They have offices in a number of centres in South Africa including Stellenbosch, Colesburg, Pretoria and Pietersburg. All of these centres provide legal services to persons in need. In their Pietermaritzburg Office they have an HIV/AIDS Project that focuses exclusively on the rights of children. The purpose of this project is to:

> *"create a legal environment which protects the rights of children affected and infected by HIV/AIDS, and to develop the capacity of children's rights organizations to advise and assist such children."*[191]

The project provides para-legal advice services, education and training, lobbying and advocacy and policy development.

Legal Resources Centre (LRC)
The LRC is an "independent, client-based, non-profit public interest law centre which uses law as an instrument of social justice"[192] . The LRC have offices in Johannesburg, Pretoria, Cape Town, Durban and Grahamstown. They have a children's rights project and have litigated around HIV issues in the past, particularly in the Western Cape.

Treatment Action Campaign (TAC)
TAC was launched on the 10 December 1998. It aims at raising public awareness around the need for affordable HIV/AIDS treatments. TAC argue that access to HIV treatments will provide an incentive for many people to volunteer for HIV testing. This will improve openness about HIV and begin to breakdown the stigma around AIDS.

TAC has launched a number of lobbying initiatives in conjunction with the Children's Rights Centre that focus on accessing treatment for children infected with HIV. They do not provide legal services unless such services are directly linked to an advocacy and lobbying campaign.[193]

National Association of People Living with HIV/AIDS (NAPWA)
The National Association of People Living with HIV/AIDS is a national non-governmental organisation acting as an umbrella body for the rights and needs of people living with HIV and AIDS.

For a number of years, NAPWA ran an 'Openness and Acceptance' Campaign aimed at encouraging and supporting people living with HIV and AIDS to disclose their HIV status in public forums.

8.1.4 Proposed Law Reform

The South African Law Commission's (SALC) Project Committee on the Review of the Child Care Act
The SALC is a body set up within the Department of Justice with the mandate of researching law reform proposals relating to current issues, such as euthanasia and HIV/AIDS. One of its current projects is an investigation into the need to replace the Child Care Act with new legislation to more holistically meet the needs of children. It is envisaged that the proposed Children's Statute will review the law relating to, amongst other things,:

- ❑ Models of care;
- ❑ Welfare grants and programmes;
- ❑ Guardianship; and
- ❑ Consent to medical treatment.[194]

The South African Law Commission's (SALC) Project Committee on Sexual Offences
In 1997, Project Committee 108 produced an Issue Paper on *Sexual Offences Against Children* which recommended reform of the laws, processes and management procedures to deal with sexual abuse against children. The Issue Paper recognized the need for review and reform of various criminal laws including the Sexual Offences Act, the Domestic Violence Act, and the Films and Publications Act. It furthermore recognized the need to improve the criminal justice process and the children's courts, in order to enable these courts to effectively deal with cases of sexual abuse against children and youth. It became clear during the course of this Project Committee's investigation that any proposed changes to the law relating to sexual offences will have a far-reaching effect on the position not only of children but of adults as well. As a result and because of various requests the Commission decided to expand the scope of the investigation to include sexual offences against adults. The investigation was subsequently renamed 'sexual offences'.

In October 1999, this Project Committee brought out Discussion Paper 85 for comment, entitled *Sexual Offences: The Substantive Law,* as part of a 3 part series. The second discussion paper due out will deal with matters of process and procedure, while the third will address the controversial issues of adult commercial sex work (prostitution) and adult pornography. The Discussion Document recommends, amongst other things:

- A set of guiding principles for dealing with sexual abuse against children;
- The adoption of a comprehensive new sexual offences act which deals with sexual abuse against children, youth and adults, and contains issues of both substantive and procedural laws;
- Broader definitions of rape to ensure that acts other than vaginal penetration are included, and that sexual penetration of a child below the age of 12 years is considered 'rape';
- Creating a new statutory offence of 'child molestation' prohibiting sexual acts with children below 16 years of age; as well new statutory offences relating to 'persistent sexual abuse of a child', and 'compelled sexual acts';
- A prohibition on the 'sexual exploitation of children'; including trafficking of children, as well as measures to combat sex tourism and other forms of commercial sexual exploitation of children; and
- A prohibition on 'cultural and religious practices harmful to children'.

Draft National Health Bill
The Department of Health has developed draft legislation which aims at creating a national health system and providing South Africa with the best possible health services within the given resources. This provides under the general rights of users in s 8:

> *"Every user is entitled to respect of their rights to, human dignity and privacy, and shall not unfairly discriminate on one or more grounds, including ……age, educational level, level of income and ability to pay for health services, disability, health status………"*[195]

8.2 Programmatic Responses aimed at Reducing Stigma and Discrimination against Children and Youth

8.2.1 Programmes initiated by the Department of Health

Key initiatives established by the Department of Health dealing with stigma and discrimination against people living with HIV/AIDS are detailed below:

Strategic Plan

The Department of Health's HIV/AIDS and STDs Strategic Plan for South Africa: 2000 – 2005 provides for four priority areas; prevention, treatment, care and support, research and human and legal rights. Priority area four dealing with legal and human rights sets out two goals:

- ❑ To create an appropriate social environment;[196] and
- ❑ To develop an appropriate legal and policy environment.

Combating discrimination clears fall within the scope of both of these goals but it is uncertain as to whether the Department has begun to implement these activities, particularly as the Department does not currently have any staff member dealing directly with the legal and human rights issues relating to the epidemic.[197] .

Beyond Awareness

During 2000, the Department of Health's *Beyond Awareness Campaign* prioritised stigma and discrimination against people living with HIV/AIDS as a core focus in all media and awareness activities relating to HIV and AIDS, in an attempt to ensure increased awareness of the rights of all people living with HIV/AIDS. This included the production of a book called *Living Openly: HIV Positive South Africans tell their Stories* in an effort to create more awareness and openness around HIV and AIDS.

Partnership Against AIDS

On the 9th October 1998, the then Deputy President Thabo Mbeki launched the "Partnership Against AIDS" as a means of encouraging co-operation between various sectors within society to respond to the epidemic. He stated:

> *"We shall work together to care for those living with HIV/AIDS and for the orphans. They must not be subjected to discrimination of any kind. They can live productive lives for many years. They are human beings like you and me. When we lend a hand, we build our own humanity, and we remind ourselves that, like them, each one of us can become infected"*

The Partnership Against AIDS has resulted in various sectors, including for example the SABC, including HIV/AIDS awareness messages in their programmes and projects, some of which have dealt with stigma and discrimination on the basis of HIV and AIDS.[198]

The GIPA Programme

UNAIDS has worked closely with government and the private sector to establish the GIPA Programme, ('greater involvement of people living with HIV and AIDS') a programme which aims to place skilled people living with HIV and AIDS within organizations and government departments to act as advocates for the rights and needs of people living with HIV/AIDS, as well as to assist such organizations in developing their response to HIV and AIDS.[199]

8.2.2 NGO Programmes

Very few interview respondents were aware of any programmatic responses to discrimination and stigma against children and youth infected with or affected by HIV/AIDS. Most saw the most useful programmes as being:

- TV programmes aiming at 'breaking the silence' around HIV eg *Beat-It* on e-TV, and *Positivity* on SABC;[200]
- Self-esteem programmes which aimed at building the self-confidence of children and youth infected with and affected by HIV/AIDS. For example at God's Golden Acre in KwaZulu-Natal, children and youth participate in weekly dance and singing classes as a way of building up their self image, which has often been impaired by discrimination and stigma;[201]
- Workshop materials developed by Save the Children (UK) on stigma and discrimination;[202] and
- The AIDS Legal Network national para-legal training programme that includes a session on discrimination, as well as a session on the rights of children and youth infected with and affected by HIV/AIDS.[203]

Some respondents reported that they were developing materials in the near future on this topic. For example:

- The Child Rights Center reported that they would be developing a section on discrimination for their Child Rights Manual. This should be ready by the end of 2001;[204] and
- Thandanani is developing a training manual for youth and children; this will include a chapter on discrimination and stigma. This manual will be used for training members of Child Care Committees (committees established within the communities to monitor and identify children and youth in need) and communities.[205]

8.2.3 Programmes within Other Countries

Given the limits of the research report and the difficulties experienced in obtaining information from other African countries, this report is unable to assess the precise impact or effectiveness of programmes on stigma and discrimination within other countries. However, innovative programmes were identified, and are listed below for their informative value in determining recommendations for a South African response.

Governmental commitment to openness and awareness around HIV/AIDS

Leaders of various African nations have recognized the importance of a high level acknowledgement of and openness around HIV/AIDS issues. In their speeches, more and more African leaders are confronting the reality of HIV and AIDS and declaring their intention to do everything possible to stop the spread of the epidemic:

- Almost a decade ago in Uganda President Yoweri Museveni reversed his opposition to condoms and began talking openly about AIDS, galvanizing a co-ordinated national response to the epidemic that is argued to have brought about the significant fall in HIV in the country;
- In Mozambique, public acknowledgement of HIV and AIDS increased with the announcement that Boaventura Machel, the brother of Mozambique's first president on independence, had died of AIDS;
- In Botswana, President Festus G Mogae prioritised HIV/AIDS as a problem to be tackled in his 5 year term, and announced in 1998 a government monthly allowance for people living with HIV and AIDS who passed a certain means test;
- In Kenya, President Danile Arap Moi reversed his long-standing opposition to condom use, stating that "Anything that can be said or done to halt the progress of the disease must be said and done";

- In the United Republic of Tanzania, President Benjamin Mkapa said, in his New Year Address, that "We must openly declare war on this killer disease … Let us not feel shy to talk about it and look for means to solve the problem";
- In Nigeria, President Olusegun Obasanjo of Nigeria inaugurated the National Action Programme Committee on HIV/AIDS with the following words: "We are determined not to allow our country to be overwhelmed by AIDS".[206]

Anti-Discrimination and Protective Laws

There is little evidence that other African countries have dealt with law reform around HIV and AIDS, particularly in respect to rights of children and youth infected with and affected by HIV and AIDS.

In 1994, the United Nations Development Programme's Regional Project on HIV/AIDS and Development, in Dakar, Senegal organized an Inter-Country Consultation on Ethics, Law and HIV. The outcome of the consultation was the establishment of the African Network on Ethics, Law and HIV, aimed at uniting national networks for the promotion of and legal principles related to HIV and AIDS. The Network had 4 principle objectives:

- Connecting persons, organizations and national networks to share experiences, resources and information on HIV/AIDS;
- Promoting human rights, empowering persons, developing guidelines, making representations and supporting national and international law reform;
- Meeting the needs of existing national networks, assisting emerging networks and assisting with the formation of new networks;
- Collaborating with other African, regional, national and international networks in achieving its aims and objectives.

The African Network on Ethics, Law and HIV supported the development of national networks in various countries, such as Tanzania, Uganda, Malawi, Senegal and Cote d'Ivoire. However, there is little evidence of law review or reform in terms of anti-discrimination or protective provisions for children and youth infected with and affected by HIV/AIDS, and at this point the African Network on Ethics, Law and HIV appears to be non-functional.

Some examples of anti-discrimination and protective laws enacted in other countries include the following:

- In Columbia and the Philippines, children's health rights have been codified to create an accessible document detailing the health rights of all children;[207]
- In Mexico a law for the Prevention and Control of Infection by HIV was passed in 1995, addressing issues such as confidentiality, the prohibition of mandatory HIV testing, and the prohibition of discrimination on the basis of HIV/AIDS in specific areas such as marriage, employment, education, medical treatment, accommodation, immigration or emigration. The law is enshrined in the Constitution and takes precedence over provincial or State laws;[208]
- Argentina passed a national law on AIDS promoting respect for human rights and prohibiting unfair discrimination, in 1990;[209]
- In terms of the Philippines *AIDS Prevention and Control Act*, 1998, the rights of people with HIV/AIDS in respect of confidentiality, HIV testing only with informed consent, non-discrimination, HIV/AIDS education at school and tertiary level and at health services, is enshrined.[210]

Access to Legal Remedies

- In India, a two-day workshop was held with the judiciary in order to sensitise judges and create awareness of HIV/AIDS issues that may emerge in court[211]

Promoting a Supportive and Enabling Environment for Vulnerable Groups

- In Kampala, Uganda the independent radio station Capitol Radio provides a popular forum for adolescents to openly discuss sex and HIV/AIDS problems with experts[212];
- In Lusaka, Zambia, 52 young people were trained as peer counsellors within primary health care clinics to provide support services, and to link staff with young clients, leading to improved respect between adults and young people in the community and breaking the silence on discussions around sex[213];

Use of the Media

- In Australia, the government ran public education campaigns from 1992-1994 called *HIV Doesn't Discriminate, People Do* and *Don't judge what I can do by what you think I can't*. The first campaign challenged attitudes and stereotypes by focusing on the fact that HIV could not be transmitted casually. The second campaign was based on research which documented the underlying causes of discrimination, found to be fears associated with HIV transmission, drug use, sexuality and homophobia. Health care workers were identified as setting the parameters of community understanding of the epidemic. The campaigns were followed up with tracking surveys that indicated a gradual decrease in discriminatory attitudes towards people living with HIV/AIDS and vulnerable groups.[214]
- In *AIDS Analysis Africa* (Oct/Nov 2001) Stally reports that the Southern African AIDS Information Dissemination Service (SAfAIDS) hosted a 3 day workshop for members of the Kenyan media to explore the extent of stigma in HIV/AIDS media and to examine the media's role in reducing HIV-related stigma and discrimination. The workshop raised key issues such as personal attitudes and beliefs of members of the media; language, terms and terminology that impacts on HIV-related stigma and discrimination; the importance of a multi-sectoral approach to dealing with HIV and AIDS; and the role of the media in a national response to HIV and AIDS. The participants developed the following recommendations as a result of the workshop: (a) the need for training for media practitioners on HIV/AIDS and stigma; (b) the need for developing a resource base where journalists can access information and resources for balanced reporting on HIV and AIDS; and (c) the need to develop a media policy on HIV/AIDS.

8.3 Problems with the Current Responses aimed at Reducing Stigma and Discrimination against Children and Youth

8.3.1 The Legal Response

Many of the persons interviewed commented that currently the law was one of the primary responses to discrimination, and that as such this was insufficient to protect children and youth from discrimination:

- Children, youth and their care givers were not aware of their rights;[215]
- Social and institutional support is not provided when implementing laws;[216]
- A focus was needed on social programmes to change underlying attitudes;
- The lack of state support for children who wanted to use their rights;
- Further law reform was needed in the form of policies within sectors (such as the welfare sector) to protect the rights of children and youth; and
- High profile cases were needed to demonstrate the effectiveness of the law in declaring certain forms of beahviour to be unacceptable.

Ms Aadnesgaard from Thandanani noted :

> *"The law will never be sufficient as the real issue is whether or not the law is being implemented. Our laws in South Africa are good but communities have a limited understanding of them."*

It was also reported that it was in any situation difficult for a child or youth to utilize legal remedies, as adults frequently did not believe them or take them seriously. For example the Children's Rights Center said:

> *"We had a case of a 14 year old boy being beaten very severely by his father; he tried three times to lay a charge against his father but the police refused to take a statement from him as he was known to be 'naughty' and deserved to be punished."*[217]

8.3.2 Programmatic Responses

It is clear that broader programmatic responses are required to combat stigma and discrimination against children and youth infected with and affected by HIV/AIDS, given the issues raised by service providers who were interviewed by researchers. For example:

- The complexity of the causes of discrimination was seen as a key obstacle to reducing stigma and discrimination.[218]
- Some also saw cultural issues as an obstacle.[219]
- Others reported that the silence around HIV or AIDS was the biggest obstacle to reducing discrimination.[220]

From our research and the interviews with the key role-players it is clear that the other problems with the programmatic responses are:

- Few programmes exist which focus on eliminating HIV discrimination[221] ;
- Gerrit Te Haar noted that many different forms of prejudice are based for example on racial, gender and other stereotypes were deeply entrenched in all of our communities. These are difficult to reason away as they are an emotional response and one needs to deal with the underlying cause of such a response.[222]
- Some work such as self-esteem programmes indirectly assist children to deal with discrimination but no other programme helps the children translate this into steps they can take to deal with discrimination; and
- Key service providers such as the Departments of Health, Welfare and Education do not appear to be running broad based anti-discrimination programmes.

[167] For example Lawyers for Human Rights reported that they had received complaints of employee's being tested for hepatitis B but then finding out that their blood was tested for HIV without their knowledge; day care centres refusing to take HIV positive children; and medical aid schemes refusing to allow people living with HIV/AIDS to join the fund. Information supplied on the 4 December 1998; Barrett Grant et al *Children HIV/AIDS and the Law Survey* Save the Children (UK), January 2001 found that 33% of all service providers surveyed reported having had to deal with instances of discrimination against children affected by HIV/AIDS.

[168] Cameron J '*The Deafening Silence of AIDS'* First Jonathan Mann Memorial Lecture: XIII International

AIDS Conference: July 2000 at para.8
[169] Office of the High Commissioner for Human Rights *Children's Rights: Creating a Culture of Human Rights* Basic Information Kit No. 3, April 1998.
[170] *National STD/HIV/AIDS Review Report,* July 1997 at p37
[171] Interview with Sonja Giese, Co-ordinator, Child Health Policy Unit, 29 January 2001.
[172] In *S v Makwonyane* 1995 (3) SA 391 (CC) the court held that binding and non-binding forms of public international law could be used to assist a court in determining the correct interpretation of a provision. See paras 36 -37
[173] s 28(1)(b) of the Constitution, Act 108 of 1996
[174] For example in the case of *Fraser v Children's Court, Pretoria North*, the court looked at the rights of unmarried fathers during an adoption, in foreign jurisdictions such as the USA, Canada and Britian
[175] Barrett Grant C, Dube T, Malunga K, Strode A *Children Living with HIV/AIDS in South Africa: A Legal Resource* Save the Children (UK) 2001
[176] Information supplied by Ms Miriam Maluwa, Law and Human Rights Adviser to UNAIDS, Geneva, participating in a stigma-aids discussion forum at **stigma-aids@hdnet.org** on the 14 August 2001
[177] Olivier M 'The Status of International Children's Rights Instruments in South Africa' in Davel CJ (ed*) Introduction to Child Law in South* Africa, Juta 2000, at 200. The NPA has identified 8 key areas of intervention. These include; infra-structure, special protection measures, education, early childhood development, child and mental health, nutrition, leisure and recreation and peace and non-violence. HIV/ AIDS is regarded as a cross-cutting issue within the Plan and is therefore to be integrated into all of the above areas.
[178] Viljoen F 'The African Charter on the Rights and Welfare of the Child' in Davel CJ (ed*) Introduction to Child Law in South* Africa, Juta 2000, at 216 -217
[179] See Articles 3, 4 and 13 respectively
[180] Viljoen F 'The African Charter on the Rights and Welfare of the Child' in Davel CJ (ed*) Introduction to Child Law in South* Africa, Juta 2000, footnote 109 at 219
[181] *Ibid* at 220 - 222
[182] For example, the *National Policy on HIV/AIDS for Learners and Educators* detailed in section 2.2.1 above.
[183] S 35(3)(g) and s28(1)(h) of Act 108 of 1996. The rights to a lawyer in a criminal trial would extend to children.
[184] The Legal Aid Board has taken a policy decision to focus on the rights of women and children, therefore in all likelihood cases involving discrimination involving children would be funded. Information supplied by Mr Brendon Christian, Candidate Attorney, Campus Law Clinic, University of Natal, Durban on the 18 October 2001
[185] The ALP was established by Justice Edwin Cameron in 1993
[186] *AIDS Law Project Annual Report* 1999
[187] Interview with Jennifer Joni, Attorney, AIDS Law Project, 20 October 2001. Also see footnote 107 for more details of the particular case.
[188] *The Black Sash Trust Annual Report* 2000
[189] *Ibid*
[190] *Children's Rights Centre Report* 1999
[191] *Children Affected and Infected by HIV/AIDS: Project Newsletter* Lawyers for Human Rights 2001
[192] Information supplied by Ms Sue Clarke, Legal Resources Centre, Durban on the 16 October 2001.
[193] For example TAC, ALP and the Children's Rights Centre have launched an application in the Pretoria High Court relating to the government's failure to supply HIV positive pregnant mothers with neviripine to prevent mother to child transmission of HIV. Information supplied in a group e-mail from the Children's Rights Centre on the 15 October 2001
[194] South African Law Commission Issue Paper 13, Project 110: Review of the Child Care Act First Issue Paper 14 July 1998
[195] Draft National Health Bill 10 June 2000
[196] This includes activities relating to a national campaign on openness and acceptance, the development of mechanisms to monitor human rights abuses and mechanisms to redress human rights abuses
[197] Information supplied by Ms Ria Schoeman, National AIDS Programme, Department of Health on the 19 October 2001
[198] Information supplied by Ms Ria Schoeman, National AIDS Programme, Department of Health on the 19 October 2001
[199] *Idid*
[200] Interview with Cati Vawda, Co-ordinator of the Children's Rights Center 24 January 2001; Interview with Musa Njoko, Presenter, SABC Positivity, 29 January 2001.
[201] Interview with Gerrit Te Haar, Chairperson of God's Golden Acre, KwaZulu Natal, 26 January 2001
[202] Workshop One (unpublished) October 2001
[203] Information supplied by Ms Ncumisa Nongongo, National Trainer, AIDS Legal Network on the 18 October 2001
[204] Interview with Cati Vawda, Co-ordinator of the Children's Rights Centre, 24 January 2001
[205] Interview with Linda Aadnesgaard, Director of Thandanani, 19 January 2001
[206] UNAIDS *Report on the Global HIV/AIDS Epidemic* June 2000, Geneva at 38-39.
[207] Barrett K, McKerrow N and Strode A *Consultative Paper on Children Infected and Affected by HIV/AIDS* Research conducted for the SALC Project Committee on the Review of the Child Care Act, January 1999.
[208] UNAIDS *Handbook for Legislators on HIV/AIDS, Law and Human Rights*, Geneva, 1999 at 37.
[209] *Ibid.*

[210] *Ibid.*
[211] *Ibid.* at 98
[212] *Ibid.* at 96
[213] *Ibid.*
[214] *Ibid* at 99.
[215] Interview with Cati Vawda, Co-ordinator of the Children's Rights Centre, 24 January 2001 and Nolundi Ndundane, Lecturer at the University of the Transkei, 31 January 2001
[216] Interview with Linda Aadnesgaard, Director of Thandanani, 19 January 2001
[217] Interview with Cati Vawda, Co-ordinator of the Children's Rights Centre, 24 January 2001
[218] Interview with Cati Vawda, Co-ordinator of the Children's Rights Centre, 24 January 2001
[219] Interview with Cati Vawda, Co-ordinator of the Children's Rights Centre, 24 January 2001
[220] Interview with Linda Aadnesgaard, Director of Thandanani, 19 January 2001
[221] Interview with Cati Vawda, Co-ordinator of the Child Rights Centre, 24 January 2001, Linda Aadnesgaard, Director of Thandanani, 19 January 2001 and Ncumisa Nongongo, National Training Co-ordinator, AIDS Legal Network, 19 January 2001
[222] For example Nolundi Ndundane reported "We need to empower the girl-child and women to change their cultural destiny through for example writing a will so as to prevent land grabbing by male relatives." Interview with Ann Strode on the 31 January 2001

GAPS AND LESSONS LEARNED

GAPS AND LESSONS LEARNE

Save the Children

In evaluating the current response to stigma and discrimination in South Africa we have analysed the existing response in South Africa, with the ideal response articulated by UNAIDS. This has highlighted a number of gaps and lessons learned.

9.1 Developing our Understanding of Stigma

9.1.1 Lessons Learned

A number of lessons have been learned regarding our understanding of stigma through this research. These include:

The Nature of Stigma

- Stigma is a social risk for children and youth infected with and affected by HIV/ AIDS.[223]
- Stigma, as a social risk facing children and youth, heightens their vulnerability to ill-health, poverty, loss of self-esteem, and even crime and suicide;[224]
- Stigma takes a number of forms, and is found within the family, communities and when children where attempting to access services;
- There are many underlying causes of stigma including fear, ignorance about trans-mission, and a lack of openness.

The Impact of Stigma

It impacts on children in a number of different ways from social ostracisation to increased child labour. In particular this report has established that stigma diminishes the resilience of children by impeding the various protective factors in a child's life.[225]

Responding to Stigma

The resilience of a child to a social risk such as HIV stigma can be enhanced through ensuring that the following protective factors are developed or enhanced:

- The child's right to equality and dignity to enhance personal characteristics such as self-esteem;
- The child's right to parental care or appropriate alternative care to ensure that the have access to a family that is able to care and provide for them; and
- Support networks eg supportive peers groups and ways of enforcing rights.[226]

Therefore, in our response to stigma we must ensure:

- The protective factors identified are integrated into any programmatic response dealing with the underlying causes of stigma. Such factors must developed into programmes of their own addressing self-esteem problems etc affecting children vulnerable to stigma due to HIV;
- The law must be used as a tool in reducing incidents of stigma and in responding to serious incidents of stigma and discrimination.

9.1.2 Gaps

Programmes Relating to Stigma

- There is no integrated national strategy and programme on openness and acceptance. It is arguable that if more high profile persons were open, this would reduce the levels of stigma and discrimination.[227]
- The few programmes that do exist do not focus on stigma and discrimination against children and youth infected with and affected by HIV/AIDS, and in particular, the rights of the girl child.
- Creative education and training programmes aimed at changing attitudes are not in place.
- A national treatment programme needs to be introduced to care for people living with HIV/AIDS as it is argued that this will increase openness and acceptance programmes, and provide an incentive for HIV testing and disclosure.[228] [229]

Additional Research

Additional information on discrimination and stigma is needed as we did not really understand why discrimination and stigma continues despite the widespread awareness around HIV/AIDS and the scale of the epidemic.[230]

9.2 Developing our Understanding of Discrimination

9.2.1 Lessons Learned

The Nature of Discrimination based on HIV Status

Discrimination is when stigmatizing behaviour results in a children and youth infected with and affected by HIV being treated differently on the basis of their known or perceived HIV status, or on the basis of some link with HIV and AIDS.

Legal Protection against Unfair Discrimination

- Unfair discrimination is prohibited in law.
- Our law does not specifically state that discrimination on the basis of "HIV status" is unfair, but the courts have recognized that discrimination due to being HIV positive is unfair.[231]
- Laws protecting against unfair discrimination will only be effective if:
  - (1) Resources are allocated towards the full implementation of such laws; and
  - (2) Resources are allocated to services which assist children and youth access such laws, for example through programmes which make children/youth aware of the law and support their ability to use the law through programmes such as the provision of legal aid.

Response to Unfair Discrimination

- We cannot simply legislate away discrimination as it has complex underlying causes and therefore a legal response needs to be one strand of a holistic anti-discrimination programme.[232]
- Any legal response needed to be supported by social services.
- Without knowledge of a child's rights and information on how to enforce them, children will not use the law to respond to discrimination.

9.2.2 Gaps

Implementation of Laws

- A core problem identified regarding legal rights is their lack of implementation. In some instances laws have been passed but not implemented (for eg the 'Equality legislation') in other instances although laws are operational, insufficient resources have been set aside to support social programmes to help people access the law.
- Furthermore, institutional support for laws is weak. For example, there are insufficient social workers who are able to travel into townships and to the places where children are most in need. Furthermore a lack of training exists to ensure that social workers and other service providers are sensitized to the issue and assisted with dealing with their own prejudices.[233]

Law Reform

Although South Africa has responded to the HIV/AIDS epidemic by creating a comprehensive legal and policy framework to deal with unfair discrimination a number of gaps still exist. These include:

- A need to create more specific HIV-related policy, such as the National Policy on HIV/AIDS for Schools, to assist service providers in accessing the rights of children infected with and affected by HIV/AIDS. This is required particularly in areas of welfare and health;
- A national welfare policy on fostering and adoption which ensures that children are not discriminated against;
- Laws that protect children against sexual abuse;[234] and
- Disability laws that recognize HIV as a disability and provide protection for children;'[235] alternatively, specific recognition of HIV status and AIDS as a ground for non-discrimination.[236]

Responding to Discrimination

- There is no national litigation strategy aiming at establishing and enhancing the rights of children and youth infected with and affected by HIV/AIDS to be protected from unfair discrimination[237] and high profile cases relating to discrimination are not being used as away of both directing media attention to the problem of discrimination against children and youth, and establishing in the public mind that discriminatory behaviour is unacceptable.
- There is a low level of knowledge of rights, and insufficient programmes include information on stigma discrimination relating to HIV and how to deal with it. There is also a lack of national awareness programmes on the importance of documents that are needed to enforce rights for example, the importance of a birth certificate in obtaining social welfare grants.
- Limited materials are available for training on discrimination.[238]

[223] See 2.4 of this Report

[224] Summary of Presentation made at *Stigma and HIV/AIDS in Africa: Setting the operational Research Agenda* by Stefan German, the HIV/AIDS Programme advisor to the Salvation Army in Zimbawe, and posted on stigma-aids@hdnet.org on 6 June 2001. In this presentation Mr German highlighted how stigma led to crime, alcohol and drug abuse, street children, chronic traumatized adults, child prostitution, violent behaviour, severe depressions, suicide and increased HIV infections.

[225] *Ibid.*

[226] *Ibid.*

[227] Interview with Cati Vawda, Co-ordinator of the Children's Rights Centre on the 24 January 2001 and Gerrit Te Haar, Chairperson of God's Golden Acre, 26 January 2001

[228] When Justice Edwin Cameron disclosed to the Judicial Services Commission that he was living with AIDS, he said he was able to speak openly about his infection as: "The choice to speak is available to me for very particular reasons; because I have a job position that is secure; because I am surrounded by loved ones, friends and colleagues who support me, and because I have access to medical care and treatment that ensures that I remain strong, healthy and productive." Reported in *AIDS Bulletin* July 1999

[229] The Child Rights Center and Thandanani spoke of their frustration in dealing with the Department of Home Affairs who did not understand the needs of children or youth or provide any assistance to them in obtaining critical documents such as identify documents and birth certificates

[230] Interview with Cati Vawda, Co-ordinator of the Children's Rights Centre, 24 January 2001, Ms Ncumisa Nongongo, National Co-ordinator of the AIDS Legal Network, interviewed on the 19 January 2001, confirmed this point

[231] See section 2.2.1 of this Report

[232] Interview with Cati Vawda, Co-ordinator of the Children's Rights Centre, 24 January 2001 and Gerrit Te Haar, Chairperson of God's Golden Acre in KwaZulu Natal, 26 January 2001

[233] Interview with Nolundi Ndundane, Social Work Lecturer at the University of the Transkei, 31 January 2001

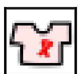
[234] Currently the SALC is busy re-drafting the Sexual Offences Act but it is uncertain as to when this process will be completed and it is unlikely that it will be passed by parliament before the middle of 2003.

[235] In the *Hoffman* case the Applicant (Mr Hoffman) argued that HIV ought to be recognized as a disability by the court but in its judgement the court choose to avoid this issue and simply found that the discrimination was unfair without stating on what basis the court had made its decision.

[236] For instance, as set out in section 2.2.1 of this report, the Equality Act makes provision for the inclusion of HIV/AIDS as a separate ground for non-discrimination, if recommended by the Committee.

[237] Barret Grant, Strode, Dube and Malunga *Legal Audit into all Laws and Policies relating to Children and Youth Affected by HIV/AIDS* Save the Children (UK) March 2001.

[238] See section 8.2.2 where the materials relating to discrimination are discussed



PRELIMINARY RECOMMENDATIONS

10.1 Legal and Human Rights Responses

The following recommendations are made:

10.1.1 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 non-discrimination. 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.

Relevant laws and policies to deal with specific issues could include:

- Inclusion of specific protection of the rights of children and youth infected with and affected by HIV/AIDS in the new children's legislation (currently being developed by the South African Law Commission Project Committee on the Review of the Child Care Act) to ensure their rights to equality, non-discrimination, privacy, and access to services;
- A National Policy on HIV/AIDS, Adoption and Fostering to protect the rights of children and youth infected with and affected by HIV/AIDS to equality and non-discrimination, and to access appropriate alternative care;
- The development of a Charter of Children's Health Rights that includes the right not to be unfairly discriminated against on the basis of HIV status;[239]
- The improvement of laws, policies and procedures relating to sexual offences against children, as is currently being undertaken by the South African Law Commission Project Committee 107; and
- The general improvement of processes, procedures and support systems to ensure the implementation of the law.

10.1.2 Access to Legal Remedies

The need to improve access to legal remedies for children and youth infected with and affected by HIV/AIDS is a priority. Our research shows that, despite access to legal services provided by the state, as well as legal and paralegal services provided by various non-governmental organizations, children and youth are clearly still unable to access appropriate redress for HIV-related stigma and discrimination.

The following preliminary recommendations are made:

- Creating awareness of existing legal remedies that are available to assist children and youth;
- Creating awareness of legal organizations available to assist children and youth;
- Increasing legal services dealing with the rights of children and youth infected with and affected by HIV/AIDS, which could be achieved by ensuring that all legal, paralegal and human rights organizations are trained specifically on children, HIV/AIDS and the law;
- Building the capacity of statutory bodies, such as the SAHRC, to respond;
- Increasing lobbying and advocacy for the rights of the child, and access to resources, in the context of HIV and AIDS;
- A need for non-governmental organizations to co-operate in developing a litigation strategy aiming at high-profile cases dealing with discrimination against children and youth infected with and affected by HIV/AIDS;
- A need for judicial training for magistrates and judges on the rights of, and discrimination against children and youth infected with and affected by HIV/AIDS[240];
- The need to make judicial processes and procedures child-friendly, so that they are responsive and sensitive to the needs of children and youth infected with and affected by HIV/AIDS;

This was supported by the AIDS Law Project who further recommended that penalties should be imposed for HIV discrimination[241] .

10.1.3 Legal Literacy

The continued existence of stigma and discrimination, despite the progressive and protective legal framework in place in South Africa, highlights a need for 'non-legal' remedies to accompany any law review or reform initiatives. This includes the need for:

- Increased awareness around the rights of children and youth infected with and affected by HIV/AIDS broadly, and within key service sectors;
- Increased media campaigns promoting acceptance, tolerance and support in relation to children and youth infected with and affected by HIV/AIDS; and
- Increased media dealing with prevalent myths and misconceptions those continue to prevail regarding the transmission of HIV.

In a similar vein the AIDS Law Project recommended that a positive image of people living with HIV/AIDS should be created through positive role models, offering incentives for people living with HIV/AIDS to be open about their HIV status, and the provision of treatment.[242]

The AIDS Law Project in their report recommend that basic education on human rights and how people's dignity is violated by intolerance and stigma. They quote Jonathan Mann:

> *"Awareness of the personal and societal importance of dignity can be readily translated into concrete action at individual, community and institutional level. Within their own spheres of activity and influence, people can promote and protect dignity; in other words, by being aware of the manifold forms and expressions of dignity violations people can learn to avoid the subtle, pervasive and often unrecognized ways in which others may not be "seen", their individual identity respected, their personal space invaded, or in their sense of self-humiliated."*[243]

10.2 Other Programmatic Recommendations

10.2.1 Social Programmes

In *Children on the Brink – Strategies to Support Children Isolated by HIV/AIDS*[244] Hunter recommends a number of different strategies to reduce stigma and discrimination:[245]

- The introduction of social programmes to reduce fear;[246]
- 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.

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 experience from Australia[247] shows that thorough preliminary research can result in awareness and media campaigns that directly target the source of stigma and discrimination, and in so doing, can deal with the underlying causes of stigma and discrimination against children and youth.

Preliminary recommendations include:

- 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;

10.2.2 Access to Health Services

The UNAIDS *HIV/AIDS and Human Rights International Guidelines* recognize that the provision of appropriate health care information and education, as well as services such as HIV testing, counselling, reproductive health services and treatment and care programmes, is a key factor in ensuring that children and youth infected with and affected by HIV/AIDS are less vulnerable.

In South Africa, providing treatment to all infected children has been recognized as a key issue, as an incentive for families to come forward for testing, treatment, care, support.[248] This openness would in turn assist with de-stigmatizing the epidemic. Richter further recommends that voluntary testing and counselling services be extended as this would enable more people to become aware of their HIV status and in turn it would reduce the stigma attached to HIV/AIDS.[249]

Preliminary recommendations include:

- 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; and
- Ensuring that children and youth have access to child- and youth-friendly health care services that promote their dignity and self-respect.

[239] Barrett K, McKerrow N and Strode A, *Consultative Paper on Children Infected and Affected by HIV/AIDS* Research conducted for the South African Law Commission Project Committee on the Review of the Child Care Act, January 1999 at p 43.

[240] As was done in India, see section 8.2.3 above. In an interview with Ann Skelton of the Department of Justice, on 19 October 2001, she indicated that the Department of Justice are planning a workshop with magistrates to alert them to the needs and problems of children affected by HIV/AIDS, in particular with regard to access to placement options for such children.

[241] Richter M *Preliminary Assumptions on the Nature and Extent of Discrimination against PWA in South Africa* Research Conducted for the AIDS Law Project, 2001, at footnote 5 p39

[242] *Ibid* footnote 5 at p37 -38

[243] *Ibid* footnote 5 at p36

[244] USAID, 1997

[245] *Ibid* at 10 - 11

[246] This recommendation was also made by Clacherty and Associates in *The Role of Stigma and Discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS* Research conducted for Save the Children (UK), 2001 at 81.

[247] See section 8.2.3

[248] Interview with Cati Vawda, Co-ordinator of the Children's Rights Centre, 24 January 2001

[249] Richter M *Preliminary Assumptions on the Nature and Extent of Discrimination against PWA in South Africa* Research Conducted for the AIDS Law Project, 2001, at footnote 5 p37

CONCLUSION

CONCLUSION

"The way in which we define a problem determines how we approach its solution. Its time to replace the notion that HIV is just a virus whose spread is affected by risk factors and biological co-factors with a broad concept of vulnerability to heterosexual HIV transmission. This shift will entail augmenting our existing strategies for prevention with programmes and policies that address the central inequalities underlying the vulnerability to HIV/AIDS."[250]

This research project has attempted to redefine the way in which we approach stigma and discrimination faced by children and youth infected with and affected by HIV/AIDS. This however has been a difficult process due to the lack of other similar research focusing on children. We trust that it will help in starting a process of identifying possible solutions to stigma and discrimination which will in turn have the long term effect of reducing the vulnerability of children and enhancing their resilience.

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:

- 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
- 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 recognise that this is simply the first step in a long journey: as Steve Biko said:

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

[250] Mann cited in Abdool Karim QA 'Women and AIDS: the imperative for a gendered prognosis and prevention policy' *Agenda* No 39 1998 at 21