

# Aiding intolerance and fear: The nature and extent of AIDS discrimination in South Africa<sup>1</sup>

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People who are living with HIV/AIDS are one of the most vulnerable groups in our society. Notwithstanding the availability of compelling medical evidence as to how this virus is transmitted, the prejudices and stereotypes against HIV positive people still persist. In view of the prevailing prejudice against HIV positive people, any discrimination against them can, to my mind, be interpreted as a fresh instance of stigmatisation and I consider this to be an assault on their dignity. The impact of discrimination on HIV positive people is devastating. (Justice Ngcobo *Hoffmann v South African Airways*<sup>2</sup>)

## 1 INTRODUCTION

Prejudice, irrational fears and ignorance form the roots of discrimination. Historically, South Africa had mainly to grapple with the racism, sexism and homophobia of its people. However, it has only been fairly recent that a new type of discrimination has emerged in South Africa – that of bias and intolerance against people living with HIV/AIDS (PLWAs). Like all the other forms that injustice takes, AIDS discrimination impairs the quality of life of its targets, hampers their functioning as equal citizens in society, and impacts negatively on how other people value them and the way in which they perceive themselves.

Current estimates are that one out of every nine South Africans, or 4.7 million South Africans in total, had been infected with HIV by the end of 2000.<sup>3</sup> This means that a large number of South Africans could already have experienced some form of discrimination based on their HIV status, and that many more have the potential to become vulnerable to rejection, stigma and prejudice once their status becomes known to others. Discrimination can be seen as unfairly disadvantaging a person on the basis

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1 This article is based on research prepared for a combined tender by the AIDS Law Project and Strategy & Tactics. The tender on AIDS discrimination in South Africa was commissioned by the Department of Health (full report forthcoming).

2 2001(1) SA 1 (CC) at para 28.

3 'National HIV and Syphilis sero-prevalence survey of women attending public antenatal clinics in South Africa'. 2000, Department of Health.

of some capacity or quality attributed to that person.<sup>4</sup> Discrimination is a highly subjective phenomenon as it is mostly determined by *perceptions* and *preconceived notions* of the person who is discriminating. It does not have to be based on verifiable facts – for example, a person who is rumoured or suspected to have HIV/AIDS can be a target of discrimination as much as someone who has tested positive and has disclosed her/his status to others.

## 2 METHODOLOGY

This article draws extensively on the experiences of the AIDS Law Project (ALP). ALP material containing telephone enquiries, complaints that were acted upon by the ALP, court cases, reports, published articles and papers presented by ALP staff were investigated, while ALP staff were interviewed. A number of organisations that are known to deal with AIDS discrimination issues was also approached for input. Literature relating to the working of discrimination and prejudice in general was studied, while a number of surveys on HIV/AIDS was also examined.

This article will focus primarily on the different forms that AIDS discrimination takes by considering the types of cases handled by the ALP. It will also formulate hypotheses about the changing nature of AIDS discrimination, invisible acts of discrimination, and the changes in the groups or types of people targeted by discrimination. In order to provide a context for the current situation in South Africa, the article will begin with an overview of the legal protection that South African law currently affords PLWAs, and then go on to focus on the different types and forms of AIDS discrimination prevalent within South African society.

## 3 AIDS DISCRIMINATION AND THE LAW

Since 1994, a number of laws and policies have been enacted that protect the rights of PLWAs. Ten years ago, no express legal protection for PLWAs existed. At present, special protection in South African law is afforded to PLWAs:

- Section 6 of the Employment Equity Act<sup>5</sup> specifically prohibits unfair discrimination on the grounds of HIV infection, while section 7(2) prohibits HIV testing of employees, unless permission has been obtained from the Labour Court.
- Section 34(1) of the Promotion of Equality and Prohibition of Unfair Discrimination Act<sup>6</sup>, requires the Minister of Justice and Constitutional Development to give special consideration to HIV/AIDS as a prohibited ground of discrimination. A schedule attached to the Act names discrimination on the grounds of HIV/AIDS in the provision of insurance as an example of unfair practices in the insurance sector.

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4 The Constitution of the Republic of South Africa (Act 108 of 1996) draws a distinction between fair and unfair discrimination. For the purposes of this article, the term "AIDS discrimination" will be employed to denote any action that is unfair to a person living with HIV/AIDS and may disadvantage or cause harm to that person.

5 Act 55 of 1998.

6 Act 4 of 2000.

- Section 3(4) of the National Education Policy Act<sup>7</sup> prohibits unfair discrimination against learners, students and educators living with HIV. Empowered by this Act, the Minister of Health promulgated the “National Policy on HIV and AIDS for Learners and Educators in Public Schools and Students and Educators in Further Education and Training Institutions” in 1999.
- The National Policy for Health Act<sup>8</sup> includes a national policy on HIV testing that prohibits irrational testing. In terms of section 2 of this Act, the minister promulgated this “National Testing Policy for HIV”, which was published in August 2000.
- The Medical Schemes Act<sup>9</sup> prevents Medical Aid providers from discriminating on the grounds of ‘state of health’ and requires that the schemes comply with prescribed minimum benefits (PMBs) – that are reviewed every two years.
- A Code of Good Practice on Key Aspects of HIV/AIDS and Employment was promulgated in December 2000 by the Minister of Labour, and attached to both the Labour Relations Act and the Employment Equity Act.

In addition to the enactment of legislation, jurisprudence has affirmed the fact that PLWAs are entitled to special protection of the law and may not be unfairly discriminated against. In 1993, the Appellate Division ruled that a doctor may not disclose a patient’s HIV status to other doctors without the express consent of the patient or where a clear duty to disclose exists.<sup>10</sup> In 1997, the Cape Provincial division rejected the prison authorities’ defence of budgetary constraints for not providing antiretroviral medication to the applicants (who were HIV positive), while upholding the applicants’ rights to ‘adequate medical treatment’. It held that prison authorities had to provide antiretroviral medication to two of the four applicants.<sup>11</sup> Most notably, the Constitutional Court ruled in *Hoffmann v South African Airways*<sup>12</sup> that SAA had infringed Hoffmann’s right not to be unfairly discriminated against as a PLWA and violated, in addition to his right to equality, his rights to dignity and fair labour practices. The court held that SAA unfairly discriminated against Hoffmann when they refused him the job of cabin attendant when the HIV test they required of him, came out as positive.

#### 4 THE AIDS LAW PROJECT

The AIDS Law Project (ALP) is a Non-Governmental Organisation (NGO) that offers free legal advice to people who seek legal remedies in reaction

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7 Act 27 of 1996.

8 Act 116 of 1990.

9 Act 131 of 1998.

10 *Jansen van Vuuren and Another NNO v Kruger* 1993(4) SA 842 (A). This case is commonly known as the ‘McGeary case’ and centred around the fact that McGeary’s doctor’s disclosed his HIV status to two other health practitioners on a golf course.

11 *Van Biljon and Others v Minister of Correctional Services and Others* 1997(4) SA 441. It must be noted that this case focused specifically on the conditions in prisons and the rights of prisoners.

12 *Supra* note 2.

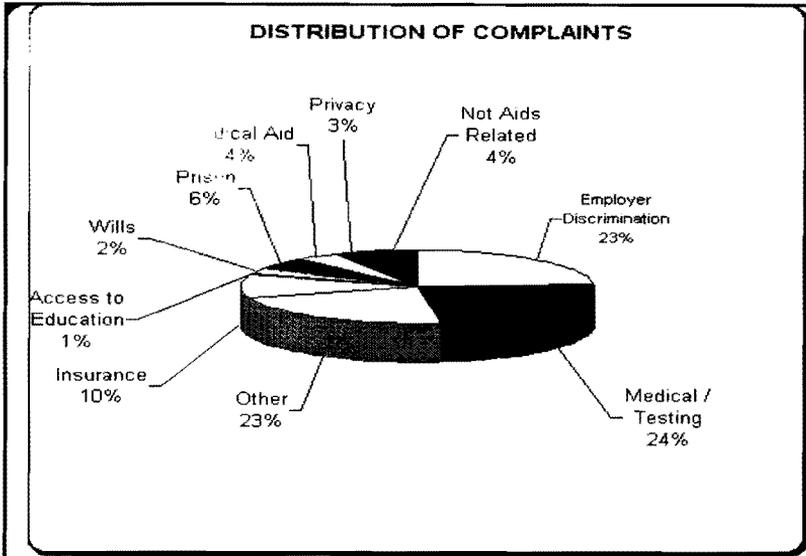
to AIDS discrimination that they might have experienced. The ALP undertakes public impact litigation, while also assisting in the formation of policies, guidelines and laws that will afford PLWAs maximum inclusion in society and protect them from discrimination.

The ALP has had hundreds of enquiries about AIDS discrimination since its inception in 1993. Many people approach the ALP for advice by telephoning the ALP directly or coming into its offices to consult with an ALP attorney or paralegal officer. About 95% of calls are dealt with immediately by providing the information sought or advising the person about the options open to her/him. A number of enquiries are taken up as ALP "cases" if the client is in need of legal representation, if the issue is complex or if it would be able to serve as a test case in order to challenge discriminatory policies, laws or practices.

The figure below schematically describes the cases handled by the ALP from 1993 to 2001, by classifying them into ten categories:

**Figure 1: Classification of ALP cases from 1993-2000**

Complaint	Year								Total
	1993	1994	1995	1996	1997	1998	1999	2000	
Employer Discrimination	3	9	6	18	11	12	9	9	77
Medical/Testing	1	9	5	20	10	13	8	13	79
Other	3	18	6	12	3	10	10	12	74
Insurance	2	3	0	7	1	7	5	7	32
Access to Education	0	0	0	1	0	0	1	0	2
Wills	0	0	2	4	1	0	1	0	8
Prison	1	5	11	0	0	0	1	0	18
Medical Aid	0	1	0	3	1	2	3	2	12
Privacy	0	1	2	2	0	2	1	3	11
Not Aids Related	0	2	2	4	0	2	1	3	14
Total Cases	10	43	29	63	22	39	40	44	290



#### 4.1 Some notes on the method of classification

It must be noted that the above classification of cases is semi-arbitrary. The fact that a certain issue occupies a category of its own is not necessarily an indication that it is more common or more important than those assembled under the 'Other' classification. For example, 'Death Certificates' falls under 'Other', but contains nearly as many cases as does 'Wills' that occupies a category in its own right. It should also be noted that an entry under a category can represent a case brought on behalf of one individual, or on behalf of a whole group of people. One specific case may also involve a number of issues and could thus be classified under two or three categories at the same time.

#### 4.2 Discussion of Types of ALP Cases

- *Employer discrimination* mostly included practices that involved employees (or potential employees) being sent for HIV tests in order to ascertain their HIV status. Their applications for a specific job or for permanent status in the companies would subsequently be rejected and those already employed would be demoted or dismissed from their jobs.<sup>13</sup>

<sup>13</sup> The ALP has handled a great number of employer discrimination cases that involve domestic workers. Domestic workers are particularly vulnerable to discrimination because of a variety of factors that are discussed later in this article. Another example of employer discrimination is that of ALP case 96/019 in which the client was demoted when the employer found out her HIV status. The client originally worked as a radio controller for the company and was subsequently demoted to a security guard and then to a 'cleaning position'. She was eventually dismissed and the employer failed to provide her with her 'blue card' which would have enabled her to draw unemployment benefits.

- *Medical/Testing* includes the practices of conducting HIV tests on people without their informed consent, or without pre-and post-test counselling; health workers informing employers about the HIV status of their employees without the employees' consent (sometimes not even informing the employee about her/his own HIV status), health workers refusing to treat people with HIV,<sup>14</sup> treating them differently from other patients,<sup>15</sup> withholding treatment from them or even administering dangerous drugs to them (like the trial substance Virodene for example<sup>16</sup>).
- *Insurance* refers to the rejection of insurance policies for PLWAs due to their HIV/AIDS status. A number of cases also involved the refusal of home loans or credit to clients on the grounds that they could not obtain the life assurance that is required by banks as surety for the granting of loans. The latter policy is of particular concern for people from low-income groups who do not have wealthy relatives who can stand surety for them. If surety cannot be obtained, life assurance is made a precondition for the granting of home loans. Some policies also refused to pay out benefits (for example funeral costs) to families, after it was ascertained that the deceased had died from AIDS-related illnesses.
- *Access to Education* entailed enquiries about the refusal of access to centres of learning for pupils with HIV/AIDS.<sup>17</sup>
- The *Wills* category applied to legal help sought for the drawing up of wills (including 'living wills') for PLWAs.
- *Prison* deals specifically with AIDS-related discrimination in prisons, where HIV testing is done without consent or counselling, with inmates subsequently separated from other prisoners and placed into single cells. Some cases also included demotion from prisoners' regular tasks (like preparing food), being branded as 'AIDS prisoners' by the wardens and not receiving adequate medical help.

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14 A woman went to hospital for a hernia operation and was taken into the operating theatre where she waited for 3 hours. When she eventually asked a nurse when she was going to have her operation, the nurse replied that the doctor was not willing to operate until he had her HIV results. The woman was told to come back in a week's time. When she did, she was told the doctor refused to operate on her as she was HIV positive. It was not clear from the report whether the woman had known about her HIV status before or whether she discovered it in the hospital for the first time. When she approached the ALP, she had still not had an operation and was in pain. ALP case 94/018.

15 An ALP client was discharged from the hospital without receiving the operation that he was admitted for, after being subjected to an HIV test without his knowledge or consent. When he approached the receptionist of his doctor to make an appointment, he was given a date far into the future. When he questioned the receptionist about the possibility of an earlier appointment, she replied that "People like you don't deserve to live" and expressed the hope that the client would die if she made the appointment for a far-off future date. ALP case 96/041.

16 A doctor supplied patients with the unregistered substance "Virodene" (that contains industrial solvents) telling them that it is a cure for AIDS. He also failed to inform them that it had side-effects. ALP case 97/016.

17 ALP cases 96/057 and 99/013.

- *Medical Aid* mainly deals with the exclusion of PLWAs from medical aid policies, or not receiving the benefits or coverage that they thought they were entitled to.
- *Privacy*. This classification was applied only to cases in which a person's HIV status was disclosed in a non-medical setting (like inserted on a bank data base<sup>18</sup> or a so-called 'life registry' circulated amongst insurance companies<sup>19</sup>) or in the workplace.<sup>20</sup>
- The *Other* category involved a number of miscellaneous cases, some including the following issues:
  - *Harassment* Complaints about friends, community or family members who start harmful rumours or telling other people about the client's HIV status with subsequent rejection and discrimination.<sup>21</sup> This category also includes physical assaults infringing the security and dignity of a person.<sup>22</sup>
  - *Wilful transmission* Several clients alleged that their sexual partners knew that they (the partners) had HIV, but took no precautions to prevent the client from contracting HIV from them.<sup>23</sup>
  - *Adoption of children* the ALP has assisted in negotiating adoption, foster care and organising places of safety for children living with HIV/AIDS or for children who have lost their parents through AIDS.
  - *Death Certificates* Assisting clients to change the cause of death on death certificates from 'AIDS' or 'Immune Deficiency' to 'natural causes'. This is done in order to prevent the deceased's HIV status from becoming publicly known and to avoid potential discrimination and stigma to the deceased and her/his family. The practice of revealing the deceased's AIDS status on a public document like a death certificate violates a person's right to keeping his/her HIV status confidential.<sup>24</sup>

18 ALP case 00/046.

19 ALP case 98/047.

20 An African female nurse went for an operation and it was discovered that she had HIV. Her doctor wrote a referral letter recommending rehabilitation as well as further treatment. When the nurse went back to her work, the (white, female) matron opened the letter ignoring the nurse's protests and the fact that "Confidential" was written on the envelope. After this incident, the matron's behaviour towards the nurse changed and made the nurse's work very unpleasant. ALP case 99/016.

21 Acquaintances of an ALP client informed her that they had discussed the HIV status of herself and her baby. They accused her of bewitching her husband and that it was the reason why he had chased her away and refused to pay maintenance. ALP case 00/016.

22 A woman who worked as a "Gender and HIV/AIDS Co-ordinator" for a state department received strange, silent calls at night. She was also threatened by a group of men who tried to force entry into her flat at night, clearly knowing her name. It was not clear from the report if the reason for this harassment was due to the fact that she was herself HIV positive or whether it was that she worked in the HIV/AIDS field. ALP case 96/007.

23 One example is that of a woman who had talked to her boyfriend about AIDS and was told that he was faithful, that he was informed about the facts of HIV/AIDS, and that he intended to marry her. She also noted the fact that he sometimes wore an AIDS ribbon. She subsequently found out that she was HIV positive when she was tested for insurance purposes. She confronted her boyfriend and it transpired that he had known he was HIV positive for 3 years. ALP case 00/020.

24 In 1998, new regulations under the Birth and Death Registration Act were made. The new death certificate now has a second, confidential page. This page has to state what

[continued on next page]

- *Benefits* Helping clients to obtain money from Provident Funds, pensions, estates or Workmen's Compensation.
- *Closure of medical facilities* The ALP was approached when HIV clinics or related organisations were threatened with closure.<sup>25</sup>

From figure 1 it can be seen that medical and employment malpractices are a main source of complaints, and have remained fairly constant over the years. It is interesting to note that a great number of cases involved the combination of irregular medical testing with that of employer discrimination. Typically this would involve an employer sending an employee to the employer's private doctor, where HIV testing is done without any regard to the requirements of informed consent, pre- and post-test counselling, and the results relayed to the employer without the consent of the person being tested. A positive result inevitably ended in dismissal, as "[m]ost employers still operate with the assumption that an employee with HIV is (in a matter of time) a dead employee with a replacement cost".<sup>26</sup>

Today, these practices are categorically proscribed by legislation such as the Employment Equity Act and the SAMDC "Guidelines on the Management of Patients with HIV infections or AIDS". Unfortunately the Health Professions Council has not thus far adequately engaged with complaints arising from medical malpractices. Also, certain structures like the South African National Defence Force (SANDF) are excluded from the provisions of the Employment Equity Act and are still engaging in pre-employment testing practices. A paralegal officer who has been at ALP since 1994 noted that he does not think that AIDS discrimination has become less over the years, but that people have become more aware of AIDS discrimination and have subsequently been perpetrating it in more subtle, but also more deliberate ways.<sup>27</sup>

Since the enactment of the Medical Schemes Act, medical aid schemes are not allowed to refuse people medical cover on the grounds of ill-health, or make ill people pay higher premiums. Medical aids may not refuse PLWAs treatment of opportunistic infections, but do not have to pay for antiretrovirals. Clients have approached the ALP to help them negotiate benefits from *ex gratia* provisions from their medical aids in order to help them with the medical costs associated with the management of HIV/AIDS.

An attorney who served as a member of ALP staff between 1996 and 2000 gave an overview of how the ALP's work had evolved over the

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the deceased died of and requires other information like the deceased's occupation. This information is only kept for data collection, for example for health planning purposes, and must be kept strictly confidential. The first (public) page of the death certificate may only state whether person died of 'natural' or 'unnatural' causes.

25 In a recent case, an independent rape-intervention organisation was unlawfully evicted from state hospital premises when the MEC for Health of the province instructed that no doctor employed by the Department of Health was allowed to prescribe post-exposure prophylaxis medication to rape survivors on government premises. The organisation had been assisting rape survivors and made medication that could prevent HIV infection available to them on request. ALP case 00/056.

26 Heywood and Rahiman 2000.

27 Interview with Teboho Kekana, ALP paralegal officer, 27 March 2001.

years.<sup>28</sup> She noted that the ALP's work mirrored the shift in the focus of AIDS discrimination issues in South Africa by initially focusing on getting PLWAs into spheres where they were excluded like the workplace, the medical aid and insurance industry. When legislation and policies regarding the workplace and medical aids changed and PLWAs could enter these areas, energies were directed at obtaining the same benefits and privileges for PLWAs that other people were entitled to in those areas. Now the focus is on attaining life-saving treatment for PLWAs.

She also noted that in 1996 it was very important for clients that their HIV status was kept confidential, while the cases generally focused on maintaining and protecting a client's identity and privacy. Many cases involved HIV testing and disclosure without consent or counselling. She remarked that this emphasis on privacy has changed over the years and that many PLWAs are more comfortable with their HIV status and therefore more willing to disclose it openly. Her sense was that there was more solidarity among PLWAs in that a PLWA would take on a case not necessarily for individual benefit, but with the knowledge that it might set a precedent that will assist other PLWAs. This was partly facilitated by the fact that there is now more public awareness about AIDS issues and that PLWAs are "treated less like lepers".

In her work at ALP, the attorney also saw a shift in issues related to employment. She noted that companies and organisations originally thought that they could keep HIV/AIDS away from their workplaces by conducting pre-employment testing on applicants. Whereas previously companies whose discriminatory employment practices were challenged would rather pay an applicant to get him/her out of the workplace, there has now been a gradual shift towards accommodating PLWAs in the workplace. Yet, despite the fact that organisations are currently more willing to employ PLWAs and to a large extent accommodate them, they do not want the PLWAs to cost them more.

### 4.3 Findings from interviews

A number of interviews with people from different service-organisations were conducted to test some of the conclusions drawn from the study of the ALP's files and interviews with ALP members of staff. An AIDS worker noted that over the last ten years people have become more aware of HIV/AIDS and also more accepting.<sup>29</sup> She noted that there has been more mobilisation regarding HIV/AIDS issues and that people now know that there will be consequences if the rights of PLWAs are infringed. She noted that AIDS discrimination still abounds because people may understand AIDS on an intellectual level, but cannot deal emotionally with the issues of death and dying that are associated with the AIDS epidemic. Evidence

28 Interview with Fatima Hassan, previous ALP attorney and deputy-head, 18 April 2001. I quote Ms Hassan at length as I believe her observations give a thorough overview of ALP cases and how they relate to AIDS discrimination.

29 Interview with Makie Kunene, Senior AIDS Educator and Counsellor, AIDS Training, Information and Counselling Centre (ATICC), 17 Esselen Street, Hillbrow, 17 April 2001.

of the fact that people may be able to intellectually comprehend HIV/AIDS and the injustice of AIDS discrimination, but fail to act on this knowledge when being confronted personally by AIDS may be found in the 1998 survey conducted by the Community Agency for Social Enquiry (CASE). This study conducted a survey of people's knowledge of human rights and found that

a large majority of respondents (88%) agreed [that people with HIV should be protected from discrimination], especially among Indian (98%), African (91%) and coloured respondents (85%). This means that support for PLWAs is at least in theory, prevalent, though there is a significant minority who do not agree, especially among whites and people in higher income brackets.<sup>30</sup>

This excerpt shows that people may discriminate against a PLWA despite the awareness that the discrimination is wrong and that PLWAs should be protected against discrimination. It also illustrates how race and income brackets condition the response of people towards the AIDS epidemic: people who wield power within South African society (being wealthy and to a large extent white) may deem themselves impenetrable or untouchable by the HIV and its effects and therefore may not consider it necessary to protect the "other" people who may be regarded as vulnerable groups. This is echoed by another AIDS worker who noted that people are still in a stage of denial about HIV/AIDS. She remarked that people deny the existence of HIV/AIDS or the possibility that they may be infected even though people close to them are dying, and that these people would rather attribute the deaths to "known things" like tuberculosis or that the infected person was bewitched or possessed.<sup>31</sup>

Most notably, it would seem that discrimination by health workers and in medical facilities has not diminished over the years. The *National STD/HIV Review* of 1997 noted a wide variety of malpractices by medical personnel in all nine provinces in South Africa,<sup>32</sup> while the ALP deals with similar complaints on a daily basis. In 1992, the Medical Association of South Africa published guidelines on HIV testing which included the requirements of informed consent, pre- and post-test counselling for all patients as well as the patient's right to confidentiality. These guidelines have been blatantly ignored by many health workers and have resulted in discrimination against, and abuse and mistreatment of PLWAs. To date, the ALP has lodged 28 complaints against medical practitioners with the Health Professions Council (HPC), but not one doctor has been found guilty of unprofessional conduct by the HPC.

## 5 TARGETS OF AIDS DISCRIMINATION

As there is a powerful social stigma attached to HIV/AIDS, it can be asserted that all PLWAs whose status becomes known run the risk of falling victim to discrimination. AIDS discrimination is levelled against people

30 Pigou, Greenstein and Valji 1998:155.

31 Interview with Mrs Mhlongo, AIDS worker, Sinikithemba HIV/AIDS Centre, Durban, 18 April 2001.

32 Fröhlich 1997.

who are known to have HIV (whether the PLWA has disclosed the fact out of own free will or someone else disclosed it to others), who are thought to have HIV and often against those people who are associated with PLWAs.

Despite the fact that the categories of people just enumerated are likely to be subjected to discrimination, certain groups of people can be identified as more likely to experience AIDS discrimination in more aggravated and all consuming forms. These people constitute already vulnerable groupings in society and are identified by markers such as race, gender, sexual orientation, class, level of education and economic activity. Vulnerability can be defined as “a lack of power, opportunity and ability (skills) to make and implement decisions that impacts on one’s life”.<sup>33</sup> This pre-existing vulnerability, due to factors other than HIV infection, such as racism, sexism, homophobia, elitism and other forms of xenophobia, compounds and exaggerates the discrimination felt on the grounds of HIV infection and can also be seen as initiating it. Renee Sabatier describes this dialectic in the following way:

Once the AIDS virus has entered a society, it tends towards the path of least resistance. Globally, that runs directly through some of the world’s least powerful communities: the poorest, most disadvantaged and underprivileged groups whose members constitute an increasingly disproportionate share of the world’s total AIDS cases.<sup>34</sup>

Partly because of the AIDS epidemic’s perceived roots in gay and African communities, other forms of discrimination intensify the discrimination levelled at PLWAs, while in return, AIDS discrimination feeds into, and therefore strengthens, pre-existing prejudices. The result is a vicious circle of intensifying acrimony and intolerance. This is borne out in research conducted by the Panos Institute in the 1980s. They assert that “the fear of AIDS may have deeper and older roots than the epidemic itself. Hostility towards people with the infection in some cases may be no more than a mask of already existing prejudices”.<sup>35</sup> These vulnerable groups are found to be easy and identifiable targets for human rights violations as well as restrictive measures in order to curtail the epidemic.<sup>36</sup>

Most interviewees in the present study indicated that women, Africans<sup>37</sup> and people who are either from the working class or unemployed people are more susceptible to becoming targets of AIDS discrimination. Other

33 Tallis 1998.

34 Sabatier 1988:4.

35 Panos Institute 1990:25.

36 “The general pattern of human rights violations has been repeated in the context of AIDS: violations have been at their worst for the people least able to assist and protect their rights, such as prisoners, commercial sex workers, asylum seekers, or drug-dependent persons. They have become targets of compulsory, or coercive AIDS control measures” in Mann, J *et al* (eds) 1992: 542.

37 The terminology employed in this paper is in keeping with that used by *Statistics South Africa*. It recognises that the word ‘black’ refers to all racial groups disadvantaged under apartheid in South Africa, while under this broad category, the following groups are specified: African, ‘Coloured’ and Indian.

vulnerable groups that were mentioned were children,<sup>38</sup> illiterate persons<sup>39</sup> and gay and lesbian youth.<sup>40</sup>

It can therefore be asserted that factors such as race, gender, sexual orientation, class, economic activity, level of education, literacy and class status determine a person's access to information, social support structures, medical treatment and care, resources, quality of shelter, food and water and influence in decision-making structures. They therefore influence the impact and degree of AIDS discrimination on that person.

These factors would also determine people's responses to and coping strategies for their HIV status, as well as influencing their decision to openly declare their status or not. This is borne out by the testimony of Justice Edwin Cameron who publicly declared his HIV positive status in April 1999. He noted that he was able to do this because of support from friends, family, carers and colleagues, that his position as judge guaranteed him job security, and that he could afford life-saving medication because of the "happenstance of affluent connection".<sup>41</sup> His status as a public figure, and the fact that he knew the law and would therefore know how to protect himself against discrimination, also facilitated his openness.

## 6 DISCUSSION OF A CASE STUDY

In an attempt to draw out the subtlety and variety of factors that operate within the experience of discrimination, a case study was selected from the ALP files. In view of the fact that the material contained in the file did not include detailed information on the client's life, and that an interview with the client was not possible, a number of hypotheses about her experience of discrimination was constructed. What follows, are the facts of the client's complaint and a discussion of the aspects that could precede and exacerbate the AIDS discrimination she was subjected to.

### Case Study

In 1995, a 38-year old unmarried woman approached the ALP for advice. Ms X was the mother of four children and responsible for five dependants (one of them being her own mother) and working as a domestic worker at a middle-class white family in Johannesburg for R30/day. She was responsible for the usual domestic work duties in the home of her employer, as well as looking after their 1-year old son. After working there for two months, her employer informed her that she had to be tested to see whether she was healthy enough to care for the child. In her statement, Ms X says the following: "I asked her what if they find out that I am sick. She replied that she would help me, because she also is a woman."

38 For an in-depth study of the effects of AIDS discrimination on children see Barret-Grant and Strode.

39 Thembi Zungu argued that an illiterate person would experience more discrimination because he/she would be less likely to know what his/her rights are. Ms. Zungu is the NAPWA Provincial Co-ordinator for the Eastern Cape. Interview conducted on 18 April 2001.

40 Paddy Nhlapo noted that gay and lesbian youth were the most vulnerable groups in the epidemic as there are very few safe sex education initiatives that are geared specifically towards gay and lesbian sexual practices, which therefore ultimately endanger gay and lesbian people. Mr. Nhlapo is the NAPWA Provincial Co-ordinator for the North West Province. Interview conducted on 18 April 2001.

41 Cameron 2001.

The employer's doctor tested Ms X for HIV and spoke in English, which she could not understand. The employer translated it into Afrikaans, but Ms X still did not grasp what was being done to her. After some time, Ms X returned to the doctor where she was given a letter by the receptionist. The employer opened the letter and informed the client that she had AIDS. She was given R400 to go to hospital and subsequently dismissed.<sup>42</sup>

It would appear that the discrimination against Ms X on the grounds of her HIV status was compounded and precipitated by a variety of factors. These could possibly include:

- *Gender* Because she is a woman, she must take responsibility for looking after the economic and emotional well-being of her children as well as other family members. Her gender also generally constrains her to finding a job in the domestic sphere, which is known to pay less than other sectors of employment. The possibility also exists that she contracted HIV as a result of not being in a position to negotiate safer sex.
- *Race* As a 38-year old African woman, it is likely that Ms X did not have access to an education that provided her with marketable skills. One of the very few avenues open to her is to compete in the already-saturated market of domestic work, which entails low pay and long hours. In a racially-divided society, she is also subjected to her white employer's terms because she is black.
- *Economic status* As a domestic worker on these terms, she has little or no bargaining power and therefore has to accept the working conditions laid down to her by her employer. She would also not have the money to invest in a medical aid or insurance to provide medical care for herself, or to provide for her family if she were to become incapable of doing so herself.
- *Education and Access to Information* The fact that she grew up in apartheid South Africa, determined her access to education and the type of languages she would understand or not. It is also unlikely that she would have access to information; that she could refuse to be tested for HIV; or that she knew that the doctor and employer were acting unethically and unlawfully when testing without her informed consent.
- *Geographic location* It is very likely that Ms X came from the rural areas of South Africa or from the former homelands. Because of the concentration of wealth and skills in urban areas, rural areas are underdeveloped and to a large extent cut off from services and information. This would have had an impact on the education, skills, services and information accessible to Ms X and disadvantaging her in relation to her urban counterparts.<sup>43</sup> Customary laws and practices, which can

<sup>42</sup> ALP case 96/001.

<sup>43</sup> An example of the disadvantages that may be inherent in specific geographic locations is illustrated by the death of Nosipho Xhabe (aged 29). She left her home and two children in the Ciskei in order to seek a job in Johannesburg - only to find survival by de-

*[continued on next page]*

include a variety of factors that would make people (and especially African women) more vulnerable to HIV infection and prejudice, still generally applicable in rural areas. Marius Pieterse in his research on HIV/AIDS, African customs and customary law, notes a number of traditions that may enhance the dangers of HIV infection i.e. the practice of polygyny, emphasis on procreation, male circumcision, skin-piercing procedures, belief in witchcraft and patriarchy dictating that women are to be regarded as inferior to men.<sup>44</sup> These customs and laws would condition a person's responses to HIV/AIDS and its prevention, as well as having an impact on the nature of the discrimination experienced.

Even from this cursory and somewhat suppositional study, it can be seen that the different vectors of discrimination work together and support and sustain each other in a number of subtle and overt ways. AIDS discrimination is thus facilitated and deepened by a variety of other and pre-existing forms of discrimination. It is plain that Ms X would probably be in a position to act on, and deal with, her HIV status in a totally different way if she were for instance in the shoes of a white, middle-class, male who is the director of a large computing company.

## 7 SOURCES OF DISCRIMINATORY CONDUCT

AIDS discrimination can usefully be classified into three broad sectors:

- *Individual* This is the type of discrimination encountered on an intimate level in the personal relationships that PLWAs have with others. Forms include harassment where those considered trustworthy disclose a person's HIV status or spread rumours to others. They would also include, the break-up of romantic, platonic and familial relationships because of the fact that others are terrified by the PLWA and reject him/her or that a PLWA withdraws because she/he might 'contaminate' his/her family, friends or community. A refusal to invest in a relationship with a PLWA or invest in the PLWA as a person may also be responses to finding out a person's HIV status.<sup>45</sup> It also involves community discrimination in which infected individuals are ostracised and possibly punished for "bringing a curse" on the community, or

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pending on a man she had met. He eventually kicked her out of his home one night when he discovered that she had AIDS. She spent the night in the toilet and was located by a neighbour who gave her a blanket. A newspaper reporter then found her under a tree where she told him that she was not "good enough for him [the man who abandoned her] anymore" as she could not cook, clean and fulfil his sexual desires anymore. She was later found dead in the shack of an absentee neighbour. From "Bigotry and ignorance in approach to AIDS" by Mathatha Tsedu, *Mercury*, 13 February 2001.

<sup>44</sup> Pieterse 2000.

<sup>45</sup> Promise Mthembu tells how her parents refused to pay for her university fees as they thought she was going to die anyway and that they should rather invest their money elsewhere. Interview with Promise Mthembu, National Mother-to-Child-Transmission Co-ordinator, Treatment Action Campaign, 17 April 2001.

being perceived as a threat to the physical and psychological well-being of the community as a whole.<sup>46</sup>

- *Institutional* This type of discrimination originates in specific institutions within societies. Certain groups of people are given preference over others.<sup>47</sup> PLWAs are typically excluded from certain forms of employment, certain positions within workplaces, not seen as subjects worthy of investment such as the building of their skills, capacity or knowledge, and excluded from insurance benefits and certain medical aid provisions, as well the protection of the law.
- *Structural* Certain forms of discrimination are built into the structures of society, and in the ways that societies function and are organised. An example already described is the position of women in society. Women have less power to negotiate safer sex than men. They are also much more likely to be the target of violence and sexual assault within a society. Women would only be seen as “good” and therefore acceptable, if they display no knowledge of sex and safeguard their virginity until marriage, or by playing the role of the passive sexual partner. These gendered conventions ultimately limit women’s access to, and knowledge of, safer sex practices.<sup>48</sup> Another illustration of structural discrimination is the fact that PLWAs who live in townships outside Johannesburg for example, have to overcome a variety of transport and communication hurdles to access services, resources, information and condoms that might be taken for granted in the middle-class suburbs of the same city.

PLWAs in rural areas may not have access to the same medical treatment or expertise as their urban counterparts. The fact that poverty and the imbalances inherent to the urban/rural divide form part of structural discrimination is evidenced in the following extracts from the UNRISD report on AIDS and development:

When we call people “poor” we are in danger of forgetting that they are made poor. Poor people are really impoverished people. They are impoverished by the inequitable socio-economic structures – on the household level, on the village level, on the national level, and on the international level of trade and

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46 Thanduxolo Doro, a programme manager at NAPWA, noted in an interview that most cases handled by NAPWA involved discrimination at the community-level and that personal relationships constituted the sector that is hardest hit by AIDS discrimination. Interview conducted on 6 April 2001.

47 Promise Mthembu told that one of her friends died in 1998 as she was told by the hospital that the government cannot treat people with HIV. Ms. Mthembu also noted that PLWAs would go to clinics seeking treatment and that health care workers would tell them that opportunistic infections are supposed to happen to them and that they should just accept it. Interview with Ms. Mthembu *supra*.

48 ‘[I]n many societies there is a culture of silence that surrounds sex that dictates that “good” women are expected to be ignorant about sex and passive in sexual interactions. This makes it difficult for women to be informed about risk reduction or, even when informed, makes it difficult for them to be proactive in negotiating safer sex. Second, the traditional norm of virginity for unmarried girls that exists in many societies, paradoxically, increases young women’s risk of infection because it restricts their ability to ask for information about sex out of fear that they will be thought to be sexually active’ Gupta 2000:18.

commerce. This becomes clear when we look at AIDS as one in a series of “shocks” experienced by the majorities of people in developing countries.<sup>49</sup>

and

In country after country, elite-controlled governments, often with international support, have pursued economic and social services policies that are urban-biased, favouring those who live and work in cities to the disadvantage of rural populations.<sup>50</sup>

A number of people interviewed noted the disadvantages experienced by rural people in the context of the epidemic. One interviewee remarked that new information and material take a longer time to reach rural communities, and that lack of services diminish rural communities’ response to HIV/AIDS.<sup>51</sup> Another interviewee noted that rural people have less access to different means of communication and that incorrect information can easily be disseminated. He also said that PLWAs in rural areas have the danger of being ostracised from the whole community, because rural communities are generally smaller and more closely-knit in comparison to urban areas where a PLWA might experience discrimination by individuals only.<sup>52</sup> The role of illiteracy in hindering the spread of knowledge about HIV/AIDS and the rights accorded to PLWAs has been noted before, and will particularly be noticeable in rural communities where literacy rates are lowest.

## 8 CONCLUSION

Discrimination against PLWAs permeates all areas of life in South African society. It has been shown that AIDS discrimination is not only present in personal relationships, the workplace, medical settings and the insurance industry, but also that a variety of different institutions in society actively perpetuate the alienation and impairment of PLWAs.

While a number of laws and policies have been enacted to safeguard PLWAs, it is clear from the above study that these laws have not gone far enough to protect this particular group of vulnerable people from the high levels of discrimination present in society. It is therefore recommended that relevant existing legislation should be interpreted to include prohibition against AIDS discrimination, while additional legislation and policies should be enacted that expressly prohibit AIDS discrimination. An example of the latter recommendation would be the inclusion of “HIV/AIDS status” in the prohibited grounds of discrimination in the Promotion of Equality and Prohibition of Unfair Discrimination Act. At the same time, it is equally important that legislation be coupled with mechanisms that educate people about discrimination, what human rights are, how to enforce rights and what penalties might be accrued if rights are infringed.

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49 UNRISD Programme on Social Policy and Development 2000:8.

50 Ibid. 9.

51 Interview with Zamokuhle Zwane, member of the Treatment Action Campaign, 17 April 2001.

52 Interview with Paddy Nhlapo *supra*.

It is only when this two-tier strategy of legal protection and rights education is successfully implemented, that PLWAs will have a greater chance at a life free from injustice and prejudice – a life free from intolerance and fear.

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