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AIDS AND POVERTY LAW: INACTION, INDIFFERENCE AND IGNORANCE

PAMELA SHIME*

RÉSUMÉ
Selon des études récentes, la pauvreté est un facteur déterminant dans l'évaluation des risques qu'une personne devienne séropositive. Ceux qui font partie de la catégorie des personnes à revenu moyen glissent bien souvent sous le seuil de la pauvreté en raison du coût des médicaments, des traitements de médecine douce et des aliments spéciaux. Dans son étude du recoupement SIDA et pauvreté, l'auteure identifie et discute des lacunes du réseau d'aide sociale de l'Ontario pour les personnes séropositives et sidatiques.

INTRODUCTION
Poverty and AIDS. It is impossible to discuss one without the other, yet it happens all the time. In poverty law publications, in fact in a broad range of poverty issue journals, there is no mention of HIV.¹ In the AIDS/HIV world, poverty is only now emerging as an issue that is afforded its own space. Although the HIV/AIDS communities constantly address issues that are inseparable from poverty, including access to drugs, poverty as an issue for the HIV/AIDS community has rarely taken centre stage.

* Copyright © 1994 Pamela Shime. Pamela Shime is a third year law student at the University of Toronto. This article was written for the course entitled “Law’s Response to Poverty”, offered by Professor Janet Mosher

¹ There is currently a debate in the medical and AIDS literature regarding the relationship between HIV and AIDS and whether or not the former is the basis for the latter. At this point, most people with HIV believe they will become sick with AIDS. This belief often results in steps that lead to some experience with the social assistance system and poverty for the person living with HIV or AIDS, if there is no such relationship already. As such, I discuss the links between HIV and poverty here as well as AIDS and poverty, although the medical debate is of great import and there is no resolution of the debate as of yet.
Certainly, the differences between the American and Canadian experiences deserve mention. A critical aspect of AIDS activism in the United States is the struggle for health insurance. The barbarism of that gap in American social welfare is absent in Canada. Unfortunately, this does not mean that people with HIV and AIDS north of the border are free of concerns regarding survival.

Poverty and AIDS intersect at countless points. In this paper, I explore the current failings of social assistance for people living with HIV and AIDS and the implications of these failings for the health, survival and well being of those living with HIV/AIDS. I begin by pointing to similarities between AIDS and poverty. I then explore certain links between the two phenomena.

In the main section of the paper, I examine obstacles to access and problems in the social assistance system for People Living with HIV/AIDS (PLHAs). In this discussion, I will comment on the only case of an openly HIV positive applicant to the Ontario Social Assistance Review Board.

After exploring barriers to social assistance for PLHAs, I will highlight the issues of drug funding and housing. I conclude with some suggestions for changing the situation for PLHAs in poverty.2

A. POVERTY AND AIDS: SIMILAR PHENOMENA
Most of this paper addresses those situations where AIDS and poverty intersect. The dynamics of this intersection stem in part from the similarities between the two phenomena. I point to some of those patterns of similarity here.

Both poverty and AIDS have an impact on longevity and quality of life.3 People living with HIV are constructed in popular discourse as innocent or "sinners", depending on certain characteristics; people living in poverty are described as deserving or undeserving of assistance, depending on similar attributes. Both epidemics have physical and mental manifestations and in large part are the lenses through which those affected experience the world, as well as those

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2. I want to acknowledge the wonderful assistance and support of Professor Janet Mosher, Gerry Hedemma, Richard Elliot, Pamela Bowes, Owen Shime and Jill Tinmouth in the writing of this paper. This article is dedicated to the memories of Vito Russo and Marlon Riggs, who died too young of AIDS, AIDSphobia, homophobia and racism.

through which they are often perceived. Both poverty and AIDS are stigmatized and usually involve some sense of shame about the condition.4

Both groups, overlapping significantly, are deemed to have little political power and as such are priorities for few politicians. Both epidemics have been fuelled from government inattention. This inattention is inseparable from the idea of those in poverty or PLHAs as wilfully in the situation they are in. This inattention has been mitigated to a certain extent by activism from both communities that results in publicity. This shames politicians into action in limited forms.

B. AIDS AND POVERTY: INTERSECTIONS

AIDS and poverty feed each other. One can often lead to the other. Recent studies identify poverty as a key factor5 in assessing risk of becoming HIV positive—as has been the case with public health problems in general.6 Explanations of this correlation include the likelihood that “AIDS education and prevention efforts...may not be positioned in terms of physical location or media type to reach those in poverty” and “the content of messages may not speak to those in poverty in ways that are either understandable or relevant.”7

Those who do not fall into the low-income category when they test HIV positive often slide quickly into poverty due to the costs of items such as drugs, alternative therapies, and food for special diets. The need for benefits, such as a drug card, that are linked to social assistance also presents people with HIV and AIDS with lose/lose financial decisions. Often people with HIV and AIDS have no choice but to quit their jobs and rid themselves of most of their assets in order to become eligible for social assistance solely to have access to the drug card.


5. I discuss factors used to assess the risk of becoming HIV positive instead of “risk groups”. The terminology associated with “risk groups” has been a damaging obstacle to HIV prevention as it provided false security to people based on their identity, for example, as straight, non-user of intravenous drugs, etc. Instead of the idea of risk groups, which often contributes to the designation of people as deserving or innocent victims of the virus, we need to look at behaviour, such as practice of safer sex, no matter how many partners a person has, and general societal conditions, such as homophobia, racism, and poverty that are barriers to education and preventative behaviour.


Just as we have begun to distinguish between the working poor and the poor unemployed, it seems poverty has embraced another distinction: that between the housed and the homeless. When we discuss poverty, homelessness must be part of the discussion, including the similarities between, and differences from, poverty for the housed.

In the HIV/AIDS context, homelessness is especially devastating. For homelessness, like poverty, is a health hazard. Homelessness, like poverty generally, can precede or follow a diagnosis of HIV or AIDS. For reasons including an increase in activities such as survival prostitution and drug abuse, as well as reduced access to AIDS prevention education and safer sex materials, homelessness increases the risk of contracting HIV or AIDS for many. For others, it is the last step of a terrifying fall between the cracks of the system.

For people with HIV and AIDS, income level, housing and employment status can mean the difference between long term survival and quick death. Quality of life, stress level, and nutritional intake are critical factors in determining survival rates for people with HIV/AIDS. Poverty and/or homelessness preclude long term survival in many instances by ensuring high stress levels, low nutritional standards, and low quality of life in various ways that affect health and welfare. 8

A 1988 proposal to the Community Services and Housing Committee regarding financial stability and people with AIDS discussed a report on the health consequences of homelessness and poverty:

“One of the consequences of poverty was a reduced life expectancy. There was evidence that suggested a seven-year drop in life expectancy for those men in the lowest income category. As well, these individuals are also at greater risk of being infected by tuberculosis, nutritional disorders and chronic stress. People with AIDS are already vulnerable to infections that are life-threatening.” 9

Being HIV positive and poor can be fatal. The choices People Living with HIV and AIDS (PLHAs) must make because of economic constraints, between drugs and housing, food and care, are devastating. In this discussion of HIV, AIDS and poverty, I am interested in exploring how a society that espouses values such as liberty, justice and decency can tolerate their absence in the lives of so many of its people.


I. **HIV/AIDS and the Social Assistance System**

"If you are infected with HIV you may want to examine how you maintain your health. It is important that you maintain a proper diet, exercise, and get enough rest. Try to eliminate unnecessary stress in your life." 10

The following discussion touches on some fundamental barriers to applying for, receiving and maintaining social assistance for people living with HIV/AIDS (PLHAs). Often these barriers apply to people who are not PLHAs as well—sometimes in different ways. Both the similarities and the differences in the experiences of these two groups with the social assistance system merit further attention.

The first problem is the veritable absence of a discussion of the specific issues for PLHAs in this area. 11

I will cite these reports extensively in the following discussion, sometimes exclusively. I do this for two reasons. First, the availability of sources for this research is quite limited. These two reports were the only ones of their kind that I found. Their comprehensive, clear, and insightful coverage of the issue ensure their importance in any discussion of these issues.

Second, in part because of these qualities, I do not feel there is a need to repeat the research painstakingly completed and documented by the authors. Much of this research was fieldwork—interviews with PLHAs and service providers. The urgency of the issue precludes the luxury of restudying the dynamics of AIDS and poverty ad nauseum. The work that has been done in these reports is more than adequate. It is not more fieldwork we need, but a high level of publicity and consequent action on the discoveries in the work already completed. Once this dialogue achieves a high profile, we will be able to analyze the role HIV status plays in determining experience. Only then will we able to develop broad anti-poverty strategies that truly include the interests of PLHAs by addressing the specific issues they confront in their interaction with social assistance laws, regulations and attitudes. 12

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12. As noted infra in Note 14, there already exist groundbreaking reports that include recommendations on these issues. There is no time to lose in implementing these changes.
A Brief Overview

The two basic sources of social assistance in Ontario are obtained under the *General Welfare Assistance Act*¹³ and the *Family Benefits Act*.¹⁴ The former is municipally administered and intended for persons in need for the short term. To qualify for assistance under the General Welfare Assistance Act as an "unemployable person", a doctor must certify the applicant as mentally or physically disabled. Receiving welfare ensures access to OHIP coverage and a monthly drug card, which covers most prescription drugs, including most HIV drugs.

In order to receive Family Benefits ("FBA"), an applicant must prove either disability or permanent unemployability.¹⁵ There is a great deal of case law, consisting primarily of Social Assistance Review Board decisions, which considers the definitions of these terms.¹⁶ Briefly, disability must continue for a "prolonged" time and must "severely" limit the activities of the normal living of the applicant. To qualify as permanently unemployable an applicant must demonstrate an inability to be employed for a "prolonged" period of time due to a medical problem.

A doctor's certification of an applicant's situation must be accepted by the Medical Advisory Board. This Board examines the doctor's report and physical evidence and makes a recommendation to the Family Benefits administrator. This recommendation is central to the final decision and seems to be almost determinative in the process.

Family Benefits provides a higher level of assistance than General Welfare. Recipients of General Welfare can transfer to FBA if approved by General Welfare administrators and if they satisfy the eligibility requirements for FBA. (Other sources of income are either private or employment based, such as Unemployment Insurance and the Canada or Quebec Pension Plan.)

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Every delay costs countless PLHAs their lives. Hence, it is not more studies we need, but more attention to the studies that have been completed.


15. Regulation 318, ss.1 (3) (b) and (c) define the terms "disabled" and "permanently unemployable" under the *Family Benefits Act*, *ibid*.

(2) Obstacles to Access: Stigma

As mentioned above, stigma infuses the current meanings of poverty and HIV/AIDS. The double stigma is an enormous burden, and has serious implications for PLHAs in need of social assistance.

Applying for social assistance and revealing a positive HIV/AIDS status entails confronting the reality of the situation—in terms of economics, health and feelings of self-worth. The psychological responses to testing positive for the virus or being diagnosed with AIDS are quite complex and beyond the scope of this paper. Yet, the necessity of facing the reality of being HIV positive or having AIDS must be noted as a potential obstacle for PLHAs considering applying for social assistance.

As a recent report concludes, relying upon the requirements for eligibility, such as a “severe and prolonged” illness or disability imposes an “emotional and social barrier” for many PLHAs. Qualifying for assistance in this way obliges PLHAs “to recognize, early on, that they can no longer work, that they are disabled and that their condition is unlikely to improve...a difficult and painful admission for many...who are still young and still apparently healthy.” The roller coaster progression of AIDS in many people also belies the need to make such an admission. PLHAs often pass in and out of periods of unemployability as opportunistic infections occur and are cured. The eligibility requirements are not adequate to manage this reality. The current need to claim permanent unemployability is thus not only a significant obstacle to social assistance for PLHAs, but also is unnecessary for many PLHAs.

Three possible consequences of the stigma attached to HIV/AIDS and poverty are that PLHAs: 1) do not apply for assistance despite being in need; 2) delay application and continue to work until they are seriously ill; 3) apply for social assistance without disclosing their HIV status, precluding enhanced benefits.

First, the stigma of poverty compounds the shame around HIV/AIDS for social assistance applicants. PLHAs who are not already in the social assistance system must face the stigma of becoming “dependent” on the state. This is a great blow to many people and adds to the depression that sets in upon discovering seropositivity. The stigma of poverty combined with the stigma of HIV/AIDS in some cases prevents PLHAs in need from ever seeking social assistance. The health consequences of this inaction are severe, since without a drug card and a certain amount of money, the essentials of life for a PLHA can be inaccessible.

Second, the stigmas operate to delay the application in question. The PLHAs thus affected often work longer than is healthy and become ill earlier than they might otherwise have. Eric Mykhailovskiy and George Smith interviewed 70 PLHAs in their recent study of access to social services; one of their interviewees recalls, "I didn't want to be—what's the word—an invalid... didn't like the idea of first of all, being on the government payroll... I've always been self-supporting since I was 15 years old."

The combination of the stigma of being sick and that of being dependent on the state resulted in dire consequences for this man: "I pushed myself too hard and I ended up with PCP... I was working literally 17 to 18 hour days. I was covering things up, you know. I figured working I didn't have to think about it... I woke up one day and I couldn't stand up and I couldn't get out of bed. I was running a fever... an ambulance came and got me and that was it." This is only one of many stories of people not applying for social assistance "until they are absolutely desperate."

Third, those who have overcome the stigma of poverty enough to attempt to apply for social assistance must confront the stigma of HIV/AIDS within the social assistance world. Revealing a positive HIV or AIDS diagnosis can result in the loss of family, friends, jobs, and housing. In this instance, it can result in discrimination in the social assistance system, including AIDSphobic remarks and actions by government staff.

Whatever shred of dignity might remain in the social assistance application process can be destroyed by the disclosure of HIV or AIDS. Some social assistance workers exhibit alarming ignorance about the virus, modes of transmission and the people who identify as positive or with AIDS. Many workers do not understand how the many young male and female applicants can be unemployable. If applicants are openly gay, homeless, prostitutes, or drug users they might be treated with disdain or mistrust. Often, their inability to work is less visible than other instances of disability or illness.

Workers are not trained about HIV, AIDS or homophobia. As a result, some of the workers who have not educated themselves, or who do not have gays,

18. Mykhailovskiy & Smith, ibid.
19. Ibid. at 12.
21. "AIDS...carries with it a stigma which makes it difficult to get needed services because of fear of disclosure;" in AIDS Committee of Toronto, supra, note 9 at 2.
22. SP Research Associates, supra, note 11 at 8.
lesbians or PLHAs in their lives greet the PLHA applicant with discriminatory remarks or actions. The stigma affecting the applicant is reinforced whenever this occurs. In this way the system directly contributes to this barrier to access.

Recipients of General Welfare who do not disclose their HIV status due to shame are then not classified as disabled or unemployable (a characterization which requires an HIV diagnosis or other accepted disability). They receive a lower level of benefits and become subject to requirements to look for work that are quite onerous.

The stigmas operating for PLHAs in need manifest themselves in different ways for different people. Mykhailovskiy and Smith conclude that "class relations, relations of sexual orientation" and other aspects of the "social location" of PLHAs such as immigration status, race, and culture influence this aspect of access to social assistance, among other services.

Stigma is often compounded when other identifying characteristics are also stigmatized in society. One of many examples of these circumstances is a man who identified as Native and gay. He "did not tell his welfare worker that he was HIV positive, out of fear of being discriminated against. As a result there was a delay in getting him' hooked up' to FBA." Stigma attached to poverty is in many ways similar to that attached to HIV. Together, often complicated by other identities associated with shame, these stigmas operate as obstacles to social assistance for PLHAs from many different communities. The mental and physical health of those affected suffers in every one of these cases. For some PLHAs, the stigma involved can be fatal.

(3) Information About the System: A Tangled Web
Confusion about the social assistance system is the rule for applicants, social service providers and welfare workers themselves. The lack of clear, accessible information is a serious obstacle for all applicants to social assistance programs. It is complicated by the incoherence of the system, which is a mishmash of regulations, laws and procedures.

23. One PLHA tells the story of a welfare worker taking three steps back and saying, "Well I really can't help you". In this case the applicant was refused an emergency cheque; Mykhailovskiy & Smith, ibid. at 41.

24. Ibid. at 6-19, 22, and 24-38.

25. Ibid. at 18.
The Report of the Social Assistance Review Committee in Ontario, *Transitions*, commented on this obstacle to access for those in need in Ontario: "social assistance...is probably the most poorly understood of Canada's social programs...To add to the confusion, our current social assistance programs have evolved through ad hoc and incremental adjustments made over many years...The result is an administratively complex system, heavily dependent on the exercise of discretionary judgment, which is difficult for both recipients and staff to comprehend."

The dearth of comprehensible information about how social assistance operates when the applicant is HIV positive or has AIDS compounds the confusion for PLHAs. "I wish somebody had just had a checklist of things I could do," comments one PLHA. The absence of such a resource can make the difference between living with AIDS and dying of it.

An example of information that is not easily accessible to applicants, or even workers, is the fact that PLHAs are eligible to receive Family Benefits or services under General Welfare's Special Assistance Program. The amount of money available under General Welfare "is not sufficient for a healthy person, let alone an HIV positive woman who has greater nutritional needs." A person who is not aware that she might qualify for Family Benefits, with its enhanced levels of support and services, can experience significant health consequences due to lack of information.

In addition to the confusion about how the system operates, access to a social assistance system which has been described as, "a complex maze which only the strongest and most determined can comprehend and access fully," is a particular challenge for many PLHA's. In this way, the system reduces life expectancy and quality of life for the people it allegedly aims to assist.

The dearth of clear, accessible information about the system and the bureaucratic obstacles creates a particularly serious obstacle for PLHAs who are already

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26. (Toronto: Queen's Printer, 13 May 1988) at 27 (Chair: G. Thomson).
30. This program provided such services as wheelchairs, transportation costs to medical trips, dental services. Many of these supports have been cut recently. See Mykhailovsky & Smith, *ibid.* at 40.
disenfranchised (including Intravenous Drug Users (IVDUs), many gay men and lesbians, a majority of the men and women of colour from low-income communities, teenagers, the homeless, and PLHAs with low literacy levels). Access to information is already an issue for most of these groups, because of education level or language barriers; in other instances, because of negative experiences with the system that result in distrust of bureaucracy and a sense of cynicism and hopelessness about equality of opportunity in receiving information or attaining services. The manner in which such individuals are treated if they seek information can also be an obstacle to services in the social assistance system. The need for clear and widely distributed information about the workings of social assistance, and for training in HIV/AIDS for workers is urgent. The absence of these is responsible, in part, for many PLHAs falling through the cracks, deterred by indifference and illness-inducing stress.

Bureaucratic obstacles to access exist beyond the need for coherent rules and procedures and information about them. Delays characterize the system. Applicants experience delays at three significant points: 1) initial contact; 2) determination of eligibility; and 3) receipt of benefits.

Many PLHAs, especially those who wait to apply for social assistance until they are in dire need, do not have a lot of time. Almost all applicants for social assistance are in need at the time of contact with the administration and require a quick response. This need is exacerbated for PLHAs. One PLHA says of his experience, “the welfare system...it’s not user-friendly. The programs don’t work quickly for someone with changing needs...and that’s the way it is for someone with HIV.”

Countless PLHAs tell of waiting in welfare offices from opening to closing with no response, over a period of days. Once initial contact is achieved, the process of establishing eligibility begins. Applicants report that it can take “sometimes three days to get through on the telephone...you may have to wait up to two weeks to have a home visit too. And on top of everything else, if you’re out of money and not able to work, it can be extremely depressing.”

33. Ibid. at 9.
34. Ibid. at 9 and 41.
35. It can take longer for FBA, during which time the applicant is still on GWA (in most cases). The difference between the amount of money received from FBA and that from GWA is enough, however, to render the wait a factor in a decline in health.
Once the initial stage of establishing eligibility is completed, including the deliberations of the Medical Advisory Board, the delay in the receipt of benefits can be unreasonably long and extremely burdensome for the PLHA. The AIDS Committee of Toronto has documented instances of housing subsidies becoming available posthumously for PLHAs. It seems certain that this could happen with social assistance benefits. The absence of a mechanism to prevent this delay results in people living and dying in unnecessarily harsh circumstances.

The anxiety produced for PLHAs by delays in the social assistance system is damaging to their health. Two important needs all PLHAs share are expedience and stress reduction. The delays from start to finish when interacting with social assistance programs fail on both counts.

(4) Eligibility

In order to qualify for social assistance, an applicant must meet certain income and asset requirements. Many PLHAs are already on social assistance when they test positive or are diagnosed with AIDS. For those who are not, the costs associated with important dietary needs, therapies, medications can begin, or contribute to, a slide into poverty.

For PLHAs who can manage many of the other costs of being HIV positive or having AIDS, the cost of the medication can be absolutely unmanageable. In order to obtain the drug card available to those on social assistance, such PLHAs must “spend down” into poverty, ridding themselves of all assets that would place them above the “cut-off” point for eligibility. This requirement underlines the inflexibility of the system in the face of HIV and AIDS. The expulsion of security from a PLHA’s life in order to survive on inadequate funds, solely to have access to medication, is extremely damaging to the survival potential and quality of life of PLHAs.

Somewhere between managing one’s own costs and qualifying for social assistance benefits is the no-man’s land of legally unrecognized poverty. Healthy survival is impossible for PLHAs at this level of income, yet the relevant regulations do not permit those affected to qualify for social assistance. PLHAs who slide into this limbo, via bona fide loss of funds or conscious spending down, find themselves in a precarious position financially and with regard to their health. This no-man’s land affects all people who do not fall into the

37. Ibid. at 40 and 41. Those waiting for Family Benefits are entitled to an emergency cheque every month until the Benefits begin. Unfortunately, worker ignorance can result in delays in this critical sustenance measure.

38. AIDS Committee of Toronto, supra, note 8 at 4.
definition of poverty sanctioned by the government. For PLHAs, the health consequences can be drastic.

The asset and income requirements are largely responsible for this state of affairs. These standards “oblige recipients to exhaust virtually all their resources, to 'spend down into poverty', and to adjust to an income seen as inadequate for even their most basic of needs. Any nest egg they once had—for emergencies, for the occasional frivolity or for re-establishing themselves—has to be exhausted.” Assets intended to provide for loved ones after death, such as life insurance policies, are also susceptible to this obligation. Furthermore, the process of enhanced verification, whereby workers can investigate how and why the applicant disposed of assets for up to three years prior to the application, places the PLHA at risk of losing security through spending down, and gaining nothing.

For PLHAs already in the social assistance system, the need to stay below the required level of income and assets does not take into account either the roller coaster nature of the illness or the true needs of PLHAs. Because a PLHA can move in and out of serious illness, she could potentially work at times. This ability can be a problem as social assistance is currently constructed, since the periods of wellness render qualifying as disabled or permanently unemployable more difficult. Moreover, the rewards of working, reflected in financial stability, support systems at work and self-esteem are thus precluded by the social assistance regulations.

The legislated inability to work prevents the mental health improvements experienced by those who are part of the workforce. The slide into poverty for many PLHAs can be frightening and unhealthy. The need to hit bottom before qualifying for assistance can have significant repercussions for PLHAs whose health depends in large part on their income. For the PLHA who can afford all but her medication costs, the de facto requirement to “spend down” into the abyss of poverty can reduce life expectancy and critically affect her quality of life.

II. DISABILITY AND UNEMPLOYABILITY

“The determination of disability for the purposes of social assistance requires urgent reform”, reported a group documenting the needs for social assistance

39. AIDS Committee of Toronto, supra, note 8 at 4.
40. SP Research Associates, supra, note 11 at 7.
41. See discussion infra.
reform in 1992.\textsuperscript{42} This urgency is underlined by the AIDS crisis. The numbers of people requiring social assistance are expanded by the slide into poverty of many PLHAs.

Some PLHAs enter the system through the disability or permanent unemployment criteria—both medical categories. Yet, the understanding of AIDS as a disability is in its infancy in Canada. There are many misconceptions about HIV, AIDS and disabilities. The sometime ill-fit of HIV and AIDS into the amorphous category of disability can mean that the disability criteria in social assistance legislation is not applied appropriately by workers who are often victims of the lack of clarity on these issues.

Qualifying as disabled or permanently unemployable under the Family Benefits system seems to be more a matter of luck than anything else.\textsuperscript{43} The importance of an "objective" medical opinion from the Medical Advisory Board, as detailed in the regulations, can be a major barrier for PLHAs in qualifying for Family Benefits. Many doctors have still not familiarized themselves with the intricacies of HIV and AIDS, and are not free of bigotry. They may not want to state for social assistance purposes that the applicant can no longer be employed. In certain instances, this reluctance is a result of their ignorance about the virus. In others, the obstacle can be located in the Family Benefits regulations requiring "prolonged," major impairment. As the most recent welfare reform group stated in \textit{Time for Action}, "certain conditions...may result in severe disability for short periods of time, after which the condition goes into remission and the person may be able to go back to work. Multiple sclerosis is one condition which often has a wax and wane effect."\textsuperscript{44}

HIV and AIDS is perhaps the best example of a "wax and wane" condition. When the condition is at its worst, the PLHA is absolutely qualified for benefits. Yet, some months later, she might be in good condition to work. At present, the system requires the PLHA to leave work permanently instead of leaving for a short time and then returning. The impact on the self-esteem, depression and

\textsuperscript{42} Advisory Group on New Social Assistance Legislation, \textit{Time for Action} (Toronto: Queen's Printer, 1992) at 64.

\textsuperscript{43} General Welfare requires certification as disabled in order to be designated unemployable and to qualify for assistance. Most of the SARB case law is about the definition of disabled and permanently unemployable under the Family Benefits regulations. I focus on that here. It is usually somewhat easier to qualify for General Welfare, although problems do exist vis-a-vis the category of disability in certain instances. Family Benefits, however, provides a higher level of income and does not require periodic checks on disability status, as General Welfare does.

\textsuperscript{44} \textit{Supra}, note 42 at 66.
financial status of the PLHA in question, never mind on workforce productivity, cannot be overstated. One group studying financial instability among PLHAs emphasized that financial crises occur when social assistance rules “do not allow the person affected by HIV to work as health permits, without penalty...the (consequent) reduction in standard of living has a direct correlation to an escalation in stress and deterioration of health.”

A PLHA’s changing ability to work can have drastic consequences in the social assistance system. If an applicant is not deemed permanently unemployable for a prolonged period of time, no assistance will be forthcoming.

In the only documented appeal of a rejection of an HIV positive applicant in the social assistance system in Ontario, it appears that ignorance, misogyny and AIDSphobia won the day at the Family Benefits office. The case throws into question the current process for qualifying as eligible for Family Benefits and sheds light on the ill fit of that process with the realities of the lives of PLHAs.

(1) **Social Assistance Review Board Case # K09-04-05:**

**A Study in Obstacles to Access for PLHAs**

In this case, the applicant was denied Family Benefits on the grounds that she was not a “disabled” or “permanently unemployable” person. This decision was made by a welfare office, upon the recommendation of the Medical Advisory Board that acknowledged the HIV positive status of the applicant.

The applicant was 36 years old and a General Welfare recipient at the time of the Social Assistance Review Board hearing. She had difficulty with her lungs, cervical displacia, cancer of the uterus, seizures, was susceptible to respiratory infection and suffered from severe depression and drug and alcohol abuse. She

45. The inescapable connection in the social assistance regulations between unemployability and disability is highlighted in all its unfairness and inaccuracy in the case of HIV/AIDS. The problems with the construction of disability for PLHAs dovetail with issues raised years ago and to this day by disability rights activists. At the same time, the ill fit for PLHAs in this case raises questions about where HIV/AIDS is placed in mainstream discourse and the illogic of the characterization of AIDS as a disability in certain circumstances. Although there is room for at least the possibility of some flexibility for certain PLHAs in the definitions of disability and permanent unemployability, in practice the permanent work leave is the rule, and it is rare that any deviation from that occurs.

46. AIDS Committee of Toronto, *supra*, note 8 at 3.


had a terminal diagnosis. There was evidence that searching for a job would create stress for her and result in a decline in her health.\textsuperscript{49}

The determination of "permanently unemployable" or "disabled" is made by the welfare office, but is based on the information provided by the Medical Advisory Board. This Board is mandated to verify disability or permanent unemployability based on "objective medical findings." Despite extensive evidence about the medical and depressive state of the applicant living with HIV in this case, the Medical Advisory Board determined that she was neither permanently unemployable, ("unable to engage in remunerative employment for a long period of time"), nor disabled ("having a major physical or mental impairment that is likely to continue for a prolonged period of time and who, as a result thereof, is severely limited in activities pertaining to normal living"). The welfare office accepted this recommendation and denied the applicant benefits.

The recommendation of the Medical Advisory Board was based primarily on submissions from the applicant's doctor who denied that she had AIDS and claimed that she was able to work. The doctor discussed the applicant's history of drug abuse in his statements and suggested that her addiction was not under control, despite her statements that it was, and that drugs, not AIDS, were the problem.

The applicant appealed to the Social Assistance Review Board. The Board granted the applicant's appeal. The Board based its findings, in part, on evidence that the current Canadian definition of AIDS discriminates against women, by excluding diseases that present disproportionately in women with HIV; and that a terminal diagnosis should be considered in determining permanent unemployability.\textsuperscript{50}

The Board also determined that the applicant was not disabled since she had no "major physical or mental impairment that was likely to continue for a prolonged period of time that severely limited her in activities of normal living."\textsuperscript{51} However, they also found that the applicant was permanently unemployable due to her evidence about the effects of her HIV positive status and her drug and alcohol abuse, in the absence of "evidence...to indicate that these medical conditions will improve in the foreseeable future."\textsuperscript{52}

\textsuperscript{49} Supra, note 47.

\textsuperscript{50} Ibid. at 2.

\textsuperscript{51} Ibid at 7.

\textsuperscript{52} Ibid.
Although the applicant ultimately received benefits, the cost of the appeal in time and anxiety to the applicant will never be remedied. The influence of this decision remains to be seen at the administrative level. The SARB decisions are difficult to track, and are often not communicated to frontline workers. Even if workers were to know of the decision, it is unlikely that that they would avail themselves of the information in order to counter letters from doctors and decisions of the Medical Advisory Board. Moreover, SARB decisions have little if any precedential value, rendering uncertain the impact of this case for other applicants.

This case reflects the sexism in the medical profession's work on HIV. Women have not been included in drug trials and, for the most part, have been ignored in studies of physical manifestations of the virus and AIDS. As a result, women die faster of AIDS, sometimes without ever being diagnosed as HIV positive or with AIDS.

The official definitions of AIDS originate at the Center for Disease Control in Atlanta, Georgia, U.S.A. Only in early 1993 did this American federal institute alter its definition of AIDS to include certain physical manifestations predominantly or exclusively found in women. To date, the Center has not conducted a single study on woman-to-woman sexual transmission of HIV. The Canadian definition of AIDS still does not incorporate the effects of the illness in women.53

The connection between the medical treatment of the virus and social assistance is inescapable. In order to qualify for benefits, PLHAs must demonstrate disability or unemployability. If women are not included in the AIDS definition, they are precluded from demonstrating that they have AIDS, a necessary step in establishing a disability or unemployability.54 If a woman has a physician who has educated herself beyond the medical literature and will write a letter certifying unemployability, she still must persuade the Medical Advisory Board, who, to judge by SARB case K-09-04-05, will likely not incorporate women's experiences into their understanding of AIDS, disability and unemployability.

The original denial of benefits in this case has implications for the interpretation of disability and permanently unemployability in cases beyond those involving

53. K. Bastow, supra, note 27 at 5.

54. Although it is hypothetically possible to prove disability or permanent unemployability, regardless of CDC definitions, the situation is actually not so clear. The dependence of the Medical Advisory Board on the doctor's recommendations presents a significant problem if the doctor determines there is not chronic or terminal illness, per se. HIV is not considered either—without a diagnosis of AIDS, it is more likely that applicants will be refused benefits due to lack of proof of disability or permanent unemployability.
HIV and AIDS. Karen Bastow finds that the "process leading to the Social Assistance Review Board decision and the decision itself are significant...The process demonstrates how punitive attitudes towards women and ignorance about women's medical conditions affect their access to social assistance at the initial level of determination."\footnote{Ibid.}

This case suggests that there is critical and urgent work to be done on a number of fronts. First, the determination of disability or permanent unemployability must be delinked from the medical profession to at least a certain extent. Medical information should be a factor, but not solely determinative of eligibility for social assistance.

Second, this case highlights the need for worker training around HIV/AIDS issues for all frontline and managerial staff in the social assistance system, (perhaps including all members of the Medical Advisory Board). Awareness of the diversity of experiences of HIV and AIDS, of the impact of the virus on employability and of problematic attitudes about innocent and "guilty" PLHAs might result in a more humane approach to determining eligibility and the overall treatment of PLHAs in the system.

Third, the possibility of obtaining legal representation that is not AIDSphobic and that is highly knowledgeable seems too unsure at this time. Training of all workers at poverty law clinics and in law firms taking on \textit{pro bono} cases is a necessary first step in establishing a meaningful right to representation for PLHAs.

Finally, it seems important to attend to the obstacles for PLHAs in the appeal process. In the first instance, it would be helpful to have some information about the numbers of applications of PLHAs to the system, and the proportion rejected. At that point, it will be critical to identify obstacles to access in the appeal process that are specific to PLHAs, as well as those that apply across the board.

Time is clearly a factor. If the right to appeal is \textit{de facto} not available to PLHAs due to delays or other obstacles, the right is meaningless. Unfortunately, this analysis has never been done in any strategic fashion. There is almost no commentary on PLHAs in the varied welfare reform reports of the last few years. The reform process seems to be replicating the current invisibility of HIV and AIDS in the social assistance structure.
III. ON BENEFITS: INADEQUACY AND FURTHER COMPLICATIONS
There is an ongoing debate about what constitutes poverty and what should be included when assessing benefit levels. There are significant disagreements about what should be included in the “basket” of necessities for which the state will provide.

A recent study of income support and PLHAs found that social assistance provides PLHAs “with an income which is considered to be inadequate to meet their basic need for food, shelter and clothing.” Some described social assistance in Canada as a “guarantee of poverty rather than a defence against poverty.”

PLHAs require not only the basics in food, shelter and clothing, but also require “special diets, special therapies and special medications.” Transportation to medical appointments, support groups, friends, family and counsellors is another aspect of the lives of PLHAs for which many require assistance. Moreover, maintaining housing when money is running out and when hospital visits create some transience in living situations is a significant difficulty for some.

Without the nutritional balance, the therapies and medications, the physical contact with support systems and stable housing, not only is the quality of life of PLHAs drastically affected, but life expectancy is severely curtailed. Absence of any one of these necessities can affect the physical, mental and emotional well-being of a PLHA.

The anxiety caused by lack of access to important medical benefits such as therapies or a special diet, by inability to travel to centres of support, and by the absence of stable housing adds to the physical decline caused by such insufficiencies. Even those who advocate a minimum basket of goods as the basis for

56. See Ross and Shillington, supra, note 2; R. Sidel, Women and Children Last (New York: Penguin, 1987); C.A. Sarlow, Poverty in Canada (Vancouver: The Fraser Institute, 1992).
57. Ibid.
58. Ibid.
59. There is an important literature on diets that enhance quality of life and improve life expectancy for PLHAs. The requirements in the recommended diets are absolutely impossible to achieve in any significant way on social assistance income, even the higher level of Family Benefits. For the nutritional needs of PLHAs, see L. Lands, Dietary Guidelines for People ving with HIV, Part I (Washington: Carl Vogel Foundation, 1993); HIV Treatment Strategy, Part II-A: Core List of Nutrients for People Living with HIV (Washington: Carl Vogel Foundation, 1993). For the connection between long-term survival as a PLHA and a nutritious diet, see Naomi Pfeiffer, supra, note 7 at 134.
determining levels of benefits would not support assistance levels that have a direct and significant detrimental effect on health.\textsuperscript{60}

It is important to note that poverty in general has this effect. The level of benefits can alter life expectancies for all people in the social assistance system. The issues faced by PLHAs are so obviously connected to health that they highlight the need for both a broad policy approach that ensures that no one is dying faster or getting sick because of the level of benefits, and a more specific social assistance package for those, including PLHAs, who enter the system with a variety of health needs.

PLHAs explain that, "health is primarily an income issue" and describe the incomes available through social assistance as "compromising their health, their well-being and their dignity."\textsuperscript{61} A long-term survivor says, "I'm spending over $5000 a year on Chinese herbs, weekly massages, lots of vitamins and some other treatments that help a lot. There's no way most people can afford this when all they're getting is $550 a month from welfare."\textsuperscript{62}

Levels of income for those qualifying for a Canada or Quebec Pension Plan disability pension or for GAINS-D in Ontario or similar programs in Alberta and B.C. are higher than rates available for those on General Welfare or even Family Benefits. Yet, even these higher rates require the recipient to live at, at best, 60% of the poverty line.\textsuperscript{63} One PLHA describes his financial situation this way:

"After paying rent I'm left with about $230 to live on for the month. I spend $25 for power and $15 for laundry a month. And I live downtown so I can walk most places, or get rides. Or I don't go." This PLHA is in touch with an AIDS Service Organization. At one point, he says, "I had to use the organization's emergency fund once to buy a fan. I can't stand the heat any more. If I had got the money from social services they just would have treated it as an advance and deducted it from next month's cheque."\textsuperscript{64}

PLHAs rarely feel that they have the strength to challenge the social assistance system regarding this and similar practices. Their status as welfare recipients affects their perception of their ability to demand the basics of a standard of

\textsuperscript{60} It is possible that those who advocate the minimum basket might exhibit punitive attitudes towards the poor and PLHAs. Whenever this is an underlying factor in policy discussions, it is best identified so as to avoid punishment as social assistance policy.

\textsuperscript{61} SP Research Associates, \textit{supra}, note 11 at 5.

\textsuperscript{62} \textit{Ibid.}

\textsuperscript{63} \textit{Ibid.} at 6-7.

\textsuperscript{64} \textit{Ibid.} at 6.
living that will not negatively affect their health. The PLHA above explains, "I take what I can get cause I don’t want the hassle; I don’t want to be resented."

The inadequacy of the benefits for PLHAs requires recipients to make terribly difficult decisions. One PLHA discusses his monthly financial experience on a Canada Pension Plan disability pension of $750 per month and a private disability pension worth $240 per month. The private disability pension is actually worth more than $240 a month, but the company deducts the Canada Pension Plan, despite the fact that the recipient contributed to both plans.

After cashing in his RRSPs and cancelling his household insurance policy, selling almost all of his furniture and his car and moving into a small apartment alone so that he would not, perhaps fatally, catch viruses which roommates might bring home, this PLHA finds himself in the following situation on a monthly basis: "I spend $360 on rent, $55 on utilities, $20 on laundry, maybe $50 on medication and bandages, $60 on massage therapy, $40 on a podiatrist and $120 or more on an old loan payment and taxes. Food probably costs me $230 a month. It doesn’t leave much for transportation, for glasses, for clothes, for the odd night out, for emergencies. Some months I had to cut way back on food in order to afford my treatments; and some months I gave up on my treatments to afford food." He adds, "The PLWA organization had to help me out when I needed special braces for my legs. Without them I simply couldn’t walk. But I couldn’t afford them.”

The term social “assistance” seems like a misnomer in this context. The basket of needs for all social assistance recipients is usually undervalued. For PLHAs, the inadequacy of services comes at great cost. As a committee on financial instability and AIDS concluded, “the cost of not meeting this need is human life.”

(1) Further Complications: Reductions and Terminations
The amount of benefits is reduced whenever other sources of money are made available to PLHAs, i.e., through insurance plans or gifts. If the system afforded benefits sufficient to provide PLHAs with enough to ensure that their health is not an “income issue”, this practice might not be a problem. In the current system, it results in PLHAs having to make difficult decisions which are detrimental to their health.

65. Ibid.

66. An interesting and important question arises here regarding state-subsidization of the (profitable) private insurance industry. I thank Richard Elliot for this observation.

67. AIDS Committee of Toronto, supra, note 8 at 4.
Another complication is the difficulty of maintaining benefits in certain circumstances. Gaining access to benefits can be a time-consuming, overwhelming feat in and of itself. Termination of benefits often necessitates a return to the process to some extent for PLHAs who, by that point, usually have neither the time nor the energy to confront such obstacles yet again.

First, the rule that any income PLHAs receive apart from social assistance must be deducted dollar for dollar from their benefits places PLHAs in a difficult situation. The combination of these rules and the inadequacy of the benefits overall creates an incentive to not report the other source of income. This could result in, “discovery, disentitlement and conceivably even criminal action.”

Second, being cut off from benefits completely is a devastating but real possibility for some recipients. One group affected by such termination is PLHAs who move in and out of the prison system, or even those who are jailed one time. Imprisonment usually entails an end to benefits. For those PLHAs who live on the street, especially those involved in prostitution, this can be a significant obstacle to getting and staying on benefits.

One AIDS Service Organization staff member reports, “you’re working on all these issues and you’re trying to get them housing and you’re trying to get them drug treatment and you’re trying to work on the issues, if they send them to jail for four months, that all goes out the window. We just have to start all over again at the beginning. And we have clients that go through that cycle every eight or nine months.”

The lack of coordination between the corrections system and the social assistance system results in further problems for certain PLHAs. If PLHAs are living in bail houses, Family Benefits administrators do not consider them in their jurisdiction. They fall under the auspices of the Ministry of Correctional Services. Only PLHAs who are lucky enough to have determined advocates will be able to reenter the Family Benefits system and gain access to a drug card, which is critical for their survival.

The increasing rate of HIV transmission in prisons renders these obstacles a crisis in and of themselves. Lack of communication and coordination among

68. Only if the recipient is part of the STEP program is this rule suspended.
69. SP Research Associates, supra, note 11 at 8.
70. Mykhailovskiy & Smith, supra, note 14 at 57.
71. Ibid.
72. Ibid.
government departments in this instance can result in early deaths and painfully low standards of living for the PLHAs affected.

(2) **Drug Funding**
Currently, the need to be on social assistance in order to get a drug card is one of the greatest obstacles to good health and survival for PLHAs. For those who do not qualify for social assistance, the requirement to “spend down”, has drastic effects on the quality and longevity of life for PLHAs. The drug card does not cover all medications necessary for PLHAs. “Many drugs, vitamins, complementary therapies, and nutritional supplements, which are important for maintaining the health of an individual with a compromised immune system...are not covered.” Experimental treatments that are being used by physicians are also not covered. These treatments provide new hope for PLHAs who are not responding to the established medication. The inability of PLHAs to try these treatments solely because of financial status is an inequality with dire effects. Another significant problem is the delay in the coverage of newly licensed treatments. This delay can often result in earlier deaths that might have been prevented by a system that is responsive to the needs of PLHAs.

(3) **Housing**
In 1988, the AIDS Committee of Toronto identified “secure housing as a critical concern for people with AIDS.” Little action has been taken since then to ensure stable housing for PLHAs. Yet, housing is a “foundation for daily


74. PWA Foundation, “Fact Sheet: Getting Nutritional Products: Government Changes the Rules” (1993). As of April 1993, PLHAs on Family Benefits are required to pay some of the cost of nutritional supplements that are covered. Although they are still covered by the drug card, this development places certain health-enhancing supplements out of the range of the many who cannot afford the additional charges.

75. In order to obtain access to such treatments, PLHAs must be accepted into a clinical drug trial. A Section Eight request or compassionate arm funding, currently being demanded by AIDS Action Now! activists, can make the difference regarding funding of such treatments. Neither option is extensive enough at present to affect enough PLHAs in urgent need of treatment.

76. Drug trials are themselves controversial. The exclusion of women from most trials has led to negative publicity, demonstrations and concessions from the drug companies and governments to alter their protocols so as not to discriminate when providing opportunities to take potentially lifesaving medication. This struggle for inclusion is ongoing.


78. AIDS Committee of Toronto, *supra*, note 8 at 3.
living.” It can affect all other aspects of health, positively or negatively, depending on circumstances.

One PLHA who was living on the street explains that moving into supportive housing after living on the street meant that he was now “dealing with HIV seriously.” Stable housing gave him a foundation for seeking treatment for substance abuse problems and gaining access to a variety of social services. PLHAs who have crime, drug use or psychiatric histories, or are otherwise considered “hard to house” have a difficult time getting into supportive housing. A recent housing study points to the need for “standards of adequacy” for housing for PLHAs and underlines the connections between social assistance and housing. Social assistance housing allowances often require PLHAs to live in unhealthy housing, or to move from communities where critical support is available to isolated, sometimes violent housing alternatives.

Partner abuse is also an issue for PLHAs in poverty. Violence escalates in times of stress and the ability to escape “domestic” violence is severely curtailed for those with financial constraints and few housing alternatives.

In Toronto, Metro Toronto Housing Authority subsidies are available to PLHAs. The delays in receiving these subsidies, however, often render them useless for PLHAs, who are either hospitalized or dead by the time they come through.

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79. Mykhailovskiy & Smith, supra, note 11 at 42.
80. Ibid. at 43.
81. Ibid. at 45.
83. Conversation with Pamela Bowes, Counsellor, PWA Foundation, Fall 1993. Public Housing can often be dangerous for PLHAs who are identifiable as such. In some instances, PLHAs become shut-ins because of the fear of violence in their buildings. This solution of course precludes access to services that are necessary for maintaining mental and physical health, such as counselling, medical services, support groups.
85. AIDS Committee of Toronto, supra, note 8 at 4.
Housing is a severe crisis for many PLHAs. The anxiety for those who are barely managing to stay in their homes, as well as for those who have become homeless due to a combination of AIDS and the inadequacy of social assistance and housing alternatives can have a detrimental influence on the health of PLHAs. Living in substandard housing or on the street due to inadequate benefit levels can kill PLHAs.

IV. CONCLUSION: WHAT IS TO BE DONE?
There are no easy answers to the crisis of AIDS and poverty. The urgency of the issues, however, demands an immediate and comprehensive response. The above discussion points to changes that need to be made in order to save the lives of PLHAs whom we have not yet lost to inaction and indifference. Below, I conclude with recommendations for action.

At one level, there are changes that can be enacted immediately without an influx of significant resources. There must be massive education about the crisis itself so as to alert people to the need for change. In any strategy for change, we must ensure that outreach and education in order to combat stigma reaches all communities. There are different issues for lesbians from gay men; for immigrants from citizens; for Asians from Natives; for youth from seniors. The stigma varies in form and content in each community. Knowledge about how is fundamental to addressing the obstacles for different groups.

A central component in any education campaign is the training of lawyers and social service workers involved in poverty work, especially those who are currently not addressing specifically the needs of their clients with HIV/AIDS. This education must accompany an extensive information campaign with the goal of eliminating the stigma of both poverty and AIDS, for these stigmas are concrete barriers to social assistance and client wellbeing. Social workers and


87. Unfortunately, lawyers in leadership roles in the profession have not acted as role models on this issue. Peter Bartlett, in “AIDS and the Law”, (1988) Equity 19, reports that Edward Greenspan told students in the Ethics section of the Bar Admission Course (Fall 1987), that “if a PWA came to his office to ask his advice, he would fumigate the office when the person left.” Clearly, education of law students, lawyers and judges is desperately needed in order to ensure the highest quality of service possible from our profession for PLHAs.
lawyers for PLHAs have a responsibility to advocate for their clients within the social assistance system in an educated and sensitive fashion.

Any strategy for education must include social assistance worker training. Such training is desperately needed in order to develop a workforce knowledgeable about HIV/AIDS and consistent in their application of rules and procedures. Those on SARBS and on the Medical Advisory Board should attend training sessions about HIV/AIDS and its implications for employability.

Dissemination of clear, comprehensive information about the social assistance system must occur as soon as possible. This dissemination must target different communities, taking into account the different needs based on literacy levels, experience with the government, and attitudes about entitlement.

Another vital change is a stable housing guarantee for all PLHAs. Social service agencies, residences, lawyers in poverty clinics, and the government need to work together to provide housing alternatives for PLHAs who are forced to move from their homes. No PLHA should be homeless or living in substandard housing.

In the short term, the process for determining disability and permanent unemployability for Family Benefits can be altered. The influence of the recommendations of the Medical Advisory Board or individual doctors might be diminished, providing a more balanced assessment for social assistance administrators. The makeup of the Board needs to be determined, in part, by taking into account the knowledge of potential members regarding HIV and AIDS. This precaution can be combined with mandatory training in order to ensure educated recommendations that do not exclude PLHAs in need from the system.

At the next level, certain changes require legislative change. Eligibility criteria for social assistance must receive urgent attention, especially in its application to PLHAs, although whatever changes are made in this area will clearly affect other applicants to the system. The income and asset requirements must be adjusted so as to ensure the health of all poor PLHAs. The changes in these requirements will be tied to whatever action is taken to provide catastrophic drug funding, as distinct from a drug card linked to the social assistance benefits structure. The interpretation of the disability and unemployability requirements must be updated to fully acknowledge the specific issues facing PLHAs, such as the roller coaster nature of the illness and the importance of working at times. These changes include a serious re-evaluation of the role and composition of the Medical Advisory Board.

An immediate reassessment of the adequacy of benefits is necessary in order to save the lives of PLHAs who are dying from neglect within the system. The
system's response to special circumstances, such as extra income or imprisonment, must be redesigned with PLHAs in mind.

These are the bare bones of what need to be the goals of the social assistance system in addressing the needs of PLHAs. Liberty, justice and decency must inform the design and reform of systems that are meant to assist those most in need in our society. The delay in addressing the crisis of poverty and HIV/AIDS is costing the lives of those who turn to the law as a last resort, and who are rarely assisted in anything but a decline in health and a quick death.