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SOCIAL SECURITY AND HIV/AIDS: ASSESSING “DISABILITY” IN THE CONTEXT OF ARV TREATMENT

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Social Security Provision and HIV/AIDS in South Africa: Assessing “Disability” in the Context of ARV Treatment

Abstract

Despite its less-than-stellar implementation, the South African government’s 2003 commitment to providing free antiretroviral therapy to those with AIDS has both provided hope to the many infected while at the same time highlighting the gross inadequacies of the current welfare system’s design. Examining circumstances in the Western Cape is a useful way of exploring the relationship between poverty and HIV/AIDS, as well as the role of government welfare programmes in influencing the success or failure of prevention and treatment interventions. This paper attempts to outline the shortfalls of the current social safety net in South Africa and the particular effects of those inadequacies on people suffering with HIV and AIDS. It focuses specifically on the disability grant in the Western Cape province, arguing that, in the absence of comprehensive unemployment benefits or a universal basic income grant, a broader redefinition of disability is needed that takes into account social factors in addition to a medical diagnosis. Finally, future legislation is evaluated, and potential solutions are suggested and critiqued.

Introduction

For a long time, AIDS in South Africa was considered an inevitable death sentence for the poor who contracted it. Despite the existence of antiretroviral drugs proven to prolong life and suppress the AIDS virus indefinitely, the majority of infected South Africans were unable to afford them, and the number of new infections and AIDS deaths skyrocketed. New statistics from the ASSA2002 demographic model suggest that currently, in 2004, 18.7% of adults and 10.8% of all South Africans, almost 4.5 million people, are HIV positive. Few of those infected have had access to treatment. Just recently, however, in August 2003, the efforts of countless individuals and NGOs began to pay off as the government announced plans for a national rollout of antiretrovirals, intended to eventually provide drugs to all those in need, regardless of ability to pay. The process has been a slow one plagued by problems and setbacks, but in some parts of the country, most notably the urban areas of the Western Cape, significant progress has been made. Ironically, however, success in the provision of ARVs has highlighted the inadequacy of South Africa's social security system, which currently provides no unemployment benefits for almost one third of the population in need of a job; [1] only those judged too sick to work are supposed to be given a small subsidy, in the form of a disability grant, that often serves as the only source of income for entire families. This is the terrible irony of an epidemic that slowly takes lives while making many unemployed South Africans eligible for just enough money to put food on the table. Now, however, in the early stages of the ARV rollout, many with AIDS are being forced to make a decision no one should have to make, between life-saving medicines and the ability to feed their families.

Given these circumstances, South Africa is a useful case study for exploring the relationship between poverty and HIV/AIDS, as well as the role of government programmes in influencing the success or failure of HIV/AIDS prevention and treatment interventions. This paper attempts to outline the inadequacies of the current social safety net in South Africa and the particular effects of those inadequacies on people suffering with HIV and AIDS. It focuses specifically on the disability grant in the Western Cape province, arguing, in the absence of comprehensive unemployment benefits or a basic income grant, for a broader redefinition of disability that takes into account social factors in addition to a medical diagnosis. Finally, future legislation is evaluated, and potential solutions are suggested and critiqued.

The Right to Social Assistance

South Africa's 1996 constitution is respected the world-over for its commitment to equality and its impressive and comprehensive Bill of Rights. Among those rights is the right to social assistance, as spelled out in section 27 (1) (c):

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[1] According to a broad definition of unemployment (South African Labour Force Survey, September 2003).

> ‘everyone has the right to have access to – (c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance’.

To implement this right, Parliament passed Act 59, the Social Assistance Bill, in 1992 and then amended it in 2001. The bill provides for a number of social grants, each aimed at a particular population. Child support grants, foster care grants, and care dependency grants target children; old-age grants and war veteran’s grants assist the elderly; disability grants are intended for those unable to work; social relief of distress grants assist those in emergencies, and grants-in-aid provide additional help for those already receiving another grant who cannot take care of themselves. Despite critiques suggesting that means-testing is an inefficient and inadequate way of targeting those most in-need, government continues to insist on assessing income before providing any type of grant[2]. Nationally, approximately eight million people receive social grants, 584,542 of them, or about 7% of the total, in the Western Cape alone (Department of Social Development 2004). At the moment, although the national Department of Social Development guides the implementation of social assistance, the distribution of funds is left to the individual provinces. In 2003/4 the Western Cape will spend R3.8 billion (approximately $550 million), or 23% of its R16.4 billion budget, on social assistance, an increase of approximately 1% from it 2003/2004 budget of R14.5 billion (Western Cape Budget Report, 2003/2004).

This constitutional mandate for the provision of social security poses a number of challenges for a middle-income country such as South Africa, especially in light of substantial poverty and inequality. A per capita GDP of $10,700 hides the fact that fifty percent of South Africans live below the poverty line, many of them in under-resourced rural areas or urban townships (CIA 2004). Despite a national unemployment rate of 26% by a strict definition, the social assistance provided for in Act 59 of 1992 is premised on full-employment, meaning that in 2001, none of the 4.2 million unemployed South Africans were eligible for help because of their inability to find work (Taylor Report 2002)[3]. And while seven million formally-employed workers are required to contribute to the Unemployment Insurance Fund (UIF), allowing them to collect benefits if retrenched, more than 2.7 million South Africans working in the informal sector do not contribute and thus are ineligible for assistance (Seekings 2002). It is clear that South Africa’s social safety net has a large hole. Whereas the

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[2] See “Research Review on Social Security Reform and the Basic Income Grant for South Africa,” Economic Policy Research Institute, 2002.

[3] A broader definition of that includes those in need of work but no longer actively seeking it puts the unemployment rate at 41.8% (see Labour Force Survey, September 2003).

right to social assistance is a real one for the young, the old, and the physically disabled, millions of poor, working-age adults without jobs are lacking even the most basic necessities for themselves and their families. Exacerbated by HIV/AIDS in recent years, this problem is one that cannot be ignored any longer.

An Overview of Disability Grants

The lack of support for the poor unemployed in South Africa has led many working-age adults to look to the disability grant as their only potential source of income. The Social Assistance Bill of 1992, section (1) defines a "disabled person" as:

> 'any person who has attained the prescribed age and is, owing to his or her physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance'.

While there may be room for interpretation, the guidelines suggest that disability assistance should be provided to those people who, due to physical or mental difficulties, are unable to obtain employment. The implicit assumption, then, and one that has been mentioned, is that in the absence of disability, employment is guaranteed. Given South Africa's 26% unemployment rate, however, this assumption is grossly unrealistic.

To qualify for a disability grant, an applicant must meet a number of criteria: men must be older than 18 and younger than 65, women must be younger than 60; an applicant may not be receiving another grant from the government, he/she must not be in the care of a state institution, and he/she must not be capable of working due to a disability. The grant is means-tested, so for a single applicant, he/she must have an income of less than R1,502 and assets worth less than R266,400. For married applicants, combined income must be less than R2,782 with assets worth less than R532,800.[4] Grant payouts are determined according to assets and income, with the maximum disability grant award in 2004 at R740/month and the minimum award at R105/month.

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[4] Means-testing criteria along with the amount of the grant payout may change every year. These figures were accurate in 2004.

The relatively generous nature of the means-test, however, results in the maximum payout for the majority of those eligible for the grant.

Overview of Disability Assessment Procedures

Given the national regulations governing disability grants, individual provinces have been left to develop assessment tools for measuring an applicant's ability to work in the open labour market. As a result, disparities exist from province to province as to who, specifically, is eligible for the grant. In the Western Cape prior to 2001, physicians at state-owned clinics and hospitals were expected to medically evaluate patients and provide a recommendation to the pension medical officers (PMO) at the provincial level. Depending on the situation, doctors could suggest a temporary six month grant, a one year grant, or a "permanent grant" that could be reviewed at five-year intervals. Along with administrators at the Department of Social Services, the PMOs then reviewed the applications and made decisions on a monthly basis. In 2001, however, the Social Assistance Bill of 1992 was amended to phase out the PMOs, who, many complained, were making decisions regarding patient welfare without ever examining the patients themselves. In place of the PMOs, the new legislation provided for two possibilities: provinces could either rely simply on the recommendations of physicians at state clinics and hospitals, and/or they could convene assessment panels to evaluate applicants. Many rural areas suffering from a shortage of doctors chose to experiment with assessment panels, comprised usually of a nurse, an employee from the department of social services, a social worker, and a community member. Some provinces even made an effort to include a representative from local disability NGOs. In addition, all provinces were required to establish a board of appeals to review and rule on previous decisions when appealed in writing.

Responding to a survey conducted by the Black Sash in 2003, an organisation which focuses on social assistance in South Africa, eight of the nine provinces commented on their experiences with assessment panels and disability grants. Limpopo, the Free State, Mpumalanga, and the North-West province each set up between two and 35 assessment panels. The Northern and East Cape provinces initiated pilot projects for the assessment panels but cancelled them due to logistical difficulties. The Western Cape and Gauteng provinces decided to make disbursement of disability grants contingent solely on the opinion of a state physician (Kallmann 2003). According to Andre Brink, deputy director of the Department of Social Services of the Western Cape province, the Western Cape chose not to make use of assessment panels for two reasons: first, the national Department of Social Development had interpreted the Social Assistance Bill of 1992 (amended 2001) to require a medical disability, and second, the national department had provided no operating guidelines for the assessment panels. In the absence of a physician and guidelines from the national department, assessment panels were making decisions based on largely social factors, including, for example, the inability to find employment in a given area[5].

Examining Trends in Disability Grant Uptake

Nationally, the uptake in disability grants has increased from 714,019 in 2002 to 953,965 in 2003, a 33.6% increase. According to the South Africa Commission for Human Rights, however, reporting on responses from the National Department of Social Development, only 943,676 people were eligible for the grant in 2002/2003 (SAHRC 2002/03). This trend of grant uptake exceeding eligibility figures is indicative of problems with reporting methods, fraud, or with ambiguities in the eligibility requirements for disability grants[6]. An examination of the grants awarded between 2000/1 and projected estimates for 2006/7 shows a general increase in uptake for disability grants. The Department of Social Services in the Western Cape attributes the substantial jump of 23.37% in 2002/3 to the phasing out of the PMOs, effectively easing the process of receiving a disability grant. Artificially high growth in 2003/4 is the result of the reinstatement of lapsed temporary disability grants due to a court order in the Eastern Cape Mashishi case – because recipients were not properly notified of cancellations, the High Court of South Africa restored 54,000 six-month grants. The net decline in 2004/5 reflects the gradual cancellation of these Mashishi grants. The 2005/6 and 2006/7 estimates reflect a natural annual increase in demand and eligibility for disability grants, probably due to the impact of HIV/AIDS in the Western Cape.

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[5] Interview with Andre Brink, Deputy Director, Department of Social Services, July 26, 2004.

[6] The national Department of Social Development and the provincial equivalent in the Western Cape estimate eligibility for the disability grant according to a model developed by Ingrid Woolard of the Human Sciences Research Council of South Africa. The model attempts to reconcile grants awarded annually with household survey results.

Table 1. Disability Grants Awarded in the Western Cape[7]

Fiscal Year	*April*	*August*	*December*	*Total*	*Growth*
2000/1	89,960	92,493	92,844	1,101,385	1.66%
2001/2	90,721	93,395	98,269	1,141,138	3.61%
2002/3	105,562	117,656	126,851	1,407,875	23.37%
2003/4	114,408	128,454	118,541	1,473,314	4.65%
2004/5	123,196	120,580*	121,806*	1,459,347*	-0.95%*
2005/6	123,348*	125,833*	128,369*	1,521,567*	4.26%*
2006/7	130,956*	133,595*	136,287*	1,615,413*	6.17%*

Note: *Projected estimates.

HIV/AIDS and Disability Grants

Given that HIV/AIDS in South Africa is such a debilitating problem, it is interesting that social assistance legislation makes no mention of it, even in the context of disability grants. As a result, confusion abounds as to when an HIV or AIDS diagnosis qualifies a poor South African for social assistance. Those suffering from the advanced stages of the disease (stage 4 as defined by the World Health Organisation's guidelines) are symptomatic with serious opportunistic infections and often bed-ridden for most of the day; these people are unable to work by any definition, and the Western Cape Department of Social Services has historically provided them with disability grants. Clinical stages 1, 2, and 3, however, are more ambiguous and may or may not be marked by symptoms and weight loss. In addition, people living with HIV and AIDS may have abnormally low CD4 counts[8] without exhibiting symptoms. The Centers for Disease Control and Prevention consider an HIV-infected person with a CD4 count of less than 200 cells per cubic millimeter of blood to have AIDS, regardless of whether they feel sick or healthy. It is possible, then, that someone in stage 1 or 2 according to clinical WHO guidelines could have a dangerously low CD4 count. And as we will see later, the recent introduction of antiretroviral drugs in South Africa has made the reverse true as well: someone in stage 4 and on treatment might feel perfectly healthy with a normal CD4 count. Neither the national Department of Social Development, nor the provincial Department of Social Services in the Western Cape has acted on

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[7] Courtesy of the Department of Social Services, Western Cape.

[8] A CD4 count measures the strength of the body's immune system and helps track the progression of HIV.

these important distinctions. Instead, both departments have added to the confusion surrounding HIV/AIDS and the awarding of disability grants.

In March of 2002, a spokesperson for the provincial minister of the Department of Social Services and Poverty Alleviation, Marius Fransman, reported in the Cape Times newspaper that “The minute you are diagnosed with [HIV/AIDS], you can apply for the [disability grant]. If you have proof from a doctor, you can apply. It does not matter what stage of the illness you are in” (Cape Times, March 21, 2002). Advocacy groups like the Treatment Action Campaign knew that those with full-blown AIDS were eligible for the grant, but they welcomed this seeming change in provincial policy as reflective of a new commitment to fighting the epidemic in its earliest stages. A few weeks later, however, MEC Fransman rescinded the earlier statement, but not before many South Africans had adopted the misconception that the disability grant was a de facto HIV grant as well. Two years later, that misconception perseveres, especially among the unemployed desperately in need of even a small monthly income. The reality however, is that the Western Cape has now moved towards a strictly medical diagnosis: only those in stage 4 of the illness, or the latter parts of stage 3, are eligible for the disability grant (Department of Social Services and Poverty Alleviation 2002). In clinics with the capacity to monitor CD4 counts, a count of less than 200, thus signaling an AIDS diagnosis, is also sufficient for the awarding of a disability grant; however, rural areas in particular often lack the necessary equipment for such laboratory testing[9].

In the context of such high unemployment and general confusion and ambiguity surrounding HIV/AIDS and disability grants, many poor South Africans, both HIV positive and negative, have tried to use the disability grant as a source of income. Many with HIV have gone to primary health clinics hoping for a disability grant recommendation from their doctor, only to be turned away. Others, many healthy, have resorted to fraud in order to qualify. Doctors and administrators from the Department of Social Services are aware of numerous “syndicates”[10] that forge applications, with the help, it is suspected, of insiders within the Department itself. Another, less explicit type of “fraud” is practiced by many of the physicians responsible for filling out disability forms at health clinics and making recommendations to the province. A number of doctors admit to recommending grants for patients with HIV who do not qualify according to the ambiguous Western Cape guidelines. They explain that patients with HIV need proper nutrition in order to remain healthy for longer; in the absence of employment and a disability grant, the majority of

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[9] According to Karen Kallmann of Black Sash, the Western Cape is the only province to have identified specific criteria for the awarding of disability grants for people with AIDS.

[10] Interview with a senior clerk at the district welfare office in Khayelitsha.

patients will not have access to the right foods in sufficient quantities. Other doctors, including those accountable to larger organisations, like Medecins Sans Frontiers, as well as those physicians employed directly by the Department of Social Services for the purpose of completing grant examinations, are more hesitant to bend the rules when it comes to disability grants. On one occasion in the Langa township, the author observed the attending physician instruct all her newly diagnosed HIV patients to eat fish, chicken, citrus and green vegetables. One patient, an elderly man in his fifties without a job, looked at her and asked how he was supposed to afford that kind of food without the help of a disability grant. The doctor had no reply as she ushered him out the door.

Recently, the national Department of Social Development has begun tightening restrictions on disability grants throughout the provinces, claiming that too many people are using the grants as a form of poverty alleviation. According to the Department, HIV is not considered a disability but rather a "chronic disease," not severe enough to prevent someone from working in the open labor market. In a January 29, 2004 statement, the Minister of Social Development, Dr. Zola St Skweyiya, emphasised the state's position on disability grants and HIV/AIDS:

> 'This fraud is partly due to the inability to distinguish clearly between people who are disabled and people with chronic diseases…The disability grant is not intended to provide relief from chronic diseases. The Government is committed to and has been implementing a comprehensive strategy to address the issue of HIV / AIDS. The Government does not, however, provide a social grant specifically or exclusively for people who are HIV Positive'.

Clearly something is awry in South Africa when those suffering as a result of poverty, unemployment, and HIV are denied care by the government constitutionally obligated to provide it.

The Plot Thickens: The Effect of Antiretroviral Provision on Disability Grants

As if things were not complicated enough, the long-awaited, albeit gradual introduction of Highly Active Antiretroviral Therapy (HAART) in some parts of South Africa is highlighting the inadequacies of current social assistance. Of the 500,000 people in the country estimated to need treatment, less than 10% of them, approximately 45,000, are receiving it, and mostly through the private sector. Only 6,000 people are benefiting from ARVs provided by the government, despite the August 2003 commitment to make available free government treatment to 50,000 within the first year. The Western Cape provincial government alone distributes ARVs to approximately 3,057 people, and due to its unusual concentration of health NGOs and academic institutions, probably provides treatment to thousands more through private channels.[11] Because of the relatively good access to ARVs in the Western Cape, the province serves as a potential microcosm for examining the effects of AIDS treatments on disability grants and vice versa.

In 2001, long before free treatment was available to the general public, Medecins Sans Frontiers began providing ARVs to a small group of AIDS patients at its Site B clinic in Khayelitsha, and today that number has grown to more than 1,000. Consequently, it was one of the first locations to come into contact with what is now becoming an increasingly common dilemma in the Western Cape concerning the provision of disability grants. Modern day antiretrovirals are able to suppress the HI virus quite effectively, allowing the body's immune system to recover and decreasing the ability of the virus to pass from one person to another. There is debate within medical circles as to when ARVs should be initiated, but doctors agree that once started, they must be continued indefinitely in order to keep the virus suppressed and to prevent drug resistance. If used correctly, ARVs can allow people with AIDS to regain their health, but because the virus remains latent in their bodies, they retain an AIDS diagnosis. For example, a patient who begins ARVs in WHO stage 4 remains stage 4 throughout his life, even if treatment rids him of his symptoms.

Whereas for the longest time an AIDS diagnosis (WHO clinical stages 3 and 4) was practically synonymous with a physical inability to work, ARVs have effectively disassociated the two and raised questions about the definition of disability in the context of HIV/AIDS. The Western Cape and the national Department of Social Development are only now beginning to realise that people living with AIDS, if they have access to ARVs, may be healthy enough to work in an open labour market. Technically, then, they should not be eligible for the disability grant, which the state claims is reserved for those who, due to a physical or mental disability, are unable to obtain employment. However, according to Western Cape guidelines, which specify that anyone diagnosed with stage 3 or stage 4 AIDS who meets the means test is eligible for the grant,

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[11] Estimates according to the ASSA2002 model and the Treatment Action Campaign (in a July 20, 2004 update).

people on ARVs *are* still entitled to the grant because medically they retain their clinical diagnosis despite improvements in health. This is a case, then, of the letter of the law in conflict with its spirit.

How are physicians responding to the apparent contradiction? As with disability grants in general, some doctors are utilising the apparent loophole to continue to provide grants to poor patients on ARVs, ostensibly to help them with food and other expenses. Others, however, are refusing to renew disability grants for patients who begin to improve on ARVs, citing that these patients are theoretically well enough to work.[12] The fact that there are no jobs available is an unfortunate side-note. For an increasing number of people with AIDS, then, the choice is rapidly becoming one between health and just enough income to care for themselves and their families.

The Department of Social Services of the Western Cape has thus far refused to address directly the issue of disability grants for people improving on ARVs, choosing instead to shift the onus of decision-making to physicians while providing only ambiguous guidelines at best. This reliance on a "medical model" for defining disability allows the state to justify inadequate social assistance by requiring doctors to assess employability in the absence of social considerations. According to the Taylor Committee's report on social security in South Africa, this model constitutes a failure to consider "social and labour market barriers, as well as broader social and environmental factors which inhibit labour market participation" (Taylor Report 2002: section 10.3.1). In effect, the state is demanding from doctors an objective outcome, namely that only those people physically or mentally unfit to work be awarded disability grants, by way of subjective decision-making. As Mr. Andre Brink, deputy director for social security in the Western Cape, emphasised repeatedly in a July 2004 interview, the Department of Social Services awards disability grants based solely on doctor recommendations. But the truth is that doctors are being pressured to do, not necessarily what is best for patients, but rather what is best for the state and its budget: namely to cancel disability grants for patients on ARVs who could theoretically find employment. The disingenuous nature of these justifications becomes evident when one considers that physicians employed by the Department of Social Services specifically to handle disability

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[12] The author was unable to locate provincial documents mandating the cancellation of disability grants for people improving on ARVs. However, overwhelming anecdotal evidence from doctors, people living with AIDS, and administrators within the Department of Social Services suggests that this is indeed the reality in the Western Cape.

grant applications at primary health clinics are instructed to cancel grants for people with AIDS receiving HAART.[13]

Implications of Canceling Disability Grants for People on ARVs

The implications of the Western Cape's policy of canceling disability grants for people improving on ARVs are somewhat disheartening: just as people are beginning to regain their health and to put their lives back together, a substantial source of income is being withdrawn. From a medical perspective, the policy has the potential to create a vicious cycle of sickness and health. The disability grant, in conjunction with ARVs, helps individuals gain access to proper nutrition and other necessities conducive to health. As soon as a standard of health that permits employment is achieved, however, the disability grant is cut, leading once again to inadequate nutrition, stress, etc., all of which undermine the effectiveness of AIDS treatments and lead to a subsequent decline in health. Sickness qualifies the individual for the disability grant once again, and the cycle is repeated. In addition to this artificial cycle of sickness and health brought about by disability grant policy, the recent cancellations create the possibility for an even more explicit set of perverse incentives. In her book *The Moral Economy of AIDS in South Africa*, Nattrass (2004) draws upon an interview from a previous study in which a young woman explains how HIV has actually improved her life by giving her access to social assistance:

> 'Yes I like this HIV/AIDS because we have grants to support us…Before I was staying with my mother and father and sister, they didn't work. Maybe I was taking three to four days without food. People discriminated against me and no one came in the house. The only thing that was helping was my grandmother's pension. We were surviving on that money. Concerning the illness, our lives are changed completely' (quoted in Steinberg *et al*. 2002b:29).

Ironically, in many parts of South Africa, the combination of poverty and unemployment has made HIV/AIDS one of the few remaining avenues for short-term survival. Now, a similar perverse incentive seems to be rearing its head for many of South Africa's poor suffering from HIV/AIDS and only now receiving access to ARVs. Anecdotal evidence suggests that as grants are cut,

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[13] Interview with physician employed by the Department of Social Services, Western Cape, to handle disability grant applications in a number of primary care clinics, July 21, 2004.

some people with AIDS may intentionally "yo-yo" on and off treatment in order to maintain access to disability grants. In addition to being harmful for the individual, this type of behavior undermines the strict treatment adherence (greater than 90%) necessary to prevent the development of drug-resistant viral strains.

Some organisations in South Africa are already beginning to question the legality of the government's disability grant policy, specifically as it affects people on ARVs. They argue that providing social assistance temporarily during periods of illness creates a "legitimate expectation" that social assistance will be continued in the absence of available employment; when disability grants are stopped, then, the state creates an "undue hardship" for the poor suffering from HIV/AIDS,[14] in violation of the constitution's guarantee that the state will take "reasonable legislative and other measures, within its available resources, to achieve the progressive realisation" of the right to healthcare and social security (Constitution of the Republic of South Africa, 1996, chapter 2, (27)(2)).

Overhauling Disability Grants Administration

The cancellation of disability grants for people on HAART undoubtedly demonstrates that social assistance in South Africa is not serving those people who need it most. But in addition to its failure with regard to people with HIV/AIDS, disability grants suffer from a host of additional administrative problems that undermine their effectiveness, including misinformation, excessive requirements, backlogs, sub-par delivery mechanisms, and fraud.

Misinformation and excessive requirements together have contributed to the inaccessibility of social grants for the poor who need them. Ambiguity and confusion surrounding disability grant criteria is compounded by conflicting information provided by the Department of Social Services through its various media channels. The Western Cape's provincial website and its free social assistance telephone information line describe different means-testing criteria for the same grant. Furthermore, ignorance among the administrative staff at some of the district welfare offices, including those in relatively affluent areas of Cape Town, makes it unlikely that accurate information is being conveyed to applicants. The manager of the Wynberg district office's assessment department for disability grants was surprisingly misinformed about AIDS in

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[14] Interview with Ms. Fatima Hassan of the AIDS Law Project, July 26, 2004.

general and the provincial policy for people on HAART; according to him, a clinical diagnosis of stage 4 AIDS guarantees certain death for the patient soon after, making disability grants unnecessary.[15] Of course, ARVs have been proven quite effective in prolonging life indefinitely for people with a stage 4 diagnosis. The fact that those responsible for distributing grants to the disabled are unaware of this basic fact is troubling and does not speak highly of the state of social assistance in South Africa. This same manager admitted that the Western Cape has intentionally withheld information from the general population in order to constrain budgetary pressures and limit the workload for government staff. He noted, for example, that a public campaign to inform South Africans of their right to appeal a grant decision would lead to an unmanageable influx of applications. Requiring that these appeals be made in writing ensures that many of the poorest South Africans, many of whom are illiterate, do not get the hearing they deserve. Convenience, then, rather than a desire to provide adequate social assistance, seems to be the priority in the Western Cape.

Eligibility and access aside, social grants and disability grants in particular suffer from excessive backlogs and delivery difficulties. Because disability grants are intended to serve the sick, the Department of Social Services guarantees that applications will be processed within 35 working days. However, interviews with people both living with AIDS and receiving disability grants suggest that the actual processing period is three months or more. A deputy director of social security at the Department of Social Services admitted that backlogs have significantly delayed the disbursement of grants and that many people desperately in need of assistance are suffering in the interim. For people in the advanced stages of AIDS without access to HAART, these delays can often mean the difference between life and death. Delivery and notification problems (such as those ruled upon in the Eastern Cape Mashishi case in 2003) have exacerbated the situation.

Finally, as previously mentioned, desperate unemployment in South Africa has led to a high demand for access to disability grants, regardless of a medical disability. Syndicates have formed to facilitate the fraudulent access to disability grants with the help of insiders within the Department of Social Services. The Department has developed a number of preventative measures to cut down on fraud and corruption, including a revised disability grants medical assessment form, but nothing has been done to eliminate the incentives that encourage people to circumvent the system in the first place. As long as

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[15] Interview with the manager of the assessment section of the Wynberg office for social services, July 19, 2004.

disability grants remain the only way for working-age adults to have access to income in the context of high unemployment, fraud seems inevitable.

The Case for a “Social Model” of Assistance

The experience of disability grants in the Western Cape highlights some of the limitations of a medical model for defining disability. Given high unemployment in the South Africa, a physical or mental disability is not the only factor, or even the primary factor, that prevents the poor from finding work and earning an income to care for themselves and their families. For those people suffering from HIV/AIDS, the medical model ensures that only those on the verge of death receive assistance, and with the cancellation of grants for those on HAART, the same model ignores the fact that treatment alone is ineffective unless combined with proper nutrition and economic empowerment.

This paper argues that, in the absence of comprehensive unemployment benefits or a universal basic income grant, a broader definition of disability is required, one which focuses not on the traditional understanding of disabilities, but rather on the social and environmental factors that are *disabling*. Within this framework, not only do people with HIV/AIDS deserve social assistance, but importantly, all people living in poverty without access to education, to employment, and to healthcare deserve state support as mandated by South Africa’s Bill of Rights. This broader notion of disability is supported by the *United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*, which “recognizes the necessity of addressing both the individual needs (such as rehabilitation and technical aids) and the shortcomings of the society (various obstacles for participation)” (UN 1993: 3). This same document argues that the cessation of social assistance to people with disabilities should depend not only on medical factors, but on economic and social factors as well:

> ‘Income support should be maintained as long as the disabling conditions remain in a manner that does not discourage persons with disabilities from seeking employment. It should only be reduced or terminated when persons with disabilities achieve adequate and secure income’ (UN 1994: rule 8 (6), pg 15).

In other words, governments should support their disability citizens not only while they are ill, but also while they are healthy and struggling to find work. The 1997 White Paper on an *Integrated National Disability Strategy*, issued by the South African government itself, makes a similar argument, advocating for a broader understanding of disability based on social circumstances:

> 'It must also be stressed that the system should not define beneficiaries according to the disability, but should rather determine provisioning in response to need' (Integrated National Disability Strategy White Paper, 1997, (10.4.3.2)).

The challenge, as identified by the UN Standard Rules, is to create a system of social assistance for those in disabling circumstances "that does not discourage persons with disabilities from seeking employment" (UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, Rule 8). Social conservatives have long used this excuse to argue against comprehensive social security and welfare benefits, but given South Africa's extreme poverty, inequality, and unemployment, the argument that helping people to meet their most basic needs encourages laziness rings hollow.

Moving Towards a Solution

In order for South Africa to realise the constitutional right to social security, the country needs to move towards a system of social assistance not premised on the illusion of full employment. Disability grants are necessary for those people too sick to work, including those people suffering with AIDS. The problem, however, is that in the absence of disability grants, South Africa currently provides no social assistance for the poor in need of work. The unfortunate consequence has been that just as people begin to regain their health with the help of ARVs, their small monthly income is cut, leaving them unable to meet even their most basic needs.

South Africa requires a social security system that does not force people with AIDS to choose between income and health. The government must streamline disability grants to remove problems of maladministration and clarify criteria both for applicants and for doctors charged with assessing their patients for disability. By making available the proper equipment and the necessary staff to operate it at primary health care clinics across the Western Cape, the provincial government could use CD4 counts to accurately measure the health of a person with AIDS on HAART, regardless of their diagnosed clinical stage. In addition, however, the Western Cape and the national Department of Social Development must provide support for all people, including those on AIDS treatments, who are unable to find work. In addition to more effective job creation, the government should adopt a proposal put forward by the Committee of Inquiry into a Comprehensive Social Security System for South Africa in 2002 calling for a Basic Income Grant for all South Africans. The Basic Income Grant would provide a universal monthly grant of approximately R100/person and subsequently tax that money back from the wealthy, ensuring that everyone, regardless of health, is able to afford food and other basic necessities.[16]

At the moment, however, the South African government is not moving in this direction. While the responsibility for social security is being removed from the provinces and consolidated under the national government in the form of the National Social Security Agency, hopefully reducing criteria inconsistencies across provinces, a new Social Assistance Bill approved in 2004 offers much of the same. It retains a medical model of disability without offering a way to address the social and economic factors that are disabling for many poor South Africans in need of a job. For people with HIV/AIDS, these changes offer little hope for the future. AIDS may unfortunately remain one of only a few ways to access social assistance, entrenching the perverse incentives that currently exist. And for those people with AIDS lucky enough to have access to life-prolonging treatments, the impending choice as their disability grants run out will remain an unenviable one between health and income.

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[16] For an exhaustive discussion of the Basic Income Grant, see Seekings (2002).

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The CSSR is an umbrella organisation comprising five units:

The Aids and Society Research Unit (ASRU) supports quantitative and qualitative research into the social and economic impact of the HIV pandemic in Southern Africa. Focus areas include: the economics of reducing mother to child transmission of HIV, the impact of HIV on firms and households; and psychological aspects of HIV infection and prevention. ASRU operates an outreach programme in Khayelitsha (the Memory Box Project) which provides training and counselling for HIV positive people

The Data First Resource Unit ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The Democracy in Africa Research Unit (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

The Social Surveys Unit (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. One core activity is the Cape Area Panel Study of young adults in Cape Town. This study follows 4800 young people as they move from school into the labour market and adulthood. The SSU is also planning a survey for 2004 on aspects of social capital, crime, and attitudes toward inequality.

The Southern Africa Labour and Development Research Unit (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. SALDRU conducted the first national household survey in 1993 (the Project for Statistics on Living Standards and Development). More recently, SALDRU ran the Langeberg Integrated Family survey (1999) and the Khayelitsha/Mitchell's Plain Survey (2000). Current projects include research on public works programmes, poverty and inequality.