Disability grants or antiretrovirals? A quandary for people with HIV/AIDS in South Africa

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According to the Department of Social Development, disability grants are available to adult South African citizens and permanent residents who are incapacitated and unable to work due to illness or disability. A number of people living with HIV/AIDS (PWAs) have accessed disability grants once they have fulfilled the criteria set down by the Department of Social Development. Current government policies entitle PWAs, at least in theory, to access antiretroviral medications. Where PWAs have been able to access antiretroviral treatment (ART) through the government’s antiretroviral programme, this has led to an improvement in their health and subsequent disqualification for a disability grant. In South Africa’s highly unequal society, the disability grant often operates as the only source of income for poor families. This has created an untenable situation as many PWAs are forced to choose between receiving their disability grant and accessing life-saving medication. We explore the intersection of social security with access to ART and argue that it presents complex problems in the context of HIV/AIDS, and thus requires urgent debate and resolution. Potential solutions to this problem, including the provision of a basic income grant to all South Africans, are proposed.

Keywords: basic income grant, legislation, policy, poverty, social security

Introduction

In short, HIV/AIDS will continue to challenge the capability of existing social security programmes to address the increased impoverishment and vulnerability of people (Committee of Inquiry, 2002, p. 19)1:

‘I am worried to hear that the grants are being reviewed because I don’t think I qualify any more. My health has improved since I started ARVs. I am very worried, because my grant is my only means of support. I think I am only alive today because of the grant’ (Disability grant recipient, Wattville, East Rand).

Section 27(1)(c) of the South African Constitution provides that everyone has the right of access to "social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.” Practically, this right has translated into the Department of Social Development providing income support to more than nine million people in South Africa, with more than R50 billion per year allocated for this function (Skweyiya, 2004). A recent project to investigate the impact of the social security system on South Africa’s social and economic dynamics found that “on balance, the impact of South Africa’s social security system is largely positive” and that these effects support economic growth, income distribution and education (Department of Social Development, 2004, p. 4). That the right of access to social security and social assistance is a vital support structure for the realisation of the range of other human rights and freedoms articulated in the Bill of Rights cannot be disputed.2

A number of people living with HIV/AIDS (PWAs), but by no means all who need it, have been able to access social assistance in the form of a monthly disability grant. With the announcement of a public-sector antiretroviral (ARV) roll-out plan (Department of Health, 2003), substantially more PWAs who rely on the public-health sector have access to life-saving medicines than in the past. This has given rise to a situation where PWAs who take ARVs and become well are in danger of losing a disability grant that in many cases provides access to basic (life-saving) services and food, not only for themselves, but often for their extended families.

Towards the end of 2004, the AIDS Law Project was approached by the staff of a state clinic that provides ARVs in Johannesburg. They raised the concern that the loss of disability grants might discourage PWAs from starting treatment, or might provide a disincentive to adhering to their treatment regime. Put differently, they were worried that their patients would have to choose between life-saving treatment and maintaining their and their families’ only means of support — indeed an alarming dilemma. The AIDS Law Project initiated a preliminary study of access to disability grants by PWAs in order to gain more insight into this situation.

The research project aimed to establish the state’s policy towards disability grant recipients whose health had
improved due to ARV treatment, whether the grants of such recipients would be terminated and what other forms of social security would be available in the event of the grant being terminated. In addition, the research sought to include the experiences of current and potential disability grant recipients and to obtain first-hand information on the availability of disability grants and other forms of social assistance to PWAs.

This article is based on the research conducted by the AIDS Law Project from October to December 2004 and discusses the findings. We begin by setting out the methodology of the study and the theoretical background to disability grants in South Africa. We briefly look at the relationship between antiretroviral and supplementary services to PWAs and conclude with a number of recommendations on how to address the potential dilemma faced by PWAs.

Methodology

The research was a qualitative study. Besides obtaining information from the national Department of Social Development, the study also focused on the policies of four provincial departments: the Free State, Gauteng, KwaZulu-Natal and the Western Cape. These provinces were selected because they reflect the various demographic differences found across South Africa (rural versus urban, and under-resourced versus relatively well-resourced).

Also, at the time the research was conceptualised, not all provinces were willing to provide information on the extent of their progress in rolling out ARV treatment, and since the research related to access to disability grants in the context of ARV treatment, it was essential to select provinces where it could be verified that the ARV roll-out was underway.

Department officials in the selected provinces were interviewed and documentation on their provincial policies on disability grants was requested. When approached for information, officials of the national department agreed to meet with an AIDS Law Project researcher to provide information on departmental policy and also to discuss the concerns that had motivated the research project. The researchers also collected other government documentation, including information from the national Department of Health.

Additionally, the researchers contacted legal advice offices and NGOs in the target provinces to obtain information on problems that their clients may have experienced with regard to accessing disability grants, the administration of grants, and whether they had received reports of grant recipients losing their grants because they had recovered their health and no longer qualified.

In-depth interviews were conducted with community workers and with current and potential grant recipients in Gauteng Province. Thirteen people agreed to participate in these interviews. The participants included:

- PWAs who were attending a wellness course, prior to enrolling in an ARV treatment programme at Helen Joseph Hospital, Johannesburg;
- support group members and a community worker at Wattville, East Rand;
- a home-based caregiver and her clients in Dobsonville, Soweto; and
- community workers in Bramfischerville, Soweto.

The participants were not intended to be a representative sample, nor were the interviews aimed at providing substantial quantitative information, which was beyond the scope of this initial research project. Rather, the interviews were used to include the voices of people infected and affected by HIV, and provided some preliminary information on the lives of PWAs, the impact of access or lack of access to disability grants in their lives, and their attitude to the potential choice between antiretroviral treatment (ART) and receiving grants.

Theoretical background

Definitions

A few terms are often erroneously used interchangeably:

- **Social Assistance** — “State-provided basic minimum protection to relieve poverty, essentially subject to qualifying criteria on a non-contributory basis” (Committee of Inquiry, 2002, p. 36). The Social Assistance Act is not of much help in defining the contents of this term; for example: “Social assistance means a social grant including social relief of distress.” The disability grant would fall under the category of social assistance.

- **Social Insurance** — “A mandatory contributory system of one kind or another, or regulated private-sector provision, concerned with the spreading of income over the life cycle or the pooling of risks” (Committee of Inquiry, 2002, p. 36). South Africa’s Unemployment Insurance Fund (UIF) is an example.

- **Social Grant** — according to the Social Assistance Act this “means a child support grant, a care dependency grant, a foster child grant, a disability grant, an older person’s grant, a war veteran’s grant and a grant-in-aid”.

Interestingly, neither the Social Assistance Act nor the Constitution provides a definition for the term social security, although one could assume that it would contain some elements of the above. Olivier, Smit & Kalula (2003, p. 24) note that “neither South African law nor international literature reveals a clear and consistent approach to the concept of social security. It has been accepted that social security is not a fixed concept, but reflects both similarities and variety”. These sentiments are echoed by the South African Human Rights Commission (SAHRC), and following the International Labour Organization’s Social Security (Minimum Standards) Convention of 1952 (No. 102), the SAHRC decided on the following definition of social security: “A public measure to address the consequences of sickness, maternity, occupational injury, unemployment, invalidity, old age and death” (SAHRC, 2004, p. 4).

The Taylor Report noted that the above definitions for social assistance and social insurance originated in developed countries and are seen to complement a formal employment relationship (Committee of Inquiry, 2002). In South Africa, where we have an unemployment rate of more than 25%, these definitions of social security are tenuous. Rather, the term ‘social protection’ and the definition provided by the United Nations is preferred:

- **Social Protection** — “… embodies society’s responses to levels of either risk or deprivation…. These include
secure access to income, livelihood, employment, health and education services, nutrition and shelter. It would seem that the current social security system in South Africa assumes that everybody who desires to be employed would be able to find a decent-paying job, and that it is only when there is an unexpected intervention such as a disability, injury or a temporary job loss, that the state is under a duty to provide relief. Thus, under current social security provisions, PWAs are only able to access social assistance — in the form of a disability grant of R780 per month — when they are too ill to be able to earn a living, and they are not offered access to broader social protection.6

Disability grants as social safety nets
The Taylor Report states that in 2002, 45–55% of South Africans were living in poverty. Mpumalanga, the Eastern Cape and Limpopo provinces displayed the highest poverty rates (Committee of Inquiry, 2002). The Department of Social Development noted the importance of social grants in alleviating poverty and reported a 74% increase in the total number of grant beneficiaries between April 2000 and February 2003 (Skweyiya, 2004). In a parliamentary address, the Minister of Social Development observed the following:

‘Although the disability grant shows a decline between April 1999 and April 2000, it has increased by 47.5% between April 2000 and February 2003, above 50% growth in the Eastern Cape, Free State and Gauteng. The increase in Gauteng (85.7%) and Free State (148%) account for most of this increase.’7

The Department of Social Development and the Treasury Department have become increasingly concerned about the increase in disability grants and have requested a review of the grants:

While we are satisfied that the reach of the disability grant has grown to ensure coverage in previously neglected areas, some unethical and desperate people have sought to take advantage of our efforts. In partnership with the Department of Health and the National Treasury, we have established a Disability Management Initiative. This initiative will look at the definition of disability, develop a national uniform assessment tool and ensure that the recipients of temporary disability grants are reviewed when their eligibility periods expire as required (Skweyiya, 2005). They commissioned an inquiry into the increase in disability grants (Delaney, 2005), but the report was embargoed at the time of our writing.8

Statistics from the Department of Social Development show an increase in the number of permanent disability grants and a decrease in temporary disability grants during the period June 2004 to June 2005 (see Table 1 and Figure 1).

Table 1: Number of disability grant recipients in South Africa

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<thead>
<tr>
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<th>June 2004</th>
<th>June 2005</th>
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<tbody>
<tr>
<td>Permanent disability</td>
<td>915 970</td>
<td>1 045 934</td>
</tr>
<tr>
<td>Temporary disability</td>
<td>375 298</td>
<td>252 683</td>
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Source: Jooste, 2005

Figure 1: Trends in the number of disability grant recipients


Note: The number of working-age people too sick to work was derived from the 2003 Labour Force Survey and extrapolated as a percentage of the population for the preceding years. (Graph supplied with permission from N Nattrass, forthcoming)
Unfortunately, the Department of Social Development database, SOCPEN, does not capture the type of disability, so it was not possible to generate data on how many of the recipients received disability grants due to HIV/AIDS (Jooste, 2005). The findings of the embargoed research concerning the increase in number of disability grants would be particularly illuminating in this regard and we hope that the findings would positively influence the department’s approach to people with disabilities and HIV/AIDS.

The relationship between poverty and disability is a complex one. A study commissioned by the Kaiser Family Foundation (Steinberg, M., Johnson, S., Schierhout, G. & Ndegwa, D., 2002) released its findings in the same year as the Taylor Report. The study examined 771 AIDS-affected households in various parts of South Africa and found that “in already poor households HIV/AIDS is the tipping point from poverty to destitution” and that it is “the poorest South Africans who are most vulnerable to HIV/AIDS and for whom the consequences [of the AIDS epidemic] are inevitably the most severe” (Steinberg et al., 2002, p. i). With high levels of poverty converging with high HIV prevalence among the poor, it does not come as a surprise that the disability grants functions as “a de facto poverty alleviation grant” (Committee of Inquiry, 2002, p. 30). In fact, the Taylor Report found that 77% of disability grant recipients were also living in poverty.

Conversely, the ‘Hitting Home’ report (Steinberg et al., 2002) showed that only 16% of the AIDS-affected households were receiving government grants of any kind, despite the fact that they were entitled to at least one grant. Those findings are echoed in research conducted in the Free State by Booyseren (2003). It would therefore seem that many HIV-affected individuals or families are unable to access any form of social assistance, while the HIV-infected individuals who have been able to access the disability grant in the past may now be in danger of losing even this source of income. It would appear that South Africa’s social security safety net does not adequately cushion the impact of the epidemic nor does it reach far enough.

**PWAs and ARVs in the public sector**

A study of social grant recipients in the Western Cape found that “… all beneficiary households spend most of their income on food” (Vorster, Eigelaar-Meets, Poole & Rossouw, 2004, p. ii). Similar findings appear in the national survey by the Department of Social Development (2004, p. 3):

- All major grants — the State Old-Age Pension, the Child Support Grant and the Disability Grant — are significantly and positively associated with a greater share of household expenditure on food. This increased spending on food is associated with better nutritional outcomes. Households that receive social grants have lower prevalence rates of hunger for young children as well as older children and adults, even compared to those households with comparable income levels.

- Research by the AIDS Law Project found that all disability grant recipients interviewed used their grants for purchasing food. As discussed below, concern about household food security once a disability grant is cancelled was a major theme among our interviewees. Therefore, it is appropriate to examine the relationship between the provision of public-sector ARVs and nutrition.

Following years of intense advocacy and activism, the South African government announced a policy for the progressive roll-out of ARVs on 19 November 2003 (Department of Health, 2003). This plan included detailed provisions on prevention, care and treatment, laboratory services, monitoring and evaluation, budget and others. In keeping with the government’s emphasis on nutrition in engaging adequately with the AIDS epidemic, the plan rightly contains various sections on nutrition and a chapter entitled ‘Nutrition-related interventions’. It stated unequivocally that “the South African government seeks to implement a comprehensive nutritional programme with the introduction of HIV and AIDS care and treatment” (Department of Health, 2003, p. 79).

In order to do so, the plan envisions the following:

- Existing programmes such as the National Emergency Food Programme and others should be integrated and expanded to meet the nutritional needs of all people with HIV and/or TB;
- The provision of supplement meals to those PWAs who have clinical AIDS, are malnourished, are eligible for ARVs and do not have access to a secure food supply;
- Children with HIV/AIDS under 14 years of age who enrol at service points should be given nutritional packages that contain a vitamin syrup and a supplement meal;
- Pregnant women with HIV/AIDS should receive micronutrient supplements and supplement meals if they are in need of it. For those mothers who choose to formula-feed their newborn babies, formula should be made available; and,
- There should be nutritional counselling for all people who access ARVs, and referrals made to the Department of Social Development’s food-security programmes (Department of Health, 2003, pp. 79–84).

It is not clear how successful the nutritional aspects of the Operational Plan have been as there is little data available on its implementation, but anecdotal evidence suggests major problems. A report by the Treatment Action Campaign & AIDS Law Project (2004), which examines findings on the state of roll-out of ARVs in the public sector 18-months after the adoption of the ‘plan as above’, considered the implementation of the nutritional aspects of the plan. Drawing on the experiences of various NGOs, community-based organisations, and public hospitals and clinics, the report found that:

In assessing the nutrition assistance programme, the 4th [Joint Civil Society Monitoring Forum] meeting noted anecdotal evidence indicating fragmentation and unevenness, with the programme being beset by problems. At the Harriet Shezi Clinic at Chris Hani Baragwanath Hospital, the largest paediatric treatment site in the country, only 6% of children who are on ARV treatment have access to nutritional support — fortified maize meal and milk formula — through the resident dietician. Often there are not enough social workers available to advise patients on where and how to access food parcels and supplements. The administrative burden of
processing hundreds of applications for food parcels also results in limited access. As at April 2005, none of the adult and paediatric patients at Harriet Shezi were accessing food parcels.

Serious gaps in the nutrition programme at individual facility level have arisen because of a shortage of social workers, dieticians and nutritionists. The lack of proper guidelines, inadequate supervision and poor resources has compounded the problem. In addition, logistical delays in getting food parcels to facilities (administered by the Department of Social Development) have also added to the weaknesses of the programme. Nevertheless, the ultimate responsibility rests with health. The Operational Plan provides that the national Department of Health is responsible for inter-departmental coordination of the country’s overall nutritional assistance programme (AIDS Law Project & Treatment Action Campaign, 2005, p. 12).

It would seem that most PWAs on public-sector ARVs are not receiving the nutritional support they need to sustain themselves and the taking of their medication.

**Eligibility for a disability grant**

While the Constitution gives everyone the abstract right to social security and social assistance, the Social Assistance Act of 1992 and 2004 and various regulations provide the details. Social assistance is currently being provided in line with the Act of 1992 and its subsequent regulations. The 2004 version of the Act has yet to become operational, and it is not clear when this will happen.

The Social Assistance Act of 1992 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".

The Social Assistance Act Regulations provide the technical criteria for assessing whether a person qualifies for a disability grant or not. Section 2(3)(1) of the 1998 Regulations sets out the criteria for a disability grant:

- The person must be 18 years of age or older;
- The person must have her disability confirmed by a medical report by a medical officer or by a report of an assessment panel. The report has to show whether the disability is:
  - permanent (the disability will continue for more than 12 months); or
  - temporary (the disability will continue not less than 6 months and not more than 12 months);
- The degree of her disability must render her incapable of entering the labour market and she must not have refused employment that is within her capabilities;
- She does not without good reason refuse to undergo the necessary medical treatment;
- She does not already receive a social grant.

At the time that the research was conducted, the four selected provinces indicated that they had previously devised their own criteria for eligibility — all of these were based on an applicant having a CD4 count of less than 200 cells/mm³. In order to qualify for a grant, the applicant would be required to submit a medical certificate from a state doctor, which would include information on the applicant’s latest CD4-count test, and a recommendation by the doctor that the applicant be provided with a disability grant. While the doctor’s recommendation could either be accepted or rejected by the Department of Social Development, in most cases, applicants with a CD4 count less than 200 cells/mm³ were awarded grants.

Spokespeople for the four provinces noted that they had been informed that the national Department of Social Development was developing a policy on HIV and disability grants and that they intended adopting the criteria as set out by the national department once it was released.

The AIDS Law Project contacted the Department of Social Development at the national level to obtain clarity about when a person living with HIV/AIDS qualifies for a disability grant, and received the following response:

Assuming that a person has been diagnosed as having contracted the HIV/AIDS [sic] and can produce medical proof to that effect. The next most important factor when a person applies for social assistance is his/her financial position. In determining whether an applicant qualifies for a disability grant, a means test will be performed. The reason for this is that grants are only awarded if the applicant’s financial resources are below a certain level. If the person qualifies based on the means test, then the capability levels of the person will be taken into consideration to assess whether the disability or chronic condition is substantially limiting to the extent that he would totally be unable to perform a job and therefore earn a living.

To date, the CD4 count has proved to be unreliable to a large extent [sic] in determining the capabilities of a person living with the virus. Some people would have a CD4 count of less than 200 and not have any significant limitation on their daily activities but still be able to continue with their normal jobs. In short, the department cannot approve the grant for a person who is HIV-positive, unless the person is diagnosed as a stage-three case of AIDS. The above criteria is currently being implemented as well to cases that are already on the system of the department. As a result there is a grant review process in place to ensure the inclusion of only eligible and intended beneficiaries (Pooe, 2004a).

The AIDS Law Project requested clarification on the disability grant review process and received the following response:

When a disability grant is approved, the approval might be of a temporary or permanent status. The short-term status refers to when the condition of the beneficiary is projected to last longer than 6 months but not exceed 12 months. A letter of notification is then sent to the beneficiary 3 three [sic] months before expiry with an advice to re-apply or appeal should the condition persist.

The long-term status means the disability will last for more than 12 months. In this case, the status of the beneficiary will be reviewed after every five years to ascertain that the beneficiary is still eligible.
Currently there is a rapid growth in the disability grant programmes, which also led to serious backlogs in terms of the review processes. The cause of the growth is under investigation but early indications are that administrative and regulatory issues are part of the reason. Unfortunately this growth impacts directly on the overall national budget to the detriment of other sectors such as education and health. As a result, there is a concentrated effort on the review processes as stated in the first response (Pooe, 2004b).

From the above, the following is clear:

- The aim of the disability grant is to provide relief for people who are physically or mentally incapable of engaging in employment;
- If a PWA becomes healthy enough to be considered capable of engaging in employment, he or she will no longer qualify for the disability grant;
- WHO Stage III criterion is used for determining whether a PWA’s health condition has deteriorated sufficiently to be incapable of being employable; and
- Disability grants are being reviewed partly because of the unexpected increased uptake of the grant.

Note that the definition of disability is currently under review and a new definition has been adopted. Unfortunately the new definition has not yet been made available (Modise, 2005) and it seems there will be further investigation into social-security eligibility for persons with chronic illnesses.

Research findings

Two major themes emerged from the information collected from advice offices, home-based care organisations, support group coordinators and PWAs who were either recipients or potential recipients of disability grants:

1. Administrative law issues relating to problems with the non-uniform manner in which grant applications are processed, the review and termination of grants, and information provided to recipients.
2. Substantive issues concerning access to social security for people who do not qualify for existing grants, but whose survival is precarious without state assistance.

Administrative law issues

Information about grants

Grant recipients we interviewed appeared to be confused about whether their grants were temporary or permanent, and many reported that they were not given any information about the review process and what this would entail. One participant indicated that she thought her grant was ‘for life’. Others reported that officials had told them that they would receive the grant for five years, after which time they would be reviewed, and they therefore understood that the state had no right to review or terminate their grants in the interim, even if they were no longer eligible. It is unclear whether the officials actually told them this, or whether they misunderstood the information the department gave them. In either case, a lack of clear communication between the department and grant recipients emerged as a serious problem. The majority of the recipients interviewed indicated that they had been given their grants on the basis of a CD4 count under 200.

Other participants reported misinformation and miscommunication with department officials. A participant interviewed at Helen Joseph Hospital in Johannesburg stated that she had two sons, aged eight and ten years old, and that she received a disability grant, which she used to support her children. She wanted to apply for child support grants for the children, but an official told her that she could not receive both a disability grant and a child support grant. This appears to be a misinterpretation of the department’s policy that a single recipient cannot receive more than one state grant, and it is cause for concern if children who are entitled to the grant are being turned away because their caregiver receives a disability grant or an old-age pension.

Lengthy and complex application process

Community workers reported that their clients often experienced problems relating to grant applications, with some applications taking well over three months to process, and that applications were sometimes refused without any explanation.

There does not appear to be any process in place to fast-track the grant applications of seriously ill people. A home-based caregiver in Soweto reported that the week before the AIDS Law Project interviewed her she had three seriously ill patients who had been waiting over three months for their applications to be processed. By the time she was interviewed, each of these patients had died.

She also reported that the grants of several of her patients had been terminated without notice or explanation. Sometimes the letter from the department, advising that a temporary grant was being terminated or that a permanent grant was being reviewed, arrived after the grant payments had already stopped. Other patients experienced delays in the review process, and waited for over three months for their grants to be reviewed, during which time they received no grant payments. None of these patients had been advised of the time period that the review process would take, and many returned to the Social Development Office each month, only to be told that their application had not yet been processed and so they should ‘try again next month’. Another of the caregiver’s patients received a letter advising her that she should reapply for her grant and submit a form completed by a state doctor; but she was unable to have the required medical examination, because she was too ill to leave the house and take a minibus taxi to her nearest public hospital, which is a long distance from her home. Her grant was terminated.

Substantive issues

Paradoxical state support

Several participants expressed their frustration with a system that provides people with financial support when they are seriously ill, but does not assist people who are not yet ill, and who would be able to avoid serious illness for longer if they had the means to access proper nutrition and a generally better standard of living: ‘Why are there only grants for people who are dying, and not for people who want to
take care of themselves before they become very ill?’ (Participant, Helen Joseph Hospital). Most of the participants were acutely aware that PWAs become sick more quickly if they live in conditions of poverty, and found it inexplicable that government should only provide support to people once their immune systems were already severely compromised, instead of helping people to stay healthier for longer.

Food security

Food security emerged as a major issue for the participants. ‘With my grant, I can afford to buy good, healthy food, and without it, I would not have survived’ (Participant, Helen Joseph Hospital). The AIDS Law Project interviewed the participants at Helen Joseph Hospital after a workshop on proper nutrition conducted by a dietician as part of the nutritional support offered to patients preparing to undergo ARV treatment. Patients were given an information sheet on healthy eating, which specifically states, ‘Take care of yourself right from the start. This way you will be ensured to stay healthy for longer’ (Hanekom, undated). After the workshop, participants who did not receive disability grants expressed frustration at being advised to eat food that they could not afford. The information sheet advises PWAs to eat at least three balanced meals per day, and to include foods from each food group in every meal. Patients are told to base all meals on starchy food, particularly whole-grain products like whole-wheat bread, oats, and bran cereals; to eat several different types of fruits and vegetables every day, and to eat more animal protein, as well as vegetable proteins such as dried beans, lentils, peanuts and soya.

One participant complained bitterly that she could not afford the foods described by the dietician. She is unemployed, and has been told that she cannot get a disability grant because her CD4 count is 300 and she is still too healthy to qualify. She relies on her partner to support her, and as he is an informal trader, selling fruits and vegetables on the streets, his income is often inadequate. Even if she were able to grow her own vegetables, she would still be unable to afford the meat, fish, chicken, eggs, peanut butter and whole-wheat products recommended by the dietician.

Unemployment and disability grants

All of the participants expressed doubts at being able to find employment, even if their health improved and they were declared fit to work. Half of those interviewed were unemployed prior to falling ill, and some had been unemployed throughout their adult lives. Those who were previously employed reported working in low-wage jobs without much job security. ‘I think the government should be focusing on people who need jobs. I have done everything that could be asked of me: I studied hard, completed school, completed further education and tried my best to find a job. But I still cannot find employment. If the state cannot provide jobs, then they must provide grants’ (Participant, Helen Joseph Hospital).

When asked about her prospects of finding a job if her health recovered, a participant who had left her job due to HIV-related illnesses explained that she did not think she would be able to return to her old job, because she had been reluctant to disclose her HIV status to her employer, and therefore had left work without giving notice or providing any explanation for her resignation. She felt that she could not inform her employer that she was too ill to work, in case he asked about the cause of her illness.

Caregivers and community workers interviewed also felt that it was unlikely that their clients who were no longer eligible for disability grants would be able to find employment. They cited clients who had been unemployed prior to being ill. They also felt that clients who had been incapable of working for many years would be at a disadvantage in the labour market: ‘People who lost their job due to illness will not find another job easily, because employers will want to know what is wrong with them, and why they have not worked for so many years.’ None of the participants had heard of or been referred to a state job-creation programme.

Transport

‘I depend on my disability grant, and if it is stopped, it will cause me serious problems because I have to travel from Roodepoort to Helen Joseph Hospital, because ARVs are not available in the hospitals or clinics near to where I live’ (Participant, Helen Joseph Hospital). None of the participants lived within walking distance of their nearest hospital or clinic, and all relied on public transport, such as buses or minibus taxis, for transport to and from state medical facilities. As only certain hospitals and clinics are currently operating as treatment sites, many people receiving ARV treatment have to travel even further for their monthly clinic visits, as the treatment sites are often a considerable distance from where the patients live. Patients on ARV treatment require regular monitoring, and for this reason, the drugs are distributed on a monthly basis and all patients undergo medical assessments each month, particularly when they first start the treatment (Roberts, 2004).

Participants reported that the cost of transport to and from their treatment site each month was a considerable expense, and stated that they would not be able to afford it without their disability grants. If patients receiving ARV treatment are unable to travel to their treatment sites for their monthly appointments, this will obviously have consequences in terms of adherence to their drug regimes, and may place their lives in danger if potentially dangerous side effects are not identified and treated in time.

Grants versus ARVs

‘At the moment, most people do not understand that if they start ARV treatment and get better, they will lose their disability grants. If they did know, I think that some people might refuse to start ARV treatment, because they have to think of their families, who they are supporting on the grant. This would make my work as a caregiver very difficult. Since ARVs have been available it has made a big difference to my work, because I am no longer seeing so many people getting sick and dying. I know how people struggle without grants, and sometimes I give them money from my own pocket, because I can’t bear to see them suffer’ (Home-based caregiver, Dobsonville, Soweto).

Interestingly, while health care workers and caregivers expressed the concern that patients who learned that their
grants would be withdrawn if their health improved might rather refuse ARV treatment or else not comply with their drug regimes, the grant recipients themselves stated that if it came to a choice, they would choose to take the drugs, even if it meant losing their grants. However, the recipients said it would be an invidious choice to face, since losing the grant would cause extreme hardship to their whole family.

Discussion

“My doctor has told me that I need to start ARV treatment, and I hope that I will be able to start soon. Treatment is very important, but so is my grant” (Participant, Helen Joseph Hospital). While the research sample was small and located in the urban areas of South Africa’s richest province, Gauteng, we consider the findings as indicative of what is currently happening elsewhere. Similar concerns from across the country have reached the AIDS Law Project through its helpline and its engagement with social workers, support groups and other AIDS service organisations.20

The research suggests that South Africa’s current social security system is not equipped to deal with the challenges of the HIV epidemic, and does little to assist PWAs who are unemployed and living in poverty, but who are not yet ill enough to qualify for a disability grant. Equally, the system is not responsive to PWAs who have become dependent on the disability grant but do not qualify for it anymore due to an improvement in health as a result of ARV treatment.

People’s loss of disability grants in conjunction with the absence of a more comprehensive package of social assistance has the potential to undermine the state ARV roll-out in a very important respect: patients with no stable form of income may be unable to attend monthly appointments as required, which will have an impact on the efficacy of the treatment, may lead to potentially dangerous side-effects going undetected, and may jeopardise people’s continued involvement in the state programme. Also, the subject of access to adequate nutrition does not appear to be adequately addressed by current state initiatives.21

Recommendations

It is clear that this problematic situation needs to be addressed with urgency. A number of studies22 — notably the Taylor Report — have highlighted the shortcomings of South Africa’s social security system and have recommended a variety of remedies. A discussion of these is beyond the scope of this article, but some solutions to the dilemma faced by PWAs concerning disability grants and access to ARVs are proposed.

Reference to the research of two authors is pertinent here. First, Simchowitz (2004) considers the impasse described above in terms of his research on disability grants in the Western Cape; he criticises the medical model used to determine disability, and suggests a movement towards considering people’s context:

... 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 health-care deserve state support as mandated by South Africa’s Bill of Rights (p. 15).

He argues for a social security system that is “not premised on the illusion of full employment” (Simchowitz, 2004, p. 16) and that includes a basic income grant.

Second, Nattrass (forthcoming) looks at the ARV/disability grant dilemma from an economic point of view, and explores three possible avenues that the government could take to manage the situation. One option that government may face is to cancel the disability grant for all PWAs altogether. Nattrass argues that that may bring to an end the so-called ‘perverse incentives’ associated with the disability grants. The perverse incentives include PWAs who may start ARV treatment and become well, but who fear losing their disability grants and so stop their treatment long enough to become sick enough to fulfil the grant criteria — only to take up treatment again. Of course this can give rise to treatment failure and treatment resistance — the latter of which could be passed on to others and undercut the benefits of the national ARV roll-out. Another perverse incentive could manifest as people who wish to contract HIV in a desperate hope to access the monetary benefits of a disability grant. Nattrass argues against cancelling disability grants for PWAs, by noting that it would be discriminatory: “People disabled by AIDS should not be any less entitled to government support than any other disabled person” (Nattrass, forthcoming). The author also notes that the disability grant is an important ‘lifeline’ to PWAs and their households, and taking it away would impact negatively on the nutritional intake of PWAs — an important component of treatment adherence and effectiveness.

Nattrass proposes that government’s second option is to continue providing the disability grant to PWAs even after they become healthy on ARVs. But she notes that the perverse incentive described above would not necessarily be reduced. She also sees an ethical problem inherent in this option: “Why should [PWAs] be privileged over other people who may be equally needy, but HIV-negative?” (Nattrass, forthcoming).

Like Simchowitz (2004), Nattrass sees an answer partly in the extension of a basic income grant (BIG) to all people in South Africa. She argues that the households that lose the income from the disability grant of a healthy PWA would at least “have some financial cushioning” if every household member had access to a basic income grant. Nattrass (forthcoming) also argues that the grant might reduce the perverse incentives associated with the disability grant, and concludes: “The point is simply that given the context of AIDS and the perverse incentives associated with the removal of the disability grant, this amounts to one more argument in favour of the introduction of a BIG.”

This article strongly supports the call for a basic income grant and the movement from social security to notions of social protection.23 Yet even if civil society and government suddenly principally agreed to a basic income grant, massive changes to the social security system and adjust-
ments to the national budget would be required. This would take time and would not address the immediate problem of PWAs who are currently losing their disability grants. Thus, urgent interim measures are necessary, and so we offer the following for consideration:

- The Department of Health and the Department of Social Development should work together more closely to ensure that every PWA who takes up treatment is able to access appropriate, healthy and adequate food as well as water. No new policies are needed for this, as frameworks are already in place (e.g., the Operational Plan and the Department of Social Development programmes described above). Rather, it is the urgent and comprehensive implementation of these policies that is severely lacking.

- Following the findings of the ‘Hitting Home’ report (Steinberg et al., 2002), the Department of Social Development should devise strategies to assist the family members of PWAs. It should alert them to the social support that they are entitled to and help them to access an appropriate social grant — for example, a child support grant or old-age pension. This could reduce the dependence of the family on the disability grant.

- Hospitals and clinics should assist PWAs who cannot afford to travel to monthly consultations with transport to medical facilities.

These recommendations focus on PWAs and, unfortunately, do not address the needs of South Africa’s impoverished population as a whole, nor those patients with chronic illnesses other than those associated with AIDS. We also acknowledge that the recommendations are counterproductive to the movement towards ‘de-normalisation’ the AIDS epidemic in order to reduce the stigma still attached to HIV/AIDS. However, we propose them as interim measures in an attempt to address the immediate dilemma that arises with PWAs, concerning access to ARVs and disability grants. These recommendations are justified in the context of a raging South African AIDS epidemic, where the support of HIV-testing, the take-up of ARVs when medically indicated, and treatment adherence is necessary, and when the avoidance of treatment resistance is imperative. Implementing the interim measures suggested here and, eventually, but speedily, rolling out a basic income grant would save certain families from destitution and thus help to interrupt the cycle of poverty, which creates a pre-disposed risk of HIV infection for some persons. Ideally, the recommendations should be implemented in tandem with the broadening and strengthening of the social safety net for South Africa’s poor — from a moral, ethical and social justice perspective, and also to reduce the perverse incentives described above. While we acknowledge that the evidence of perverse incentives is anecdotal and untested, we advise that research into this area is essential and that more strategies are needed to deal with the dreadful dilemma that some PWAs indeed face.

Summary

From a narrow viewpoint, PWAs who are also disability grant recipients, but who become well, are capable of working. Under current South African legislation and policy, therefore, they are not entitled to retain their disability grant. Conversely, this paper has argued that this position ignores the greater circumstances and living conditions of most PWAs and their families, and that it does not take into account the context of the devastation of the AIDS epidemic.

While no instances of people losing their grants due to ARV treatment were identified during the face-to-face interviews conducted during the research and writing, the AIDS Law Project was receiving an increasing stream of reports about grants being terminated under such circumstances. Since the roll-out of ARVs in South Africa is in its infancy, the complexities prefigured by the preliminary study and anecdotal evidence are most likely to deepen as more PWAs access ARVs and the Department of Social Development progressively withdraws grants from those who do not meet the current criteria.

It would seem that neither the Department of Health nor the Department of Social Development has sufficiently anticipated the difficulties that will arise with the extension of the disability grant to large numbers of PWAs along with the sudden withdrawal of the grant as a result of the benefits of ARV treatment. The far-ranging implications of this oversight have formed the basis of the AIDS Law Project enquiry.

Notes

1 The report produced by the Committee of Inquiry into a Comprehensive System of Social Security for South Africa, entitled Transforming the Present – Protecting the Future is known as the Taylor Report. The report was commissioned by the government in order to critically analyse the social security system in South Africa, and to present recommendations about its reform.


3 Statistics South Africa (2005) estimated that South Africa had an unemployment rate of 26.2% in September 2004. However, there is major disagreement among economists about the determination of the unemployment rate in South Africa, and whether an expanded definition of unemployment should be employed. The expanded definition of unemployment is: “Persons regarded as such differ from those regarded as officially unemployed in one respect only, namely that they did not take active steps to find employment in the month prior to the survey interview. If the number of discouraged work-seekers is added to persons that are officially unemployed, the expanded definition of unemployment is obtained” (Statistics South Africa, 2005, p. xvi). Using an expanded definition of unemployment, Statistics South Africa found the unemployment rate was 41% in September 2004.

4 See the United Nations Commission on Social Development, 2000 (as quoted by the Committee of Inquiry, 2002, p. 40). The UN goes on to note that “The ultimate purpose of social protection is to increase capabilities and opportunities and, thereby, human development. While by its very nature social protection aims at providing at least minimum standards of well-being to people in dire circumstances enabling them to live with dignity, one should not overlook that social protection should not simply be seen as a residual policy function of assuring the welfare of the poorest — but as a foundation at a societal level for promoting social justice and social cohesion, developing human capabilities and promoting economic dynamism and creativity.”
5 This reflects the amount of the grant for the 2005 financial year. The Minister of Social Development generally announces increases in the social grants at the beginning of each financial year, the amount of the increase being determined by the Treasury Department.

6 For a discussion of the elements of social protection as opposed to social security, see Olivier et al. (2003, pp. 24-28).

7 See Skweyiya (2004) and also Kane-Berman (2005, p. 1): “The biggest single component of social security spending is social grants…. Two-thirds of the income of the poorest fifth of the population now comes from social grants, says the Treasury. Child support grants are the biggest item, followed by disability grants (inter alia, to AIDS victims [sic]) and old-age pensions. Within the next few years, says the Budget Review, the number of people receiving direct income support from the government will rise to 12 million, or about 25% of the population.”

8 Nattrass (forthcoming) postulates five reasons for the increase in disability grants:

1) The introduction of assessment panels to determine disability in the Northern and Eastern Cape provinces. These panels seemed to use a broader definition of disability than that used in the past.

2) A court order instructed the government to reinstate all temporary grants that the government had cancelled earlier (Mashishi v The Minister of Social Development and Others, Transvaal High Court, case number 4239/03).

3) The AIDS epidemic is maturing, which means that there is an increase in morbidity and mortality. This means that more people can qualify for a disability grant.

4) Treasury suspects that fraud and misuse of the grant may be the reason for an increase in the number of disability grants.

5) Grant awareness campaigns run by NGOs may have increased awareness of social security and subsequent uptake.

9 The Nelson Mandela Foundation/HSRC Household Survey (2002, p. 54) found that while people from all income levels are at risk of HIV infection, there was generally “negative correlation between HIV and socio-economic status.” It should be noted however that “wealthy [Black] Africans have similar levels of risk to less wealthy Africans. However, in the other race groups, lower socio-economic status appears to be correlated to higher likelihood of HIV infection…” (Nelson Mandela Foundation/HSRC, 2002, pp. 62–63).

10 See the Committee of Inquiry (2002, p. 30). Also see the submission made to the Taylor Report committee by the South African Federal Council on Disability & Children’s Institute (2002, p. 3): “We would like to clarify that the [disability grant] has become a de facto poverty grant. The Disability Grant was not intended to be a poverty grant but rather to provide assistance to meet the additional needs resulting from a disability and to compensate for loss of income due to the disability. However, due to the high poverty levels and unemployment in the country the grant has become a poverty-alleviation grant that supports not only the persons with the disability but also entire households. Measures required to return the grant to its original purpose and to maximize its potential impact on the lives of people with disabilities. The disability grant will continue to have this skewed purpose as long as additional support services are not in place, for example free healthcare and accessible transport.”

11 This is additional to, or in collaboration with, other government nutrition programmes. From Tshitaludzi (2005):

• School Nutrition Programme (Department of Education)
• Integrated Nutrition Programme (Department of Health)
• Social Assistance Programme (Department of Social Development)
• Poverty Relief Programme (Department of Social Development)

• Emergency Food Relief Programme (Department of Social Development). See also Kallman (2004).

12 That is: “Regulations regarding grants and financial awards to welfare organisations and to persons in need of social relief of distress in terms of the Social Assistance Act.”

13 The Department of Social Development has until 6 March 2006 to put it into operation (Du Plessis, 2005).


15 The World Health Organization describes WHO Stage III of HIV disease (i.e., clinical AIDS) in the following way:

• Weight loss, >10% of body weight;
• Unexplained chronic diarrhoea, >1 month;
• Unexplained prolonged fever (intermittent or constant), >1 month;
• Oral candidiasis (thrush);
• Oral hairy leukoplakia;
• Pulmonary tuberculosis within the past year;
• Severe bacterial infections (i.e., pneumonia, pyomyositis);
• And/or performance scale 3: bedridden <50% of the day during the last month (WHO, 2002, p. 100).

16 According to the Minister of Health Tshabalala-Msimang (2005): “The newly adopted definition [of disability] brings key policies and procedures in line, thus simplifying the eligibility processes and eliminating some of the current duplication of efforts that frequently create barriers for disabled persons applying for benefits in each programme respectively. More importantly, it makes the distinction between eligibility for a disability grant where the emphasis is on the applicant being unfit to work and participate in economic activity and eligibility for the free healthcare programme which focuses on the applicants functioning within society as a whole.”

17 According to Tshabalala-Msimang (2005): “We will continue to work on policies addressing eligibility of persons with chronic diseases so that we can make a clear distinction between disability grants and possible grants related to the impact of chronic illness.”

18 For a more detailed account of the research findings, see Hardy (2005).

19 For a detailed discussion of the problems of the implementation of social grants in general, see De Villiers (2002). De Villiers (2002, p. 348) concludes: “Despite its achievements, one must sadly acknowledge that almost every aspect of the disability grant system crucially breaches the most fundamental rights of administrative justice.”

20 For a summary of concerns and queries about disability grants raised by NGOs, CBOs and individual PWAs, see the minutes of the monthly affiliates’ meeting held by the AIDS Consortium (2005).

21 This is echoed in research conducted by Brand (2003). In his review of government food programmes, Brand (2003, p. 11) comes to the following conclusion: “It does not seem an overstatement to say that there is currently no single coherent, overarching policy framework dealing with the right to food in South Africa.” In his study, Brand notes the following main problems with the provision of the right to food: a lack of coordination between different government departments, an emphasis on “longer-term capacity initiatives rather than on immediate food transfers” and the inability of government to recognise that there is “an endemic crisis of food security in South Africa.”


23 For views on the debate about basic income grants (BIG), see Bhurat (2002), Standing & Samson (2003), BIG Financing


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