

HIV MANAGEMENT

ON A NEVER-ENDING WAITING LIST

Toward equitable access to antiretroviral treatment? Experiences from Zambia

Peris Sean Jones, PhD

Research Fellow, Norwegian Centre for Human Rights

Universal access to antiretroviral (ARV) medication for HIV/AIDS is the clarion call of the WHO/UNAIDS 3 by 5 Initiative. Treatment coverage, however, remains highly uneven. This sharpens the question of who exactly is accessing ARVs and whether access is challenging inequality or reinforcing it. Issues of distributive justice have long been debated in health policy, but the practical challenges of ARV distribution are relatively new. In exploring what a more equitable process of ARV distribution could involve, this article draws on a human rights framework using case study material from Zambia.

People who can access drugs have money and connections with influential people. They can simply pick up the phone, speak straight to a doctor, and can bypass queues. When the government talked about 10 000 on ARV, we were shocked as we didn't know any of these beneficiaries. I must say this caused anger in us. Civil servants are getting it, soldiers, and teachers are all first priority. But the majority of Zambians are unemployed or in the informal sectors and are not getting access. An ordinary Zambian can go to the clinic; but you will find that they are put on a never-ending waiting list.

Chairperson, Network for Zambian People Living with HIV,
Lusaka, 2004

Universal access 'for everyone who requires it according to medical criteria' is the clarion call of the WHO/UNAIDS 3 by 5 Initiative to extend life-preserving antiretroviral (ARV) treatment to 3 million people by 2005.¹ It follows in the wake of sustained pressure by treatment activists and their allies who exposed the 'deafening silence' of the more affluent in their indifference toward people living with AIDS (PLWAs).² Activist pressure has contributed to, and benefits from, efforts to clarify the relationship between treatment and the right to health. The availability of essential drugs is now regarded as an integral dimension of the right to health, whose core content includes treatment, and control of epidemics, as well as prevention.³ The 3 by 5 Initiative has served to catalyse international action on making treatment a reality for PLWAs in low-resource settings.

For all of the distance covered and rapid progress unquestionably being made, however, ARV treatment coverage remains limited at 15% in developing and transitional

countries, and even lower in sub-Saharan Africa, at 11%.⁴ Universal access is still very much a distant goal. Nevertheless, the efforts to scale up are already providing valuable experiences.⁵ Among them is increased knowledge about what scale-up efforts imply for equity in treatment access. In the quotation above, a Zambian AIDS activist captures the incredibly dispiriting sense of there being a 'never-ending waiting list' for ARVs for the poor. Normative issues concerning distribution and rationing of scarce resources have been debated in health policy for a long time, but they have received relatively little attention in the context of access to ARVs.⁶ Scaling up ARVs takes place, after all, against a more general backdrop of health interventions that 'seldom reach the poor' and reflect a 'skewed distribution of basic health services within and between countries'.⁷

It is therefore critical to ask how the increase in resources and new determination of governments and donors to expand access to ARVs are being played out in countries characterised by high levels of inequality. In other words, while universal access is akin to a distant ship on the horizon, until this ship comes in, it is important to identify how scaling up reinforces or alleviates inequality.

This article explores how issues of equity and fairness can receive greater attention as access to ARVs is scaled up. There is an important role for human rights in levelling the treatment playing field by ensuring that equality and non-discrimination principles guide policies and programmes. International human rights norms, standards, and instruments have mapped out corresponding state obligations in an increasingly concrete fashion.⁸ More specifically, the International Guidelines on HIV/AIDS and Human Rights examine these in the context of the HIV/AIDS epidemic.⁹ As alluded to by other commentators, however, a broader consideration is how human rights can and should interface with systemic inequalities that create the political, social, and

Reprinted from *Health and Human Rights* (2005; 8(2)), with permission.

economic exclusion of the poor and vulnerable.¹⁰ How we move beyond human rights 'wish lists' of recommendations concerning state obligations and toward actual implementation is important in this regard. The challenges involved in scaling up access to ARVs in Zambia illustrate some of these broader concerns.

First, this article reviews the cornerstone 3 by 5 documents, pointing out that they do not devote much attention to issues of equity in access, and then reviews other documents, including the proceedings of a World Health Organization (WHO) consultation on equitable access to treatment.

Second, some of the practical dilemmas in seeking redistributive justice are illustrated through the process of setting criteria in national efforts to scale up in Zambia. Discussion of particular barriers to access is included.

Third, the article discusses systemic barriers that pose challenges to determining a fair process for ARV distribution that takes into account competing criteria.¹¹ As important as a fair process is, the influence of political (and discursive) power in decision-making – even about fair process – may have been underestimated. What appears to be critical from a human rights perspective is that upholding state obligations requires that individuals and their organisational representatives be considered legitimate participants and active agents in the process. Effective citizen participation, however, also requires that participants are able to exert leverage over policy-making decisions. Rights-based discourse and practice need to be more explicit about the role of political and social organisations in exercising and claiming rights. To that end, a rights-based approach to development (RBD) has potential to construct a politics of accountability capable of altering relations between individuals and the state. For RBD to be regarded as relevant and transformative, however, it has to acknowledge and confront the complexity of specific sites of social, economic, and political struggle over access to ARVs and, more generally, service provision.

EXISTING CRITERIA FOR PATIENT SELECTION

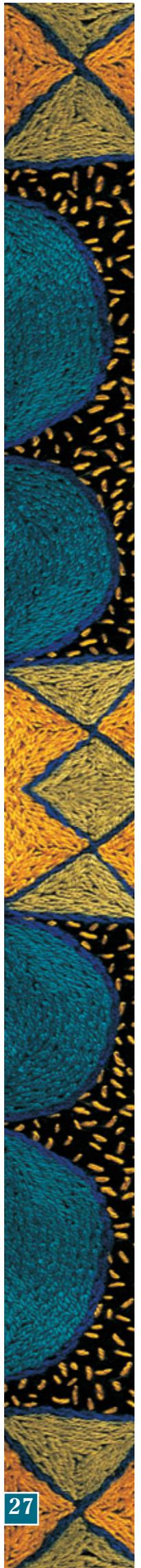
An initial Internet-based search for 'criteria' for patient selection for HIV/AIDS medication returned search hits indicating an overwhelming bias toward 'clinical', 'ethical' (concerning trials), and 'low-cost' DAJ (drug access initiative – that is, clinical) criteria. When 'eligibility' was added to the search term, the hits tended to be grouped under 'financial', 'medical' and 'therapeutic guidelines'.¹² A subsequent search through key UNAIDS and WHO documents revealed a striking absence of equity-based criteria for patient selection. In the cornerstone document, *Scaling Up Antiretroviral Therapy in Resource-Limited Settings*, the focus is upon scientific advances in the ARV field.¹³ As with 3 by 5 itself, the fundamental consideration underpinning these documents is, of course, the objective of broadening ARV access to 3 million people by 2005.

The objective of expanding access, however, assumes that it will ultimately achieve the goal of universal access 'for everyone who requires it according to medical criteria'.¹⁴ This is a necessary and noble objective, but a significant barrier to achieving it is the fact that services in resource-poor societies are skewed toward those who are better off. Although WHO refers to 'protecting and serving vulnerable groups in prevention and treatment programmes', and, in fact, states in 1 of the 11 guiding principles for 3 by 5 that 'the initiative will make special efforts to ensure access to antiretroviral therapy for people who risk exclusion because of economic, social, geographical or other barriers', the Initiative does not specify how it will achieve equity or minimise unfairness. WHO documents refer to better use of key 'entry points', such as with patients with tuberculosis (TB), but the documents do not detail means of prioritising social criteria.¹⁵ A discussion paper prepared for a follow-up meeting on the implementation of the United Nations 2001 Declaration of Commitment on HIV/AIDS does, however, mention structural factors such as lack of skilled health care workers and 'the barriers to access presented by cost-recovery mechanisms'.¹⁶

Barriers to access are invoked in some detail in rights-specific documents such as the International Guidelines on HIV/AIDS and Human Rights. The commentary on revised guideline number 6 states that '... universal access requires that these goods, services and information [that is, concerning prevention, care and treatment] not only be available, acceptable and of good quality but also within physical reach and affordable for all'.¹⁷ It also identifies the need for positive measures 'to address factors that hinder equal access', such as poverty, migration, rural location, and 'discrimination of various kinds'. A fundamental omission within all of these documents, however, is a detailed discussion about the kinds of targeted measures required to ensure greater equity in treatment access. The relatively limited attention given by WHO to equity criteria in the 3 by 5 cornerstone documents was to some extent supplemented by their Consultation on Equitable Access to Treatment and Care for HIV/AIDS. Contributions by the Pro-Poor Health Policy Team, and, especially, by Daniels and Macklin, stressed the need for 'careful decisions justified by principles of ethics and equity' in addressing the challenge of prioritising access to ARVs.^{18,19} With the backdrop of these documents in mind, the following sections look at some of the dilemmas faced when treatment access is scaled up, in the context of the challenges faced within a particular country.

ZAMBIA: CONSIDERATIONS FOR CRITERIA SETTING

Greater consideration appears, in general, to be given to clinical criteria rather than to ensuring a rights-based focus upon equity. This practice raises the question of who should be given priority in access to treatment and surfaces fundamental issues of ethics, power, and political discourse. These dilemmas and challenges can be better understood in a specific country context.



In Zambia, HIV/AIDS prevalence among people between 15 and 49 years of age is estimated to be over 16%. Over 1 million people are estimated to be HIV-positive, of whom 54% are women. It is currently estimated that 149 000 of these people could benefit from ARVs.²⁰ Since 2002, the government has subsidised medication, surpassing the initial target of 10 000 Zambians on treatment by the end of 2003 at nine provincial treatment centres. As of March 2005, however, the coverage of approximately 23 000 people (including 2 000 in the private sector treatment programmes), despite substantial progress made over the past year, means that it appears highly unlikely that the WHO and Zambian National AIDS Council target of 100 000 on treatment by the end of 2005 will be reached.²¹ Even if the target of 100 000 on treatment were reached, this would still leave another 49 000 people without ARVs.

As is the case with many countries, attempts by the government in Zambia to establish equitable criteria for ARV distribution have proved inadequate, if not non-existent. The situation in Zambia is similar to that in many countries where HIV infection is prevalent, raising questions about means of determining equity in access to ARVs. If only a fraction of those in need can access treatment, how should decisions be made about who should receive treatment first? In an effort to establish criteria for the ARV selection process, the author engaged in a short period of fieldwork in Zambia in 2004. The purpose was to conduct interviews to elicit suggestions from eight respondents selected for interview because they were identified as key cross-sectoral actors in the scale-up of ARVs in Zambia. Respondents were drawn from the non-governmental (NGO) sector, including organisations with representation on the board of the National AIDS Council, such as the Network for Zambian People Living with HIV; university-based researchers; and UN agencies such as WHO and UNAIDS. Furthermore, as he was in Zambia, Dr Alex Coutinho, Director of the AIDS Support Organization (TASO) in Uganda, a prominent HIV/AIDS organisation, was available for more general discussion of selection criteria issues.

Intended as a 'snapshot' of Zambian policy concerning selection criteria in the context of rapid scaling up of ARV treatment, the fieldwork was based upon structured interview schedules using standardised questions put to each respondent.²² Although government sector representatives were unavailable for comment, an informal discussion was held with a seconded employee at the Central Board of Health concerning scale-up. A hospital, clinic, and local hospice were also visited in Lusaka. Finally, a desk-based review of the print media was undertaken prior to the fieldwork. Respondents were asked to identify, as far as they were aware, the criteria governing access to ARVs in Zambia and whether they considered it satisfactory in terms of equity. Some of the criteria in Table I were then used as prompts in the interviews.

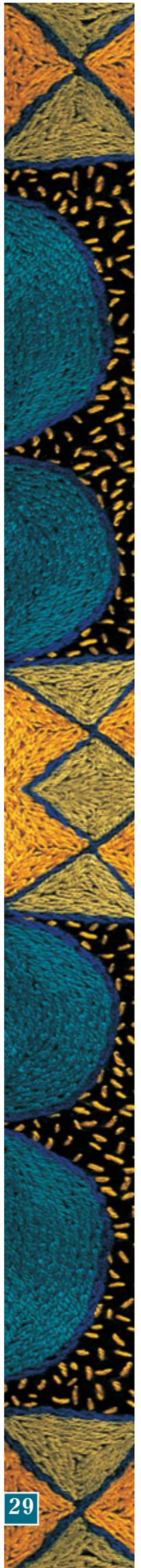
Unprompted, all eight respondents consistently identified two criteria that they believed were used to determine access to ARVs. The first were the clinical criteria commonly associated with eligibility for treatment. The second were economic

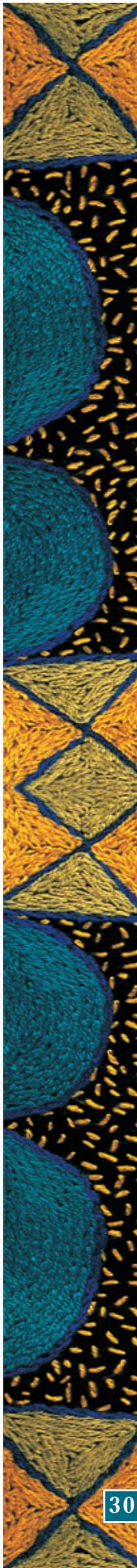
criteria. In other words, the imposition by government of cost-recovery requirements – that is, the financial contribution that PLWAs were required to make toward their ARVs, as well as associated costs such as those for testing – was identified as the fundamental barrier to access and the greatest engine of inequity. The introduction of user fees for service provision during the era of World Bank and International Monetary Fund-inspired Structural Adjustment Programs, in the 1990s in particular, has been identified, more generally, as a major factor in undermining the health of the poor.²³ In 2004, at the time of the fieldwork, a range of cost barriers excluded the poor from access to ARVs: a K40 000 (approximately US\$9.00) monthly contribution to medication, a K90 000 (approximately US\$21.00) contribution to the cost of a CD4 count, a K65 000 (approximately US\$15.00) contribution to the cost of a liver count, the K1 000 (approximately US\$0.23) contribution to the cost of HIV testing at some voluntary counselling and testing (VCT) sites, and the transportation costs for attending clinics or hospital (K5 000 equals approximately US\$1.00).²⁴

In terms of social criteria used as prompts in interviews, there was almost unanimity concerning respondent disapproval of community selection panels due to concerns over misuse and potential bias in selection. In addition, one respondent said that to give preference for treatment to PLWAs with a greater number of dependents was unacceptable: 'But who is life more valuable to? I am not going to say that I can die as my neighbor has 10 dependents and I only have 2. Come on! It should be available for whoever needs it.'²⁵

In response to questions about who should receive priority in ARV treatment, other respondents, such as Dr Coutinho, claimed that criteria that extend beyond medical criteria should be considered relevant only when determining suitability of the patient for treatment. Thus, some degree of disclosure of status to a friend or relative was considered conducive to greater chances of adherence, perhaps through encouragement of a 'treatment buddy'. The issue of providing privileged access to dependents could also be cast in this light. Prioritising mothers and/or dependents, such as partners or children, might greatly enhance openness and encourage medical efficiency through mutual support. This might also perhaps avoid situations where patients share their doses with family members.

Clement Mfuzi, the Chairperson of the Network for Zambian People Living with HIV, felt that there was a need to provide priority access to those considered to be sicker than others: 'I know that not all of us can be on ARVs; but if I see someone in hospital with advanced symptoms, then they should be first because life is not replaceable.'²⁶ If level of sickness were a key consideration in determining who should be given priority in access to ARV treatment, however, then those cared for at home who are too sick to travel to hospitals and clinics would have more of a moral claim to treatment. As the husband of the director of a local hospice pointed out, 'The problem with clinics is that they don't see those behind their wall' – in other words, they don't see the bed-ridden at home.²⁷





Some respondents emphasised the need to give children priority access, while others, although to a lesser extent, suggested that women should be given such consideration. The WHO Deputy Country Representative in Zambia stressed the 'social good' derived from targeting specific marginalised groups with particularly high levels of infection, such as truck drivers and sex workers.²⁸ Finally, Mfuzi also raised the issue of whether PLWAs who had been on drug trials, which often ended suddenly, should get priority.

The issue of whether and where treatment should be geographically concentrated also warrants consideration. Building upon existing capacity generally reflects sound health system principles; but doing so in the context of ensuring equitable access to ARV treatment frequently limits the focus to urban areas, which prevents those in rural areas from receiving treatment. Thus, most ARV distribution efforts in Zambia, for example, are geographically skewed, since possibly half of all patients on ARVs are located in Lusaka, the capital.²⁹ Taking geographical coverage into consideration when developing access guidelines might be advantageous, however, if, for example, efforts are aimed at deliberately targeting specific settlements or provinces chosen for their particular disadvantages in terms of inequity.³⁰ Many respondents identified rural areas as having the greatest degree of inequity in access.

As this discussion shows and as ongoing debates illustrate, the process of setting access priorities is heavily value laden and immensely complicated and therefore may require legal and public health guidelines. Macklin attaches great significance to consideration of competing ethical principles – in short, the criteria that are chosen reflect different values and will have different implications for who is eligible for ARV even though these choices are not always equitable.³¹ Decisions about who will or will not receive treatment will take place regardless of whether specific criteria to ensure equity in access have been established, but these determinations may well lack balance and fairness.³²

The following discussion examines how this process is being played out in national ARV policy in Zambia.

SETTING NATIONAL CRITERIA AND SCALING UP ARV IN ZAMBIA

Discussions of scaling up ARVs in Zambia must take place in the context of more general challenges of low coverage, poor quality, and insufficiently funded health care.³³ A particular concern is that 'people afflicted with HIV/AIDS seldom have adequate access to the necessary health care services, including antiretroviral drugs, facilities and food.'³⁴

According to a review of print media coverage of ARV-related issues and fieldwork interviews about the extent to which civil society had been consulted by government, there appears to have been scant public debate concerning the criteria governing access.

In 2002, the Zambian government made a first commitment to making ARVs widely available through the public health system, when it allocated K12 billion (\$US 3 million at the time) for the purchase of drugs intended for 10 000 people. The lack of discussion between government officials and members of civil society regarding access might have been the result of a number of factors, including the fact that there appear to have been few public information campaigns at the time. Furthermore, the National HIV/AIDS policy remains in draft form after over 3 years, which means that national responses have lacked overarching policy definition.³⁵ Although Zambia's Central Board of Health announced in 2003 that a country-wide HIV/AIDS drug rollout would begin within 6 weeks of the announcement, one of the major PLWA organisations, the Network for Zambian People Living with HIV, commented that '[T]here is very little communication between the government and AIDS NGOs on the matter', implying that the government had been in the process of making policy decisions without consulting those who needed the treatment the most.³⁶ One respondent from an organisation working on the legal aspects of HIV/AIDS suggested that 'The problem is that government came first with saying "10 000" but without discussion of criteria used to distribute ARVs. Even if it is free, then it won't get to the grassroots – but nobody talks about it [that is, equity].'³⁷ Apparently, the poor and powerless – those most in need of treatment – were 'completely left out of the process and [are] still not aware of how their members will benefit.'³⁸ The Network for Zambian People Living with HIV was doubtful of the government's commitment to including those most marginalised.³⁹

What little public debate about criteria for coverage did take place tended to focus on the rural/urban divide and emphasised that 'poor Zambians who live in rural areas' should 'also benefit.'⁴⁰ A number of people in prominent positions also suggested that efforts to scale up access to treatment should focus on women and girls.⁴¹ The level of public disquiet at the reluctance of government to discuss and define eligibility criteria, however, seemed to eventually prompt announcement of criteria to determine which of the country's HIV-positive people would benefit from the accelerated drug roll-out.

In 2003, according to the *Times of Zambia*, Brian Chituwo, the Minister of Health, stated that the new criteria were to be implemented after 'many people voiced concerns that the drugs were apparently available only to "privileged people".'⁴² The new criteria would, according to Dr Chituwo, 'ensure that people get these drugs on the first-come, first-serve basis.'⁴³ Access, according to the Minister, would require voluntary testing and counselling and a clinical test to determine viral load. Apparently those PLWAs with higher levels of immunity would not receive the drugs but would instead receive nutrition counselling. The only apparent concession to non-clinical criteria came with the suggestion that mothers who had been on mother-to-child transmission (MTCT) prevention programmes would continue to receive drugs.⁴⁴

These considerations were apparently based upon WHO guidelines and clearly prioritised 'clinical' over equity considerations.⁴⁵ All of the interview respondents tended to agree that the criteria weighed heavily toward clinical aspects. Arguably, as long as criteria remained biased toward clinical issues, prioritisation was more of a 'technical' endeavor devoid of equity considerations and was biased in favor of those who were better off.

BIASED FAVORING PEOPLE [WITH GREATER RESOURCES]

For the majority of Zambians living on less than a dollar per day, the economic costs mentioned earlier represent a considerable barrier to access. Many Zambians have the strong impression that people who are 'better off' are the ones getting access, whereas 'ordinary' Zambians are put on apparently never-ending waiting lists. The perception that ARVs cannot be accessed by the 'average man on the street' but rather only by civil servants is prevalent: 'If I was an average man on the street somewhere along Cairo Road [a busy street in downtown Lusaka] then I would not appreciate this [that is, prioritising civil servants for ARV treatment].'⁴⁶

Although removing cost recovery appeared morally imperative, some of the government's reasoning for adhering to this policy is complicated and cannot be detailed here other than to note that they claimed, for example, that cost recovery would enable more people to be placed on treatment, as supply would go further.⁴⁷

Highlighting some of the problematic issues related to cost recovery, the majority of respondents said that they had heard of instances in which PLWAs had sought consultation at the big hospitals in Lusaka (which, until 2004, were the only public health facilities where ARVs were available), only to be asked first whether or not they were employed – a direct implication related to their ability to pay for services. The perception of bias was also confirmed during the author's observation at an HIV/AIDS clinic at one of the largest hospitals in Lusaka, where prominence was given not to HIV/AIDS-related posters and information, but rather to a sign announcing that patients needed to present a receipt of payment before consultation. One respondent even suggested that a so-called fast-track system existed, whereby faster access to ARVs was ensured if the recipient was willing to pay more than the usual fee.

In addition to formal costs, one respondent raised the issue of bribes, or so-called informal costs, claiming that the greatest factor determining access at one particular hospital was whether the patient was willing and able to pay 'informal' costs across the chain of personnel facilitating access to ARVs.⁴⁸

On numerous occasions, it was alleged that, over and above their ability to pay, civil servants were given access priority. A majority of respondents alluded to a tacit government policy of procurement for civil servants, although it was unclear

where the funding was coming from. One respondent claimed that she had met a teacher in a rural district who had told her that ARVs were relatively easy to access, despite the immense barrier of distance, because of a scheme introduced by the Ministry of Education. The practice of privileging the employed and civil servants was also noticeable in one of the first state pilot ARV projects.⁴⁹

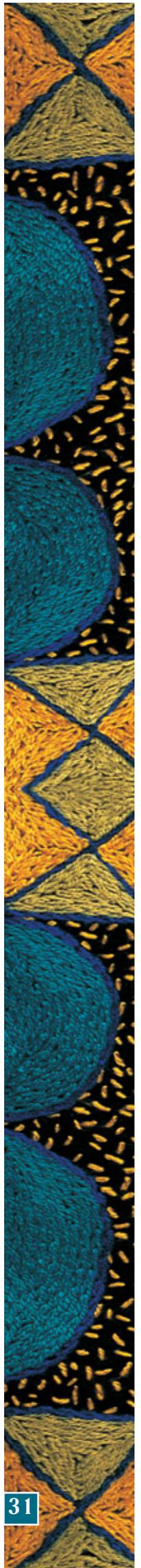
Thus, it would appear that, although it is not an official public policy, the Zambian government has allowed privileged access to ARVs for state employees. Whatever the reasons for the perception of class and geographical bias, it is a powerful and lingering impression, which will continue in the absence of public deliberation over equity considerations in Zambia.

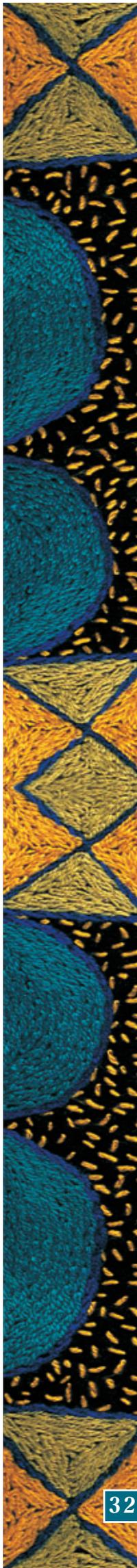
In mid-2004, in a highly significant policy departure from cost recovery, four clinics were able to start dispensing life-prolonging AIDS drugs free of charge in Lusaka at Chelstone, Kalingalinga, Matero, and Kanyama clinics. Again, however, the decision to provide a patient with access to ARVs was solely 'based on clinical examination undertaken by staff in clinics.'⁵⁰ The Network for Zambian People Living with HIV again voiced its concern that coverage needed to include rural areas where 'people were equally in need', and also called for free treatment for opportunistic infections in addition to the ARV treatment being dispensed in the Lusaka clinics mentioned.

The removal of cost barriers at these four clinics appeared to have a dramatic impact. A visit to one of the clinics confirmed the positive view of patient uptake of ARVs. A dispensary nurse informed the author that 'The response has been overwhelming, everyone is coming, men, women, all ages and the poorest. Some also came who could not continue to afford payments elsewhere. Everyone who is eligible and willing gets ARV.'⁵¹

This positive development therefore underscores the profound significance of the announcement made in July 2005 by the government of Zambia to provide ARVs and related services 'free in *all* public health facilities', as a massive step toward greater equity.⁵² There was no mention, however, of equity criteria in either the July 2005 announcement (other than mention of free coverage for refugees) or the earlier announcement of free access at the four clinics in Lusaka. Scale-up of ARV in Zambia, like elsewhere, is a dynamic process. The announcement to end cost recovery concerning ARVs shows that the government now feels it has sufficient donor funding to remove the costs. As scale-up increases, more people come forward for treatment, and existing patients return to collect medication once a month; human resources, however, are inevitably stretched. As a result, waiting lists are growing, with the implication that difficult choices remain regarding selection in the context of 'first come, first served'.

The Zambian government thus appears to be committed to making ARVs available. As many respondents pointed out, however, and as a human rights approach confirms,





availability is not the same as making ARVs accessible in financial, geographical, and cultural terms.⁵³ The principle of equality is pivotal to the right to health, with emphasis placed upon equality of access. A core obligation within this framework is to 'ensure equitable distribution of all health facilities, goods and services'. The onus is therefore placed on states through their obligation to take 'positive measures' that enable and assist individuals and communities to enjoy the right to health. Obligations to fulfil the right to health involve 'appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health'.⁵⁴ Achieving this requires a national health policy with a detailed plan. With regard specifically to HIV/AIDS, as mentioned earlier, Zambia's national plan still remains in draft form. With regard to ARVs, however, the draft Zambian National Implementation Plan appears to reflect considerable awareness of equity. Of the eight strategic objectives, one is labelled 'Strengthen the community role for provision of ART'. Within this objective, a critical submeasure under the sub-title 'Promotion and protection of rights' includes '... realization of the right to treatment, participation in ethical and equitable patient selection and other decision-making, protection of human rights and community oversight of ART programs ...'.⁵⁵

Table I summarises the range of criteria used to formulate policy regarding selection of ARV recipients. The table was compiled mainly from issues arising from the review of print media, the 2004 interviews, as well as one of the few reviews of selection criteria that currently exists.⁵⁶

The Zambian government appears to be making gradual progress in providing access to ARVs. Expanded local access, removal of cost recovery, and an implementation plan that includes equity issues are all significant policy landmarks in scaling up ARV coverage. Despite these advances, however, because an additional 120 000 PLWAs are still without treatment, monitoring of access remains inadequate, and little has been accomplished in developing targeted measures to enhance equity – ensuring fairness in access to ARVs is of continuing concern.

TOWARD EQUITY HOW?

Experiences in Zambia illustrate some of the highly complex issues associated with establishing criteria to ensure equitable access to ARV treatment. Barriers to access in Zambia, including poverty, distance, and social and political exclusion, are also generally found in other regions where HIV is prevalent. A fundamental aspect of rights-based equity in health consists of minimising the presence of *avoidable* health inequalities and barriers to access. Many observers suggest that rather than an equal allocation of resources, such as ARVs, equity implies the allocation of *fair* shares in resources. In terms of mapping out guiding principles for equity-based criteria, we can draw upon a well-known framework for the right to health emphasising availability; financial, geographical, and cultural accessibility; quality; and equality.⁵⁷

State parties' obligation to provide information about the availability of services and public information programmes is one step.⁵⁸ Another particularly important recommendation is to establish health indicators and benchmarks in order to monitor the treatment scale-up process. States parties should identify the factors and difficulties affecting implementation of their obligations. In terms of ARVs, it is particularly noticeable that disaggregated information of access, in terms of male, female, age, urban, rural, socioeconomic status, and most disadvantaged and vulnerable, is not available in Zambia. Such data are critical in order to monitor who is getting medication. The information could also be used to encourage equality and non-discrimination and to target the most vulnerable.

The obligations and recommendations stated in human rights instruments and consideration of periodic reports to the UN Committee on Economic, Social and Cultural Rights are useful tools in minimising unfairness. There is a more fundamental issue, however, concerning how to create a *process* that will be more likely to lead to their implementation. The point is not only that formal rights should be guaranteed and institutionalised – legal redress and lobbying is hampered by the non-justiciability of socioeconomic rights and the lack of an equality clause in the Constitution, but that a politics of acquiring and transforming such rights is enabled.^{59,60}

Decision-making with respect to equity considerations, for example, would appear to cut across issues concerning barriers to access. As suggested earlier, the difficulty in balancing competing principles governing eligibility for ARVs, according to Daniels, adds urgency to the requirement of a 'fair process' involving public debate and information about the principles. Daniels mentions five key principles, of which, one, *stakeholder participation*, is particularly relevant.⁶¹

According to Daniels, stakeholder participation is aimed at building consensus on 'mutually justifiable terms of cooperation'.⁶² This is one interpretation of the role of participation. It is generally agreed that PLWA and community organisation participation in HIV/AIDS-related policies and programmes is highly desirable. With respect to 3 by 5, however, specific interpretations related to the degree and nature of participation tend to vary across related policy documents. In the 3 by 5 document, for example, great scope is suggested for PLWA and community involvement in advocacy, planning, and delivery because of the implicit understanding that their participation in these activities will produce more successful responses to HIV/AIDS.⁶³

While so central to the 3 by 5 strategy, here, as elsewhere, community involvement can also be regarded in much more functional terms: it can be invaluable in providing input into programme design and management, addressing critical questions related to care, and encouraging adherence.^{64,65} In some projects, as well as potentially acting as a buffer to the 'development of local patronage or even corrupt practices', McCoy says, 'community structures have also been established to ratify and legitimize decisions about patient selection'.⁶⁶ All

TABLE I. SUMMARY OF SELECTION FOR TREATMENT CRITERIA

| Selection | Comments |
|---|---|
| <p>Clinical As defined by WHO regarding CD4 count, etc., and adapted for low-resource settings</p> | <p>Most commonly used criteria, although even here there is debate with respect to biomedical criteria, with evidence of a need for flexibility in criteria in low-resource settings. But in the interests of equity, treatment policy should not be divorced from consideration of additional criteria mentioned below.</p> |
| <p>Efficiency (prioritising the following) Patients considered to have higher probability of successful outcome with treatment:</p> <ul style="list-style-type: none"> ■ Those already receiving treatment through prevention of mother-to-child transmission (MTCT) programmes and perhaps their partner and/or children ■ And/or people already receiving TB treatment ■ Those already tested versus those not yet tested | <p>Here it could be argued that it is more efficient to target those who already know their status, as well as children and partners of pregnant women. But the problem is that this penalises non-pregnant women. Medical efficiency, in terms of likelihood of successful outcome, raises dilemmas in the context of the additional criteria stated below.</p> |
| <p>Economic Based upon patient ability to make a financial contribution for services received</p> | <p>This tends to exclude the poor and especially the poorest of the poor. Payments also drain household resources and treatment may not be sustainable, hence patients may have existing treatment terminated due to inability to pay.</p> |
| <p>Social/geographical</p> <ul style="list-style-type: none"> ■ 'First-come, first-served' basis ■ Patient's punctuality in keeping appointments* ■ Degree of disclosure ■ PLWA's number of dependents ■ Eligibility through local residency ■ Community selection committees | <p>Problems with 'first come, first served' include: bias toward people who are better educated or informed, or those from urban areas, possibly biased toward men. Specific measures are required to overcome barriers to access – for example, travel costs, targeting females, also requiring awareness-raising, particularly through 'treatment literacy'?</p> <p>Time-keeping and some disclosure may increase efficiency and adherence.</p> <p>Criteria concerning number of dependents would be unfair to those with fewer.</p> <p>Eligibility through geography becomes problematic in the context of transitory populations and creates unfairness in areas geographically excluded from treatment.</p> <p>Community participation in selection committees appears transparent but may encourage bias and/or corruption.</p> |
| <p>Ethical/rights-based (priority given to the following)</p> <ul style="list-style-type: none"> ■ Stigmatised social groups ■ Post-exposure prophylaxis for health care workers and women and children exposed through rape or sexual abuse ■ Those too sick to travel to hospital/clinic[†] ■ Poorest of the poor ■ People whose drug trials end abruptly | <p>Many groups such as men who have sex with men, sex workers, orphans, migrant workers, and refugees need special efforts because they are particularly marginalised and often considered 'undeserving' by society.</p> <p>An additional category includes the bed-ridden at home unable to get to a clinic and requiring particular attention.</p> <p>Other dilemmas include whether those patients who have been involved in drug trials ending abruptly require special entitlement.</p> <p>Overall, there is the medical efficiency argument (above) that basing selection criteria partly on those most marginalised is not necessarily compatible with determining a more efficient outcome. The counterargument is that specially targeted resources and social support is required for marginalised groups.</p> |
| <p>Administrative/political State employees getting preference</p> | <p>Due to burden upon states of cost of absenteeism and death of civil servants, the latter may be given preference for treatment to non-civil servants. This may also reflect a regime's political considerations regarding its support base.</p> |

* Médicines sans Frontières (MSF), in sub-Saharan Africa, initially agreed to provide treatment to only those patients who were on time for three appointments, and if relevant, those who brought a parent or guardian with whom they shared their status. In Khayelitsha, outside Cape Town in South Africa, MSF requires that patients be on time for four appointments and if necessary undergo prior TB treatment, with the stated goal of achieving better outcomes for adherence to ARVs. The assessment of eligibility also includes a home visit to verify geographical eligibility, disclosure criteria, and evidence of commitment to long-term therapy and safe sex practices. Preference is also considered on the basis of the number of dependents as well as health status, with the very sick getting priority; income (the very poor receiving priority over those being able to afford treatment); and, as stated, disclosure and degree of political activism. Elsewhere, eligibility committees are also considered, such as the multi-sectoral committee in the Benin Initiative, which determines anonymously who receives treatment and appropriate financial contribution. (Sehonou in Attawell and Mundy, *ibid.*)

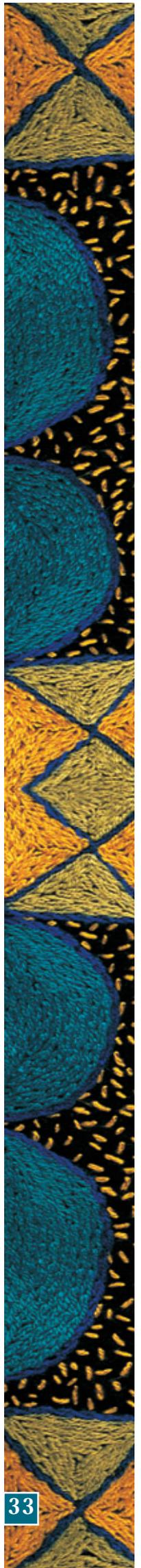
[†] In Zambia, the number of PLWAs who are sick at home and physically unable to attend clinics is very large. Most respondents were particularly concerned about PLWAs receiving home-based care and how they would access treatment.

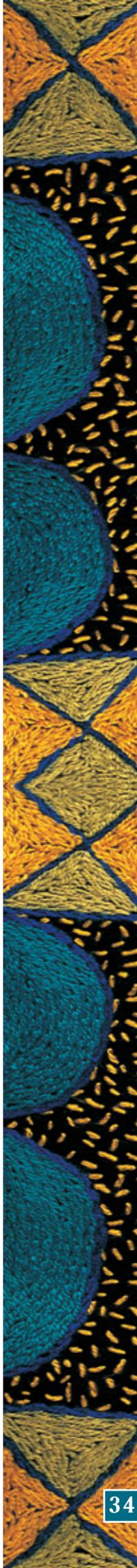
of these considerations are undoubtedly vital to the success of 3 by 5. The benefits of community participation are thus numerous and far reaching, and such involvement should continue to be encouraged.

Despite the many positive aspects of community involvement, however, limitations of participation at this level need to be considered. In assessing the full impact of community participation, one must first clarify the reasons for seeking such involvement – is it considered a 'means' to deliver policy objectives, or an 'end' in itself? Additionally, the terms need to be clarified: does participation, for example, involve acting in a consulting capacity, playing an advisory role, delivering somebody else's policy, or, more profoundly, transferring some

degree of *power* between stakeholders? According to Cooke and Kothari, who summarise a collection of articles reflecting on over 25 years' experience of development projects, in all likelihood, participation reinforces the status quo rather than challenges it.⁶⁷

While participation, on the one hand, is a principle integral to human rights discourse, the latter usually fails to interface with critical accounts of participation emerging in development studies that identify co-optation of participants and/or lack of transfer of power to participants (or certain individuals and groups of participants) due to institutional, social, cultural, and political dynamics. A case in point is the observation made by one interview respondent concerning a





public 'consultation' meeting undertaken by the Zambian National AIDS Council, which he attended. The meeting had the appearance of a participatory process, but in essence it was a controlled process, with public participation orchestrated merely to rubber-stamp decisions apparently already taken concerning government policy.⁶⁸ Furthermore, in view of the problems with participation, while civil society is represented on the board of the Zambian National AIDS Council, the actual quality and effectiveness of the participation upon decision-making processes requires closer scrutiny.

Development studies and practice, on the other hand, tend not to emphasise equality or non-discrimination principles, nor do they focus on the most vulnerable. Above all, the development 'community' tends to be more preoccupied with localised and micro-developmental versions of participation in specific projects.

There would therefore appear to be extremely fertile ground in bridging developmental practice and experience with the broader emphasis within human rights upon state obligations and political and civil rights of excluded individuals and groups. In the quest for greater equity, a rights-based approach to development (RBD), arguably, therefore has the exciting potential to combine both.

'A rights-based approach to development', according to Frankovits, 'integrates the norms, standards and principles of the international human rights framework into the plans, policies and processes of development.'⁶⁹ The approach therefore impacts on national planning priorities by having the ability to redirect resources and to militate against policies that undermine the realisation of economic, social, and cultural rights. The missing link for the transformative potential for human rights in development is not so much about asserting legal claims, as catalytic as they sometimes can be. Rather, following Uvin, human rights should be considered 'tools that crystallize the moral imagination and provide power in the political struggle, but do not substitute for either.'⁷⁰ The significance of a more political interpretation of RBD is that participation and political rights are attached to holding State parties – and other parties, including donors – accountable and transparent in different institutional and policy fora.

CONCLUSION

This article has shown that progressive realisation of access to ARVs in Zambia is getting medication to an ever-increasing number of people. As praiseworthy as this rapid progress undoubtedly is, equity issues are not being addressed adequately in scaling up. Obligations and recommendations drawing on Zambia's compliance with the International Covenant on Economic, Social and Cultural Rights (ICESCR) are an important step toward enhanced equity in access to ARVs. National laws and policies should be brought into line with international human rights standards so that effective remedies are available when human rights are violated. A first-

come, first-served approach to treatment, while intrinsically 'fairer', requires additional targeted measures to ensure equity. Criteria setting is an important initial process, which does not appear to have taken place in Zambia beyond clinical criteria.

Projects and programmes should clearly be planned and implemented in ways that enable affected people to participate. The removal of cost recovery is fundamental to more equitable access. The recent announcement by the Zambian government to provide free ARVs and related services in all public sector facilities, requires, nonetheless, special attention to target particularly excluded groups such as people in rural areas, children, those too sick or poor to get to clinics and, more generally, reversing a culture of exclusion of the poor. The important role for information campaigns and disaggregated data for monitoring access has also been mentioned. It is also increasingly evident that local-level clinic delivery of ARVs will be vital in providing more equitable access but also, in doing so, circumvents rationing implicit in hospital waiting lists.

More broadly, however, while 3 by 5 confronts structural problems concerning under-resourced health systems, it is also shaped by the prevailing (im-) balance of power between donors and recipient countries, on the one hand, and state and civil society within countries, on the other. One explanation for the apparent neglect of equitable access may be that it would entail reorientation of institutional, political, and social power and resources away from the included to the excluded. It is clear that synergy among communities and state and non-state implementers can have a critical bearing upon ARV policy interventions. A critical barometer of the success of scaling up ARVs will be the extent to which institutional structures in Zambia, as elsewhere, such as National AIDS Councils and Global Fund Country Coordinating Mechanisms, enable *genuine* and *effective* participation, which reflects some degree of transfer of power to civil society decision-making. Donors must be bolder in enabling this to happen because in Zambia, thus far, general lack of co-operation, with mutual suspicion between civil society and the state – sometimes unwittingly assisted by donors and NGOs – results in participation being a de-politicised and 'technical' endeavour. Otherwise, there is an additional concern that governments are more accountable to donors than to civil society.

To encourage accountability of duty bearers, civil society actors, including social movements, must themselves be enabled to scale up in order to participate above and beyond the micro project level. It is here that greater dialogue between the human rights and development communities concerning participation could be fruitful. It could reinsert the role of political and civil rights and state obligations in promoting an equitable process of development but in a way in which human rights interrogates, and consequently can alter, the relationship between individual and government. Rights-based approaches can provide a powerful platform in catalysing action in order to challenge inequitable government policy positions. This will make a tremendous

difference to the prospects for equity in universal access to ARV. It will also assist in democratising the broader social, economic, and political forces of exclusion, of which the HIV/AIDS epidemic is such a powerful expression.

Acknowledgments

The author would like to thank NORAD for financial support. Thanks are also warmly extended to SIDA for financial and other support provided to present an earlier version of the paper in a SIDA session at the XV International AIDS Conference in Bangkok. I am extremely grateful to all the respondents for taking the time to provide such stimulating opinions while in Zambia. I would also like to thank Marlise Richter for useful comments. Finally, the referees provided very thorough and constructive suggestions, for which I thank them.

REFERENCES

- WHO, *Treating 3 Million by 2005: Making It Happen* (Geneva: 2003): p. 6.
- E Cameron, 'The Deafening Silence of AIDS', *Health and Human Rights* 5/1 (2000): pp. 7-24.
- Article 12(2)(c), International Covenant on Economic, Social and Cultural Rights; see Committee on Economic, Social and Cultural Rights, The Right to the Highest Attainable Standard of Health, General Comment No. 14 (2000), UN Doc. E/C.12/2000/4.
- WHO, *Progress on Global Access to HIV Antiretroviral Therapy - An Update on 3 by 5*, UN Doc. A/59/CRP.4.
- See for example, M Heywood (ed), *From Disaster to Development? Development Update* 5/3 (Interfund: Johannesburg, 2004). HEALTH AND HUMAN RIGHTS 99
- N Daniels and J Sabin, *Setting Limits Fairly* (New York: Oxford University Press, 2002).
- Ministry of Foreign Affairs, 'Fighting Poverty: The Norwegian Government's Action Plan for Combating Poverty in the South Towards 2015' (Oslo: 2002): pp. 33-36.
- ESC Committee (see note 3).
- UNAIDS/WHO, *International Guidelines on HIV/AIDS and Human Rights* (Geneva: 2002).
- See for example C Ngwenya, 'The Recognition of Access to Health Care As a Human Right in South Africa: Is It Enough?' *Health and Human Rights* 5/1 (2000): pp. 27-44; M Heywood and Dennis Altman 'Confronting AIDS: Human Rights, Law, and Social Transformation', *Health and Human Rights* 5/1 (2000): pp. 149-179.
- Daniels and Sabin (see note 6).
- More specialist websites such as the Center for HIV Information (www.HIVinsite.ucsf.edu) refer to clinical guidelines based on those of WHO (see below). The Centers for Disease Control and Prevention's AIDS Information website also refers to criteria as 'clinical'.
- WHO, *Scaling-up Antiretroviral Therapy in Resource Limited Settings: Treatment Guidelines for a Public Health Approach* (Geneva: 2004: p. 7).
- WHO (see note 1), p. 6.
- WHO, *A Public Health Approach to Antiretroviral Treatment: Overcoming Constraints* (Geneva: July 2003).
- WHO (see note 4).
- UNAIDS, HIV/AIDS, and Human Rights International Guidelines, revised guideline number 6, 'Access to Prevention, Treatment, Care and Support' (Geneva: 2002).
- See background papers for the Consultation on Ethics and Equitable Access to Treatment and Care for HIV/AIDS, Geneva, Switzerland, January 26-27, 2004, R Macklin, 'Ethics and Equity in Access to HIV Treatment'; Pro-Poor Health Policy Team 3 by 5 Initiative; 'Priority in Treatment and the Poor'; N Daniels, 'How to Achieve Fair Distribution of ARTs in 3 by 5: Fair Process and Legitimacy in Patient Selection'. Available at <http://www.who.int/ethics/>.
- Macklin (see note 18).
- WHO, *Zambia Summary Country Profile for HIV/AIDS Treatment Scale-up* (Geneva: June 2005).
- Ibid.*
- Relevant questions included: 'How would you characterize consultation between government and civil society concerning ARV?', 'Which stakeholders have been able to influence process/which haven't?', 'What are the existing criteria for a person to receive ARV?', 'Do you regard these criteria as adequate?', and 'Who is perceived as currently getting access to treatment?'
- D Narayan (ed), *Can Anyone Hear Us? Voices of the Poor* (World Bank Group: Oxford University Press, 2000).
- Based upon responses of interviews, particularly those of Dr Senkutu, WHO Deputy Country Representative for Zambia (Interview, Lusaka, September 15, 2004).
- Mrs Mataka, Director, Zambian Network on HIV/AIDS (Interview, Lusaka, September 8, 2004).
- C Mfuzi, Chairperson, Network for Zambian People Living with HIV (Interview, Lusaka, September 7, 2004).
- Personal communication (Lusaka, September 14, 2004).
- Senkutu (see note 27).
- 'Scaling Up Antiretroviral Treatment for HIV/AIDS in Zambia: National Implementation Plan 2004-2005', draft, Zambian National AIDS Council (August 2004): pp. 11-12.
- Such as MSF's geographic coverage of Chiradzulu province, see note 24.
- Macklin (see note 18).
- Rosen and Sanne *et al.*, in B Beresford, 'Reflections and Lessons from Frontline Treatment Providers', *From Disaster to Development, Development Update* 5/3: pp. 265-275 (see note 5).
- 'Consideration of reports submitted by state parties under Articles 16 and 17 of the Covenant: Zambia', Committee on Economic, Social and Cultural Rights, 34th session, UN Doc. E/C.12/1/Add.106 (2005).
- Ibid.*
- This is also noted in the National Implementation Plan (see note 32), which calls for 'an enabling policy/legal environment for the scale up of ART'.
- Martin Chisulo of the NZP+, IRIN, *Plus News* (March 28, 2003).
- Director of ZARAN, Zambia AIDS Law Research & Advocacy Network (Interview, Lusaka, September 8, 2004).
- Winston Zulu, NZP+ founder, IRIN, *Plus News* (April 1, 2003).
- Kunyima Banda, Acting National Co-ordinator of NZP+, *Ibid.*
- The Post* (March 16, 2004).
- The Times of Zambia* (March 11, 2004).
- www.kaisernetwork.org, August, 21 2003.
- Ibid.*
- See also AIDS MAP (2002) stating that partners and infants born with HIV should also be prioritised based on WHO recommendations, similar to Botswana, although the latter is also prioritising TB patients. See *Plus News* (2002).
- C Sozi, UNAIDS Country Representative, Zambia (Interview, Lusaka, September 14, 2004).
- Mataka (see note 28).
- See note 45.
- TJ Ngulube, Director, Centre for Health and Social Science Research (CHESSORE) (Interview, Lusaka, September 10, 2004).
- A respondent suggested, with regard to one of the first treatment projects, at Ndola Central hospital, that they were told by the Managing Director that, of hundreds of patients, not one single patient had been selected who could not afford to buy ARVs on the open market. The justification apparently given was with regard to sustainability issues - in other words, should the hospital run out of drugs, the patient would have the means to purchase medication elsewhere. Goran Carlsson, Advisor, Central Board of Health, Zambia, personal communication (December 20, 2004).
- Times of Zambia* (July 5, 2004).
- Observation as Kalingalinga clinic (September 15, 2004).
- 'Free Antiretroviral Therapy (ART) Operational Guidelines for Health Facilities in Zambia', Government of the Republic of Zambia, Ministry of Health (Ndeke House, Lusaka: July 18, 2005): pp. 2, emphasis added.
- Concerns were also raised by two respondents over the 'quality' of care provided, with poorly prescribed treatment regimens identified as often having lethal consequences, particularly in unregulated private practices.
- ESC Committee (see note 3).
- 'Scaling Up Antiretroviral treatment for HIV/AIDS in Zambia' (see note 32).
- Such as K Attawell and J Mundy, *Provision of Antiretroviral Therapy in Resource-Limited Settings: A Review of Experience Up to August 2003* (Department for International Development: November 2003).
- B Toebes, 'The Right to Health', in A Eide, C Krause, and A Rosas (eds), *Economic, Social and Cultural Rights* (The Hague: Kluwer, 2002): pp. 169-190.
- ESC Committee, General Comment 14 (see note 3) and ESC Committee, consideration of Zambia report (see note 36), respectively.
- Although Zambia has ratified the ICESCR, it has not incorporated it into domestic law; social and economic rights therefore remain as directive principles. The absence of an equality clause was brought to my attention by ZARAN (see note 40).
- P Jones and K Stoke (eds), *Democratising Development: The Politics of Socio-Economic Rights in South Africa* (Leiden: Martinus Nijhoff, 2005).
- Daniels mentions them all as The Publicity Condition, with agreement on the transparent deliberation of priorities, to include, particularly in light of 3 by 5, publicly provided rationale of decisions; The Relevance Condition and Stakeholder participation, to include consensus on rationale to 'seek mutually justifiable terms of cooperation', enabled through broad range of stakeholders being involved; Revisability Condition, with scope to change policies in light of new evidence; and, finally, Enforcement Condition, to assure that these points are followed through (see note 18).
- Daniels (see note 18): p. 17.
- WHO (see note 16): p. 5.
- Ibid.*
- Through, for example, DOT-HAART treatment supporters and, critically, support groups. Furthermore, a study of community involvement in ARV in Zambia echoes the observations of many respondents, in that, generally, people do not feel that they are consulted sufficiently: they want to be heard and be better informed about ARV treatment and about the system proposed for handling it. International HIV/AIDS Alliance, *Voices from the Community - A Report of a Community Consultation on Antiretroviral Treatment in Zambia* (November 2002).
- D McCoy, *Health Sector Responses to HIV/AIDS and treatment access in Southern Africa: Addressing Equity*, Equinet Discussion Paper 10 (October 2003): p. 33. When put to respondents in Zambia, however, interestingly, all unanimously suggested that community selection was inherently problematic and undesirable.
- B Cooke and U Kothari (eds), *Participation: The New Tyranny?* (London: Zed Books, 2001).
- Ngulube (see note 51).
- A Frankovits, 'Introduction', in *Empowerment, Participation, Accountability and Non-Discrimination: Operationalising a Human Rights-Based Approach to Development, Human Rights Development Yearbook* (Leiden: Martinus Nijhoff, 2002): pp. 3-14.
- P Uvin, *Human Rights and Development* (Bloomfield: Kumarian Press, 2004): p. 176.