Regional Network for
Equity in Health in
Southern Africa

EQUINET POLICY
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NO. 14

Can human rights serve as a tool for equity?

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EXECUTIVE SUMMARY

This paper was prepared for the Regional Network for Equity in Health in Southern Africa (EQUINET), in the network's theme work on health rights.

Background

Despite growing advances in medical technologies, inequalities in global health status continue to increase. Equity is a key challenge for developing countries, who are facing greater scarcity of resources and an increasingly hostile international economic order that undermines their ability to regulate and choose policies independently. Few would dispute the value of human rights in promoting human well being, and the need for health professionals to respect human rights. However, some public health approaches may argue that a concern for human rights can actually impede the achievement of public health objectives, such as equity, access and efficiency.

Much of the conflict between the human rights approach and the public health approach is based on differing interpretations of what human rights are, and what human rights approaches imply. This points to the need for EQUINET to muster a more sophisticated approach to the analysis and practice of public health strategies aimed at promoting equity, incorporating the lessons learnt by human rights advocates involved in health struggles in Southern Africa. This paper explores the relationship between human rights (and human rights approaches) and health equity, in order to generate a conceptual framework on which to base future work on health rights.

Methodology

Existing literature was reviewed to capture the theoretical base and three Southern African case studies were reviewed for evidence. Case study information was derived from documentary reviews and limited interviews with relevant organisations.

Theoretical background

More recent models of public health are calling for greater agency, within a social justice framework, by communities most affected by public health policy and practice, as opposed to relying on traditional paternalistic State intervention. Bioethics is dominated by the model of individualist client-provider interactions, and further work needs to be done to provide a coherent public health ethical framework for addressing health equity.

Human rights approaches, correctly applied, recognise the following key issues: power, social justice, anti-discrimination, the indivisibility of rights and the right to health. Considerations of social justice and social patterning are central, providing a platform for rights activists to contest State policy.

Human rights standards and norms can be used:
- to develop policies and programmes
- to analyse, critique and monitor government performance
- to facilitate redress for those who suffer violations of their rights
- to support rights advocacy and civil society mobilisation.

The argument that the concept of human rights is a Western construct and the counter-response to label cultural relativism as a way of justifying discrimination under the mantle of social norms needs to be more nuanced, since it must be acknowledged that talk of human rights can be used by elites in non-Western countries to serve their own best interests. In developing human rights-based approaches to health and health equity, cultural arguments need to be critically understood as neither inherently pro- nor anti-human rights, but as considerations that explain how fundamental rights could and should be expressed in the ethnic and social context of a particular society.

Particularly in Africa, international human rights law has increasingly begun to address groups deserving of the same protections afforded to individuals under international human rights law. Rights proponents have to engage all national and international agents, in both the public and private sectors, who shape policies impacting on health, directly and indirectly. International solidarity amongst non-governmental organisations (NGO's) has opened space for supporting struggles in developing countries. However, much work remains to be done.

Findings and conclusions from the case studies

Human rights approaches are powerful tools for supporting social justice and institutional transformation when:

- they are predicated upon casting rights in a group context, specifically vulnerable groups,
- agency is given to those most affected, and
- rights include the full range, from civil and political, to socio-economic rights.

Public health concerns for equity are then entirely consonant with human rights-based strategies.

Seven key themes emerged:

- Rights alone are not enough, but need to be coupled with community engagement.
- Rights, appropriately applied, can strengthen community engagement.
- Rights, conceived in terms of agency, are the strongest guarantors of effective equity-promoting impacts.
- Rights should strengthen the collective agency of the most vulnerable groups.
- Rights approaches should aim to address the public-private divide.
- Transparency and access to information are key to human rights approaches that build equity.
- Human rights approaches provide additional opportunities for mobilising resources outside the health sector.

Further work is required to test these preliminary findings by extending the analysis to other case studies. For example, what are the critical strategies that make a rights approach successful at opening the space for community engagement, and how sustainable are such strategies? How do health equity initiatives reinforce the potential mutuality of the relationship between rights and community agency, and what strategies ensure that the agency of the most marginal are prioritised in the development of such initiatives? Can equity approaches help to develop a better theorisation around group rights and the role of collective agency in ways that benefit the people of developing countries? How best can rights approaches support equity initiatives that address both national and global health inequalities? Lastly, health systems analyses need desperately to muster stronger rights arguments to ensure equity-promoting transformation.

Can human rights serve as a tool for equity?

1. BACKGROUND AND MOTIVATION

Despite growing advances in medical technologies, global health status inequalities continue to increase (Sen and Bonita, 2000; Loewenson, 1999; Evans et al, 2001). Health personnel in developing countries struggle to balance conflicting needs (Cosmas and Schmidt-Ehry, 1995), especially when the goal of social justice is in conflict with the macro-economic adjustments made in the name of national economic development (Chen and Berlinguer, 2001; Leon et al, 2001; MacFarlane et al, 2000; Braverman and Tarimo, 2002).

Despite claims to the contrary, there is growing evidence that globalisation has had a negative impact on the poorest countries of the world (Navarro, 1999; Cornia, 2001; Sitthi-amorn et al, 2001; Thankappan, 2001; Baum, 2001, Loewenson, 2001; Weisbrot et al, 2001; Watkins, 2002), with increasing impoverishment and rising inequality (Cornia, 2001). The deregulation of markets puts workers in developing countries at greater risk in the workplace because, in their desperation for paid employment, they are more likely to tolerate hazardous working conditions (Loewenson, 1999). Deregulation in the private health sector has also led to a massive expansion of poorly planned private health care, adverse affecting equity and access to health care for the majority of people in Asia and sub-Saharan Africa (World Bank, 1994; Collins et al, 1994; Gilson and Mills, 1995; Sen and Koivusalo, 1998). Prioritisation of foreign debt repayments and economic structural adjustment programmes have reduced social spending (cited in Braverman and Tarimo, 2002: 1626; Werner and Sanders, 1997), resulting in greater inequalities than ever between rich and poor.

In post-apartheid South Africa, moves towards equity (van der Heever and Brijlal, 1997; Mcintyre et al, 1999) have promoted the rapid expansion of infrastructure such as primary care clinics, water supply in rural areas, and sanitation services (Buthelezi et al, 1997; Budlender, 2000). However, conservative macro-economic policies have curtailed public expenditure in key areas (Marais, 1998) and there is some evidence that progress in the redistribution of health care resources has been reversed in recent years (Gilson and McIntyre, 2001). Reversal of gains made post-independence in Zimbabwe has accompanied the adoption of structural adjustment programmes locally (Werner and Sanders, 1997).

Under these circumstances, do the concepts and discourse of human rights offer opportunities for public health practitioners to restructure health care better in countries in transition? Some public health approaches may argue that concerns for human rights can impede the achievement of public health objectives such as equity, access and efficiency (Frerichs, 1995; Minister Zuma, cited in Cherry, 1999; De Cock et al, 2002), by favouring the individual, or groups of individuals, over the community or nation (see illustrations in McCoy, 2001; Muller, 2003; or Mkize, cited in London, 2002). For example, limited resources in South Africa mean that there is a conflict between using them for anti-retroviral rollout for HIV, or for poverty relief and building schools (Kindra and Deane, 2003).

Alternatively, public health practitioners may simply be unable to translate human rights issues into operational policy. Much public health thinking presumes health to be a right but does little to address the practical implications of such a link. Rather than automatically assuming that human rights and public health are inevitably consonant, one should use careful analysis to identify the specific human rights mechanisms that may be used to promote equity (London, 2002). The reason for examining this relationship is because human rights arguments are, on the one hand, increasingly being used in public debates on policy developments in health (for example, the World Health Organisation has been moving to 'mainstream' human rights in its health work). Courts are increasingly being drawn into decisions on health policy based on arguments drawn from international and national human rights law (e.g. in South Africa there was a court challenge by the Pharmaceutical Industry to government regulations aimed at enabling easier access to drugs for diseases such as HIV, TB and malaria; also, the South African Constitutional Court ruled that the government should provide antiretrovirals as part of a comprehensive programme for the prevention of mother-to-child-transmission).

Tools to evaluate the human rights impact of public health policies have been developed (International Federation of Red Cross and Red Crescent Societies and the Francois-Xavier Bagnoud Centre for Health and Human Rights, 1999) and recently extended to providing a human right framework to choose between policy options that have implications for socio-economic rights (London, 2002). Human rights researchers have also recently begun a tentative exploration of the relationship between equity and human rights (Braverman and Gruskin, 2003a and 2003b).This paper therefore seeks to clarify when and how human rights approaches can be synergistic with public health objectives, such as equity (London, 2002).

Advocacy and research are increasingly addressing the interface between rights and public health in a setting of health system reform. The People's Health Movement (http://www.phamovement.org), an international network of civil society organisations, professionals and popular movements committed to rekindling the spirit of Health for All, developed the People's Health Charter, which reaffirms the notion of health as a right contained in the original Alma-Ata Declaration on Primary Health Care (Chowdhury and Rowson, 2000). The Charter also makes clear the role of a rights conception of health as a principle that informs a broader social mobilisation for equity.

The Network for Equity in Health in Southern Africa (EQUINET) has similarly drawn professionals, civil society members and policy makers together to promote policies for equity in health in the Southern African Development Community (SADC) region. In its primary focus on interventions to address vertical equity by allocating resources preferentially to those with the worst health status (pro-poor policies), EQUINET also seeks to understand and inform the power and ability of people (and social groups) have to make choices over health inputs and their capacity to use these choices towards health.

This framework has led EQUINET to explore the relationship between Human Rights and Equity, by commissioning a discussion paper on health and human rights in the region (Klugman and Kgosidintsi, 2000) and convening a workshop at its conference at Broederstroom in September 2000. Building on questions emerging in these and other EQUINET discussion papers , this research project identified key areas of debate as the starting point for study – what exactly is the complex interface between human rights approaches, community engagement and equity; how do conceptions and practices of rights approaches make a difference; and how should individual entitlements be met within approaches that aim to maximise community empowerment?

This project therefore seeks to respond to the particular need emerging in progressive public health circles in the Southern African region to explore this question of the relationship between human rights and public health. The study aims to develop a framework for approaching the question of whether human rights can be a tool for achieving equity in the health sector, and, if so, how best human rights can be utilised in this way. In doing so, the study aims to move beyond discussion of the seeming contradiction between human rights and public health to considering both the theoretical and empirical basis for how human rights approaches can be applied in ways that make them consonant with public health objectives. This study therefore forms the first part of a two-phase proposal funded by EQUINET, which aims to enable the organisation to engage civil society actors in the region around advancing equity. In particular, it is anticipated that this paper will initiate a discussion with civil society groups in Southern Africa in order to begin to explore how human rights can be integrated into EQUINET's future work.

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2. METHODOLOGY

The research was conducted in two parts:

- In the first part, a literature review was conducted to address conceptions of human rights in relation to health issues, especially public health and health planning. Also reviewed was literature on the practical operationalisation of health as a socio-economic right and the relationship between rights, procedural justice and popular participation in generating social capital. Tools for evaluating public health policies for human rights were identified, and evaluated according to their usefulness in the equity debate. Use was made of general search engines (Google and Yahoo) and health-specific archives (PubMed, SciLit), as well as list-servers (PHA-Exchange, HHRNET, PAHO and Spirit of 1848) and contacts in the EQUINET Steering Committee. Websites of key organisations were used (see references at the end of this paper). While on sabbatical at the Francois-Xavier Bagnoud Centre for Health and Human Rights in the School of Public Health at Harvard University in 2002, the author also identified important resources and links for this work.
- In the second part, three local case studies were chosen for detailed review. The case studies were chosen from a longer initial list generated as possible examples with which to explore the relationship between human rights and public health. Criteria used to narrow the focus down included: a) spread of cases across the region; b) applicability of the topic across the region; c) illustrative of different ways in which social mobilisation has been linked to human rights approaches; d) accessibility through the EQUINET networks. Of the final list of six case studies, the first three were chosen to form the basis for the empirical research in this project, while the latter three cases were retained as potential areas for future investigation. They are:
    - the Treatment Action Campaign, or TAC, concerning treatment access for HIV and AIDS sufferers in South Africa
    - patients' rights charters in South Africa, Malawi and Zimbabwe
    - the Community Working Group on Health in Zimbabwe
    - land reform and food security, especially regarding the movements of rural people
    - notification for HIV and human rights in Southern Africa (SADC region)
    - community participation in malaria control in Southern Africa (SADC region).

Data collection took place through a mix of archival research, published articles, document review (web based and hard copy) and interviews with selected informants. Participants in the informant interviews were given the summaries of discussions for their feedback and were invited to join a health rights reference group, to provide feedback in the course of the project. Comments from participants in a workshop with civil society organisations in November 2003 and from the EQUINET Committee were incorporated in the final draft.

Key Concepts for the interface between human rights and health equity

A "**Public Health Approach**" is that which addresses the health of whole populations, rather than individuals, using population level analyses to identify and implement strategies for improving well-being of communities, groups or whole populations.

"**Effectiveness**" is about whether a policy or programme achieves what it set out to accomplish. Put simply – does it work? Adding in considerations of cost (cost-effectiveness) allow planners to consider whether a different intervention could achieve the same objective.

"**Efficiency**" is the dimension of doing public health with the best balance of inputs and outputs, maximizing the latter whilst minimizing the former. In its most simple form, efficiency could be characterized as cost-effectiveness – i.e. how does one achieve a given outcome (health outcome or disease prevention or remediation) for the least input (cost).

"**Equity**" (vertical equity) refers to policies and programmes that aim to address the prevention of health inequalities - differences in health outcomes that are unnecessary, avoidable and unfair, for example, by allocating greater resources to those in greater need. "Vertical equity" therefore applies to the process of reaching equal outcomes, and of allocating greater resources to ensure reductions in health outcome differentials

A "**human rights approach**" embraces four elements:

1. The use of human rights standards and norms to develop policy and programmes
2. The use of human rights standards and norms to analyse and critique government performance, sometimes combined with a monitoring function
3. The use of human rights standards and norms to facilitate redress for those who suffer violations of their rights
4. The use of human rights standards and norms to support advocacy and civil society mobilization.

3. THEORETICAL BACKGROUND

3.1 Definitional issues

Braverman and Tarimo (2002) point to the problem that lack of clear definitions in public health results in use of concepts "which may mean different things to different people in different societies at different times." This loose use of human rights language and public health concepts may make it more difficult to implement human rights and public health interventions, and may undermine their effectiveness. For example, De Cock et al (2002), in arguing against the appropriateness of human rights approaches to the HIV epidemic in Africa, invoke the notion of social justice as grounds for calling for widespread routine HIV testing in health services, to balance the limits placed on public health by human rights concerns for preventing discrimination. However, what the authors understand by social justice is not clear from their argument, and human rights approaches, correctly understood as promoting the agency of the most marginalised in society, may be far more effective in advancing a social justice agenda than widespread testing (London et al, 2002). Therefore, this section provides clarification on the key concepts listed in the box above.

Effectiveness

In public health terms, effectiveness is about whether a policy or programme achieves what it set out to accomplish. Put simply – does it work? Cost-effectiveness is frequently inseparable from other considerations of effectiveness in policy evaluations. By contrast, whether the objective of the policy or the programme is sound, fair, just or reasonable is not necessarily directly relevant to deciding its (public health) effectiveness. Evaluating the effectiveness of public health policies can be difficult because they are often unclear about their objectives, or have different levels of objectives with differing degrees of precision.

Efficiency

In its simplest form, efficiency is cost-effectiveness: how does one achieve a given output (health outcome, or disease prevention or remediation) for the least input (cost)? Central to efficiency is a concern for striking the best balance between inputs and outputs, irrespective of the contextual relevance of fairness or justice. Neither effectiveness nor efficiency are necessarily concerned with the distribution of an outcome in a population.

Equity

Numerous definitions of equity have been presented in the literature. These range from an aspirational concept embracing values of fairness and justice (Bryant et al, 1997; Braverman and Tarimo, 2002; Peter and Evans, 2001) to attempts to operationalise equity in terms of unnecessary, avoidable and unfair differences in health status (Whitehead, 1992), and, particularly, social differences generated by power and the lack of power (EQUINET, 2000; Braverman and Gruskin, 2003a; Farmer, 1999)

In almost all cases, the notion of need, however defined, is central to the idea of equity. The intention of addressing equity is that all persons should have opportunity to be healthy, not just have equal access to health care (Bryant et al, 1997) and that need rather than privilege should determine resource allocation (Braverman and Tarimo, 2002). The problem is, however, that there is little agreement on how valuations of need should be made. Criteria based on utilitarianism, the predominant thread in public health practice, imply allocation according to capacity to benefit (Morrow, 1997) and have resulted in the dominance of considerations of effectiveness in public health debates on health equity.

In contrast, where need is clearly framed as a social phenomenon, often as the product of injustice, equity is primarily about redress of those causative factors, and is therefore firmly linked to values such as social justice (Kriger and Birn, 1998; EQUINET Steering Committee, 2000; Braverman and Gruskin, 2003a).

Commentators (Diderichsen et al, 2001; Braverman and Tarimo, 2002) have extended the conceptualization of equity as recognizing the underlying power imbalances between groups that determine the patterns of avoidable disparities in health If human rights are to be a tool for equity, they have to engage in the processes by which power is expressed and distributed in society.

The focus of this project is therefore not with the relatively uncontroversial concept of *horizontal equity* (treating equals as equals) but with the more contentious notion of *vertical equity.* Vertical equity refers to, for example, allocating greater resources to those in greater need (McIntyre and Gilson, 2002), and seeks to address the prevention of health inequalities - differences in health outcomes that are unnecessary, avoidable and unfair (Whitehead, 1992). Considerations of vertical equity cannot be made independently of the political and social context in which equity is examined (EQUINET, 2000).

Linked to discussion on equity, there are calls in public health to revisit and revive the notion of community agency in public health practice. Rather than framing the poor and marginalised as candidates for protection or redistributive policies by a benevolent state authority, researchers, activists and policy analysts have called for a "new" public health that takes seriously its commitment to community empowerment (Chowdhury and Rowson, 2000). Such calls have identified roles for active participation in resource allocation in health (Mooney and Jan, 1996; McIntyre and Gilson, 2002; Mooney et al, 2002).

Over the past decade, the emphasis on efficiency and effectiveness as tools for achieving better public health has given way to the realisation that greater emphasis on equity is required if public health is to meet its goals (McIntyre and Gilson, 2002). Interventions must respond to 'upstream' causes such as poverty (Evans et al, 2001; Braverman and Tarimo, 2002), as well as the impact of globalisation and neoliberalism.

Public health

Numerous definitions of public health exist. This paper adopts the simplest common conception of public health as being that which addresses the health of whole populations, rather than individuals, using population level analyses to identify and implement strategies for improving their well being. In that sense, utilitarianism is key to the ethos of public health practice and ethics (for example, Doyal, 1995) although there is no clearly homogenous ethical framework on which public health is based (Roberts and Reich, 2002). Key concepts for good public health practice include effectiveness, efficiency and equity, which we have already discussed.

Contested threads in public health

However, what is also characteristic of public health approaches is the diversity of strategies subsumed under the notion of promoting population health (Jacobson and Wasserman, 2001). The dominant North American approach that addresses population health through individual behavioural interventions has been severely criticised for its detachment from public health roots and lack of depth in understanding the causation of health and illness (Kriger, 1994; Pearce, 1996; Lomas, 1998; McKinlay and Marceau, 2000). Rather than shifting responsibility to individual patients (addressing proximate causes), population-oriented approaches could employ a range of collective strategies to address the distal causes, such as regulating hazardous dietary substances or regulating safer workplaces to remove hazardous factors. For this reason, it may be useful to think of public health as an amalgam of disciplines, tools and strategies under the rubric of population health promotion, rather than as a monolithic entity.

Public health ethics

While there is a great deal of overlap between ethics and human rights, there are also important differences. The World Health Organisation (2002) describes ethics in terms of norms for conduct of individuals based on religious, cultural and social factors, involving reflection on the complexity of a moral choice, whereas human rights refers to 'an internationally agreed upon set of principles and norms embodied in international legal instruments.' (WHO, 2002: 24). Thus ethics primarily provides guidance to individual health care professionals facing moral dilemmas, while human rights provides standards, recognised in international law, that anchor professional behaviour in respect for human dignity.

In the field of public health, ethical codes have, until recently (Akhter and Northridge, 2002), been scarce, and ethical frameworks are much weaker and less developed in public health than in biomedicine. Even the more recent attempts to develop a theoretical basis to health equity (e.g. Wikler, 1997; Marchand et al, 1998; Beauchamp and Steinbock, 1999) tend to fall back on what is known as the *principalist approach* in biomedical ethics, which is well-suited to the individualist context of health care provider-patient interaction, premised on preoccupations with personal autonomy and civil liberties, but is not easily applied to the population context. Meyer and Schwartz (2000) argue that when health problems that are fundamentally social issues are placed into this kind of public health discourse, there is a risk that what are essentially political struggles become individualised. For example, framing homelessness as a public health problem invites research and policy questions that ask why certain individuals become homeless, or cannot cope with homelessness, rather than asking why homelessness is allowed to occur in a society that can afford to look after all its people.

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Peter and Evans (2001), drawing on Rawlsian philosophy, have begun to develop a theory on the ethical dimensions of health equity. Simply put, Rawlsian philosophy argues that people generally feel morally better if they know that worst-off in society are ‘looked after’ in a socially just manner, so equity is consistent with meeting that moral need. . However, neither the contribution of international (in)justice to the equity debate in public health nor the importance of participatory, inclusive policy formation as a critical dimension of ethical practice are adequately addressed in current theories on public health ethics.

Reich and Roberts (2002) have pointed to three competing ethical frameworks in public health, viz. utilitarianism, rights approaches and communitarianism, and have argued that public health practice frequently fails to reflect which should be applied in which case. In the absence of a clear and widely accepted ethical framework for public health, health policies have, when faced with a different set of economic and market values ‘…increasingly sacrificed ethical concerns in the race to contain costs and the pursuit of ‘efficiency’.’ (Whitehead et al, 2001: 310)

A human rights approach

Human rights and health

Human rights have best been described as the rights of individuals in society that take the form of ‘legitimate, valid, justified claims … to various ‘goods’ and ‘benefits’ ‘deemed essential for dignity and well being (Henkin, 1990: 4). Human rights were first embodied in the Universal Declaration of Human Rights (‘UDHR’), adopted in the aftermath of World War II, and then incorporated in various international treaties. Unlike principles of medical ethics, once a treaty is ratified by the State, it becomes law.

One key strand in debates on human rights has been the separation of civil and political rights, and socio-economic rights. The Cold War witnessed a split into a (largely) US-led emphasis on traditional freedoms as contained in the ambit of civil and political rights, and the emphasis of (largely) socialist or social-democrat states on social and economic rights as central to any considerations of human dignity. These divergent strands were expressed in the adoption of two covenants, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Social, Economic and Cultural Rights (ICESCR).

Traditionalist arguments have favoured civil and political rights as somehow ‘more’ fundamental because they are supposed to be easy to litigate (justiciability argument), are easier to enforce because they are ‘negative’ rights (the state must refrain from violating them) and do not cost the state anything to enforce. However, this false dichotomy is unfounded. Many civil and political rights require positive action from government (e.g. providing access to information), are costly (e.g. the right to vote requires an entire election apparatus that must be fair), and are expensive to implement (e.g. prison systems). Moreover, test cases are increasingly demonstrating the justiciability of social and economic rights across the globe. For example, in 1998, South Africa’s Constitutional Court found in favour of a homeless community in a peri-urban area outside Cape Town threatened with eviction, on the basis of the State’s obligation to provide children with shelter (Ngwena, 2000).

Moreover, international human rights law has recognised the right to health in different ways. The UDHR (Article 25) cites the right to "… a standard of living adequate for the health and wellbeing of himself and of his family, including food, clothing, housing and medical care and necessary social services…" and singles out childhood and motherhood as warranting special care and assistance. The International Covenant on Economic, Social and Cultural Rights (ICESCR) (UNICESCR, 1966) specifies in more detail in Article 12 ‘the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’ and sets out steps to be taken by State Parties to achieve realisation of this right. This formulation is much more restrictive than that in the World Health Organisation definition of health (WHO, 1946), which recognises health as ‘a state of complete physical, mental and social well being’. This distinction exists precisely because the ICESCR it is intended to set standards to which governments and other parties could be held legally accountable whereas the WHO conception of health is only intended to serve as a guide for the WHO and its member states (Gruskin and Tarantola, 2002). In 2000, the ICESCR issued a General Comment 14, which outlined the following core obligations, on the part of the State, that are needed to achieve the highest attainable standard of physical and mental health:

- to ensure right of access to health facilities, good and services without discrimination, and prioritising services for vulnerable groups
- to ensure access to minimum essential food to ensure freedom from hunger
- to provide essential drugs (WHO essential drugs list)
- to ensure equitable distribution of facilities, goods and services in health care
- to adopt and implement a national public health strategy and plan that addresses the health of the population, to be monitored, particularly for human rights indicators.

In addition, the following obligatory services and activities were identified:

- reproductive, maternal and child health care
- immunisation against the country’s major infectious diseases
- the prevention, treatment and control of epidemic and endemic diseases
- education and access to information on the main national health problems and their control
- appropriate training for health professionals, including on human rights training.

The implied obligations are:

- recognition of the right to health and the provision of remedies for redress
- the obligation of the State to refrain from laws, policies and activities that impede the realisation of these rights

(Source: adapted from Chapman, 2002)

Many national constitutions around the world focus on the right to health care rather than health because it is easier to operationalise as an outcome (Leary, 1994). However, Toebes (1999) points out that the right to health embraces far more than just health care: health is also the product of the full spectrum of other rights contained within international human rights law, such as non-discrimination, autonomy, access to information, education, food, shelter and participation, amongst others, (Toebes, 1999; Gruskin and Tarantola, 2002), and so must be examined within this full context.

Moreover, international human rights law includes the concept of *progressive realisation* of socio-economic rights (e.g. Article 2 of the ICECSR). *Progressive realisation* balances the recognition of the limitations of existing resource constraints, with the obligation on the State to increase, over time, its legislative and financial commitments to meet the socio-economic entitlements of the most vulnerable.

What is a human rights approach?

Whereas definitions of human rights, and of health as a human right, are relatively well addressed in the literature, the notion of a *human rights approach* (for example, to health) has had relatively less clarity. As a result, people use the idea of a human rights approach to embrace a wide range of discourses and activities.

Human rights standards and norms can be used:

- to develop policies and programmes (UNDP, 1998)
- to analyse, critique and monitor government performance (UNDP, 1998)
- to facilitate redress for those who suffer violations of their rights (UNDP, 1998)
- to support rights advocacy and civil society mobilisation (Haywood and Altman, 2000).

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However, reliance on the law to deliver change is not realistic (Haywood and Altman, 2000), especially in light of the historical contribution of political pressure, grassroots mobilisation and activism from which human rights emerged (Odinkalu, 2003). An analysis of human right approaches needs to acknowledge the importance of power, social justice and anti-discrimination as key dimension of rights work. In that sense, the use of human rights to support advocacy and civil society mobilisation (the last bullet point above) would be an overarching application of a rights approach more suited to addressing health inequalities.

In adapting these different conceptions of human rights approaches, one must remain mindful of:

- the notion of the indivisibility of rights and how socio-economic rights are integral to any rights-based approach (Haywood and Altman, 2000)
- how health itself if a socio-economic right,
- the centrality of human dignity and anti-discrimination in rights analyses, and how this links human rights approaches to considerations of social justice and social patterning
- how the provisions in international human rights law relating to progressive realisation of socio-economic rights offer an arena for contestation of State policy by rights activists.

It is probably not by chance that the rise of the human rights movement has coincided with a decline in past decades of ‘left’ politics. Although there is no research to explore what underlies this linkage, it is perhaps worth considering the implications of this expansion in human rights organizations and programmes for discourses of power. Rather than replacing or helping to obscure power imbalances that underlie inequity and social injustice, human rights needs to uncover and render transparent such power dynamics.

3.2 Key conceptual tensions

Cross-cultural issues: Human rights as a Western construct

Central to the human rights debate is the argument that human rights represent a Western construct not applicable to non-Western cultures. An implicit corollary of this argument is that human rights are not universals but are relative to the particular culture in which the rights must be actualised.

Traditionally, human rights activists have responded by labelling cultural relativism as a way of justifying discrimination under the mantle of social norms that benefit the powerful leaders in traditional societies (Channock, 2000). For example, gender rights analyses of the HIV epidemic have shown how important the recognition of gender power relations is to understanding the factors driving HIV (Whelan, 1998; du Guerney and Sjoberg, 1999), and how culture can be both used and reconstructed to justify the male privilege that underlies women’s vulnerability to HIV and lack of control over reproduction (Ray, 1992; Freedman, 1999a and 1999b; Susser and Stein, 2000).

A second response is to expose how the notion of ‘culture’ is typically used in an ahistorical and acontextual way when making the claim of cultural relativism. However, culture is neither homogenous nor static, but constantly evolving and adapting (Kelsay, 1988).

A final response to the argument that rights are incompatible with non-Western systems, is that, in non-Western systems, rights do exist but in forms specific to that culture (Chinsman et al, 1988).

Is a human rights approach compatible with respect for cultural difference? If 'rights-talk' also speaks to concentric circles of privilege (Nhlapo, 2000) that extend beyond groups and countries to questions of global privilege, rights-based strategies can become tools to promote respect for cultural difference, whilst recognising equality and fairness. For example, South Africa's Constitution explicitly recognises the right to participate in, and to enjoy, one's own culture, affording a legal standard for balancing conflicting rights.

Therefore, in developing human rights-based approaches to health and health equity, cultural arguments need to be critically understood as neither inherently pro- nor anti-human rights, but as considerations that explain how fundamental rights could and should be expressed within the ethnic and social context of a particular society (e.g. Freedman, 1999a and 1999b, identifies the way debates on population policies have been framed (in dichotomous arguments of universality versus culturally relativity) as serving only to benefit political interests opposed to changes that enable women to set the course of their lives).

Individual rights versus group rights

The perceived individualism of traditional Western human rights is the source of significant criticism (Jacobson, 2002; Odinkalu, 2003, and described in Freedman, 1999b). From a public health perspective, health inequities are usually related to social discrimination. Addressing inequity on an individual level, framed as an individual entitlement, is not always effective. For example, in South Africa, restitution to asbestosis sufferers involved establishing a screening process, which excluded many from eligibility, raising questions of discrimination without actually addressing the problem of reducing pollution.

Is it possible for a group to have human rights, as they normally apply to individuals? Many individuals are discriminated against on the basis of their membership to a particular (usually vulnerable) group. Human rights activists are increasingly starting to investigate how to apply the traditional concept of individual rights to groups in terms of international human rights law. This has been particularly evident in the development on international instruments to protect the rights of women (UN, 1979), of children (UN, 1989) and of indigenous peoples (ILO, 1989; UN, 1993), which have been paralleled by active social movements and NGO activity in these fields. Moreover, it is important to realise that aspects of established international human rights law address many elements of group rights, for example, in provisions that recognise peoples' rights, autonomy and self-determination (Article 1 of both the ICESCR and the ICCPR, 1966). Group rights include the right not to be oppressed by another group, the right to self-determination and the right to socio-economic development.

The utilitarianism typical of public health practice would be better integrated with human rights approaches if the latter were able to develop a sound theory of group rights. With an individualistic focus, the public good (health) could potentially conflict with the individual's well being, whereas, if rights are vested in a group, it becomes easier to see public health benefits as consonant with a (group) rights argument (Freedman, 1999b). Moreover, the duties imposed on government by its obligation to meet socio-economic rights (e.g. health services, education, etc) are, by definition, population-based.

Newer conceptions of public health, such as communitarianism (Roberts and Reich 2002) and the recognition of group preferences in determining the allocation of resources (Mooney et al, 2002), are more compatible with human rights approaches based on collectives.

National versus international purview, and the public-private divide

The human rights paradigm is critically dependent on the responsibility of the nation-state to uphold its obligations to its own people. However, current dominant neoliberal economic frameworks have increasingly disempowered national governments by subjugating national will, elected or otherwise, to trade rules and decision-making processes without democratic participation, transparency or fairness. In relation to health, these developments have led to the ceding of decision-making on key policy matters to supranational fora. For example, discussions have explored the extension of the Global Agreement on Trade and Tariffs (GATTS) to health services, and the Trade and Related Intellectual Property (TRIPS) agreement under the World Trade Organisation (WTO) have been cited as key obstacle to access to affordable medicines (Loff and Heywood, 2002). In many instances, large multinational companies wield greater power over the conditions necessary for health than do national governments. Rights proponents, therefore, have to be able to engage both national and international agents (including multinational corporations and development banks) who shape policies impacting on health and do so in ways that utilise what is unique about human rights in the service of the most vulnerable. While some evidence exists that, for example in the area of HIV, international solidarity amongst NGOs has opened space for supporting struggles in developing countries (Loff and Heywood, 2002), and that international human rights law has led to significant gains in international agencies programmes to protect the most vulnerable (Patterson and London, 2002), the theoretical elaboration needed to ground human rights emphatically as a tool to bring supranational players and the private sector to account is still in development, and is an ongoing challenge.

Can human rights serve as a tool for equity?

3.3 Summary

What constitutes a public health approach is as much contested ground as what constitutes a human rights approach, and both are equally affected by, and responsive to the global context in which neoliberal economic paradigms seeks increasingly to disempower that nation state in favour of supranational, predominantly trade-driven, governance. As a result, trends in public health emphasising the need to engage communities actively in determining the policies and programmes that affect their own health, are emerging to contest traditional technocratic approaches that rely on paternalism and utilitarian principles to shape health policy nationally and globally. Similarly, human rights paradigms are increasingly being challenged to move beyond a focus on individual rights or rights concerned with civil and political liberties, to address the broad spectrum of rights, including those to social and economic entitlements.

Central to both health equity and human rights are the core questions of discrimination, power, and social justice. How the consonance between rights and equity can be operationalised will be explored through the following three case studies, which will be used to highlight what kind of human rights approaches promote health equity.

4. CASE STUDIES

Three case studies are presented below to identify lessons for what kinds of human rights strategies are best suited to the objectives of building equity in health. The cases were chosen based on: a) spread across the Southern African region; b) applicability of the topic area across the region; c) illustrative of different ways in which social mobilization has been linked to human rights; d) accessibility through EQUINET networks. All three cases present different aspects of the “new” public health that takes seriously its commitment to community empowerment (e.g. Kriger and Birn, 1998; EQUINET Steering Committee, 2000; Chowdhury and Rowson, 2000; Beaglehole and Bonita, 2000; MacFarlane et al, 2000).

From the case studies, key themes are drawn from which to develop a clearer understanding of the relationship between health equity and human rights, and on which to base actions for equity work in the region (Section 5 of this paper). For each case, this is done by teasing out:

- how links are made between civil and political rights, and socio-economic rights
- how the organisation/movement engages with the state in its work and how its work builds community engagement
- what kinds of rights strategies have been used to promote health equity
- how the work of the organisations links or could be linked to global struggles
- what intersectoral interventions have been possible through the adoption of rights approaches

4.1 Treatment access for HIV: Case study of the Treatment Action Campaign (TAC), South Africa

TAC was started in 1998 as a lobbying and advocacy group for people with HIV/AIDS in South Africa. Their intention was, and is, to 'campaign for greater access to treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments.' (TAC Website: http://www.tac.org.za: August 2003) Initially inspired by similar rights-oriented HIV organisations in the developed world, TAC rapidly developed into a broad-based social movement, filling to some extent the hiatus left in South African civil society around health and development with the demise of many NGO's and community-based organisations (CBO's) following the first democratic elections in 1994. TAC has helped to facilitate regional mobilisation around HIV, culminating in the Pan-African HIV/AIDS Treatment Access Movement.

TAC's work has been at the centre of a robust civil society debate in South Africa around the provision of antiretrovirals to HIV+ people, testing many of the questions around human rights' contribution to public health objectives.

Given TAC's rights-based approach, what has been its relationship to government?

While TAC initially enjoyed a tentatively comradely relationship to the South African government, working hard at lobbying key committees and individuals, their relationship has become increasingly adversarial. While much of this has to do with the idiosyncratic views of President Mbeki on HIV, the fundamental unease stems mostly from contestation of who is allowed (by the South African state) to engage in discourses of power (Fassin and Schneider, 2003). TAC has a significant working-class black membership, including many township women – a constituency close the ruling party's traditional support base. Consequently, TAC and TAC-aligned organisations and individuals have been effectively shut out from engagement with the government, resulting in their disobedience campaign in early 2003.

How has TAC harnessed a human rights approach in support of mobilisation around a health demand?

Firstly, legal strategies have been key to TAC's successful campaigns (Geffen, 2003). From the starting point that South Africa's constitution provides the opportunity to make socio-economic rights justiciable, TAC has effectively used the Courts on explicit rights grounds to win a campaign for provision of anti-retrovirals (ARVs) for the Prevention of Mother-to-Child Transmission of HIV (MTCTP). The Human Rights framework of the South African Constitution provides a set of legal standards that enables civil society to hold government accountable, even when it is reluctant to meet its constitutional obligations. Legal strategies have been used in support of government against the pharmaceutical industry, when it opposed regulations for the parallel importation of cheaper generic drugs.

Secondly, TAC has consistently matched legal strategies with grassroots mobilisation in ways that are mutually reinforcing, arguing that 'human rights arguments and legal action alone are of limited use. It is crucial to combine them with mass mobilisation, including human rights awareness campaigns' (Geffen, 2001). For example, TAC runs workshops to train members and raise awareness of treatment as their right. In this way, new members obtain an understanding of human rights by joining TAC or, if they already have a rights consciousness, are attracted to TAC because of its explicit human rights message. The human rights thread manifests in TAC media, which have explicit human rights messages (Geffen, 2003).

By comparison, one of the seminal cases highlighting the justiciability of socio-economic rights in South Africa, the Grootboom case, was hailed for its important legal precedent (e.g. Ngwena, 2000), but produced virtually no grassroots impacts, other than halting the evictions of the particular community. Despite the Grootboom decision, no major shifts in housing policy have eventuated, nor have communities and groups in most need been able to make use of the decision to improve their situation. Legal strategies alone, therefore, are limited in impact without popular mobilisation.

Thirdly, TAC recruits and retains members by offering those stigmatised by HIV legal mechanisms for redressing not only violations of civil and political rights (e.g. freedom from discrimination), but also violations of socio-economic rights. This is not the case in most other countries in the region, where legal protections are poor. Ironically, South Africa, despite its contradictory policy on treatment access, has one of the best legal frameworks to deal with HIV-related discrimination (e.g. the Employment Equity Act prohibits exclusionary HIV testing as part of pre-employment medical examination unless permitted by the Labour Court; evolving national schools policy precludes exclusion of learners with HIV), and use of this framework helps to build participation in civil movements.

TAC's rights-based approaches have therefore included both the use of human rights standards and norms to analyse and critique government performance and to facilitate redress for those who suffer violations of their rights (UNDP, 1998) but also the use of human rights standards and norms to support advocacy and civil society mobilization (Haywood and Altman, 2000). Links between civil and political rights, and socio-economic rights have been core to TAC's work to date, illustrating the practical importance of the indivisibility of human rights. Moreover, through its legal strategies, TAC has exploited those progressive realisation provisions in the South African Constitution that are related to socio-economic rights to help it increase popular and legal pressure on the government to provide access to HIV treatment.

How has treatment access work been linked to health systems and equity?

One of the main criticisms of treatment access work from within the health sector, has been a perceived failing of TAC to link treatment for HIV to broader questions of access to health care and the strengthening of health systems (e.g. McCoy, 2001). Could this in any way be attributed to a 'single issue' rights focus in TAC's work that keeps their vision too narrow? To some extent, TAC has engaged with some health care issues beyond HIV. For example, the AIDS Law Project poster used by TAC covers rights relating to broader health care, such as the right to confidentiality. Moreover, the highest uptake of MTCTP programmes has occurred in areas with strong TAC branches, illustrating how community mobilisation is correlated with uptake and demand. For example, TAC campaigning and demonstrations in Guguletu and Delft (suburbs of Cape Town) and East London have successfully induced local facilities to offer various services, such as MTCTP and fluconazole treatment.

Nonetheless, the effect of human rights on equity needs to be tackled in relation to HIV treatment access, since rights, construed as individual entitlements, will be seen as negatively impacting on resources allocation processes to the detriment of equity (McCoy, 2001; Muller, 2003; or Mkize, cited in London, 2002). As Muller (2003) argues, 'The fact that TAC has the financial clout to take the government to court does not mean that its case is more important than that of people living in rural poverty.' What this argument implies is that TAC is itself a kind of aristocracy amongst marginalised people, an urban elite compared to the rural poor and that within this hierarchy, different interests necessarily play off against each other.

However, there is no empirical evidence that strong treatment access campaigns in urban areas have led to deprivation in rural areas. Moreover, TAC has set up activities in underserved and marginalised rural communities, actively focusing on the most marginalised and vulnerable groups, instead of focusing on individual rights. This resonates with pro-poor public health choices (Farmer 2001; Loewenson, undated). TAC's perspective is that the most overwhelming inequity in South Africa is that between public and private health sectors and, by focusing on access, TAC is taking on the private-public divide (e.g. by legally challenging insurance company discrimination and working with private health care providers to improve access via the Medical Association). Geffen (2003) also disputes the idea that equity implies that everything must move at same pace. Even if, initially, TAC's urban constituency benefits more than rural HIV+ people, rights approaches that prioritise the most needy will lead to mobilisation in other areas. Other health and community-based organisations in rural South Africa have chosen to use similar rights-based mobilisation approaches (e.g. the elderly persons NGO, Aged in Action, (Geffen, 2003).

What have been the links between civil, political and socio-economic rights?

Based on the TAC experience, Haywood and Altman (2000) make the useful observation that by ensuring that rights approaches simultaneously embrace both civil and political dimensions, as well as socio-economic rights, there is an inevitable confluence of social justice and rights advocacy. Indeed, in the absence of such a comprehensive approach, rights advocacy runs the risk of blunting its transformative potential.

How has TAC's work been related to the global context?

Despite its assault on national sovereignty, globalisation has afforded the treatment access movement increased opportunity for mobilising support through the global human right movement, and this support has, in turn, served to strengthen government's capacity to regulate in favour of pro-poor policies, both at national and international levels. TAC's success in taking on the pharmaceutical industry arises precisely because of its international support. Similarly, at international level (Loff and Heywood, 2002), collaboration between NGO's broadly aligned to treatment access initiatives and the governments of southern countries was able to ensure that treatment access was addressed at the Doha round of WTO talks. The ways in which TAC has been able to build alliances across national boundaries that strengthen opportunities for marginalised communities and countries to contest global privilege, is an important buttress against any possible cultural relativist critiques of its rights-based HIV work.

What agency is conferred on communities by a human rights-based approach?

Does TAC's use of rights approaches help to build social capital (which in turn is key to health status and reducing health inequalities)? Successful past interactions between local TAC branches and local health services illustrate that community involvement can result in positive changes to health systems. Moreover, a human rights framework allows community participation by encouraging individuals to speak out, assemble freely and campaign actively. This facilitates not only treatment access but also preventive work. For example, it would be difficult to introduce condoms into schools unreceptive to notions of rights.

How has TAC's rights-based work engaged across sectors?

Given that many of the determinants of health status lie beyond the health sector, can a human rights approach in health assist in levering resources beyond the health sector? By aligning with, or providing a template for, other civil society organisations, TAC's approaches might impact on factors regarded as critical for health and reducing inequities. For example, TAC has played an effective role in contributing to the Basic Income Grant (BIG) coalition, an initiative that is both driving an important social security strategy, and also developing as a burgeoning civil society movement. The BIG coalition brings the trade union movement into an alliance with a range of civil society players. While not an explicitly health or HIV-related issue, TAC's rights-based focus has led it into this alliance to meet its long-term goal of promoting structural change to address the needs of HIV+ people in South Africa.

By partnering with single-issue campaigns (whose mobilising strengths frequently derive from the single-issue focus), health activists concerned with equity and building sustainable health systems can help to extend focused single-issue campaigns so that they address fundamental causes of health problems in ways that build health system capacity. Civil society movements are often small and fragmented and prone to factionalism. The challenge is how to link single-issue campaigns in a way that is mutually strengthening and that can serve health equity objectives.

A particular strength of TAC's work are its alliances with non-vulnerable groups (, e.g. organised labour, researchers, health professionals, etc) thereby linking its constituency with other active civil society actors in ways that are far more effective. One cannot take individual campaigns out of context, since they resonate with structures and needs existing at the grassroots and in communities.

4.2 Patients' rights charters and patients' rights approaches: Malawi, South Africa and Zimbabwe

Charters that promote the rights of health care users have been widely adopted in many developed (Rigge, 1997; Angel, 2000; Sbaih, 2002; Anonymous, 2003) and developing countries, including, in Southern Africa, Zimbabwe, South Africa and Malawi. With the objective of improving the quality of health care they represent, at face value, the most obvious expression of a rights approach to health care. However, given wide differences in the development and implementation of these charters, important lessons may emerge for understanding the contribution of human rights approaches to health equity.

Malawi

The origins of the Malawian Patients' Rights Charter emerged from an advocacy-training programme hosted by a US NGO, the National Democracy Institute (NDI), in Malawi in 2000. Civil society participants subsequently established the Malawi Health Equity Network (MHEN). The MHEN initially focused on tackling conditions of service for health workers, but shifted to a patient advocacy approach, because of seemingly insurmountable problems in labour relations in the health sector. By doing so, it drew in a broader constituency, including not only professional associations for doctors, nurses and midwives, but also statutory councils, the National Association of People With AIDS (NAPWA) and the Consumer Association of Malawi. Its advocacy programme on patients' rights, developed as a project of the MHEN, focused on what were the minimum rights available to patients in Malawi when receiving health services.

What approach has been used in working with government?

The Malawi Patients' Rights Charter originated from participative research with key stakeholder groups, including patient lobby groups in hospitals and TB services and government officials. The Charter was completed in 2000 and presented to the Portfolio Committee on Health in the Malawian Parliament in 2001. Because, at that time, the practice of public presentations to a parliamentary committee was a novel development for Malawi, both parliamentarians and civil society groups were on a steep learning curve as to the usefulness of public access to Parliamentary processes. In theory, the purpose was to assist parliamentarians to interpret complex policy issues in health, be equipped to comment on proposed legislative changes and advise other parliamentarians on health matters. In practice, they also helped to build trust and rapport between the legislature and civil society. Because channels of communication were opened, the process of developing the Charter has increased citizens' access to policy makers, an essential element of the human rights approach.

Despite these developments, progress through Parliament since submission of the Charter has been slow. One possible reason may be the lack of a strategic objective for the process, since it was not clear at the outset what kind of institutional adoption was intended by the group – a Charter as policy, as legislation (regulation) or as a practice guideline? The MHEN also relied on leadership from the Ministry to drive the Charter to finality. This meant that when the Ministry experienced organisational difficulties due to restructuring, key meetings could not be held delaying progress. Furthermore, the Ministry established a Quality Assurance Task Team to take responsibility for the Charter at a time when the Charter was still in draft form, requiring considerable technical work. Because the Task Team included very senior public servants (such as, amongst others, the Permanent Secretary for Health), the difficulties of coordinating such a high-level task team, meant that little progress was made.

By hitching the Charter to ministerial processes, agency was removed from civil society, and the Charter became subject to ministerial organisational priorities. Moreover, despite the apparent opening up of channels to parliamentarians, there is some sense that access to information is being closed down again. For example, despite the launch of the Malawi Poverty Reduction Strategy paper in 2002, no information has been forthcoming from government, leading to an impression that 'legislation here is available to the privileged [only]' (Muula, 2003). The right to information is a key element to operationalising the right to health, as outlined in Section 3.1 earlier, and are key determinants for the realisation of human potential (Sen, 2000).

How has the Network harnessed a human rights approach in support of its objectives?

The Malawian Constitution does refer to human rights broadly, but has up till now not been seen as a useful tool for enforcing these rights, because of a legacy of the use of law to promote political patronage and nepotism under the Banda government. As a result, Malawian political culture during the democratic transition has up till now actively discouraged the use of the law as a tool to promote rights (however, with the very, very recent decision that the President was not going to seek a third term in office (and amend the Constitution to do so), there is a possibility of restoring public faith in the Constitution (Muula, 2003). In contrast, rights have been high on the agenda of funders and multilateral institutions, and discourses that cite human rights and gender have achieved considerable donor and political sympathy. However, rights promoted by donors have usually been civil and political rights only, in contrast to the inclusive notion of human rights including socio-economic entitlements (Section 3.1).

Approaches adopted by the MHEN have been adapted to different stakeholders. Within the health care setting, the Charter has been framed for professionals as an ethical issue rather than a rights tool. In contrast, for government, the Charter has been marketed as a 'demand-side strategy' for the implementation of the Essential National Health Package, and not as a 'supply-side strategy' (e.g. in terms of training, accountability, etc). Thus, the Charter has been framed as a public health measure through the use of utilitarian discourse, reinforced by government's reluctance to see the Charter as a legal set of minimum standards to which it could be held accountable (Interview: Muula: 2003). For policy makers, concerned about resource allocation and operationalisability, the Charter has been framed rather as an aspirational goal to encourage support and to convert doubters, and therefore used as a set of non-legal standards for advocacy to improve the quality of health services. This is in contrast to the South African experience of HIV treatment access, where the explicit use of legally enforceable standards has been deployed very effectively.

How has work on the Patients' Rights Charter been linked to health systems and equity?

The Patients' Rights Charter is applicable to both private and public sectors, which has made the right to emergency care a contentious issue in Malawi. If a private health care provider sees a patient in an emergency, uncertainty about payment has led to the exclusion of the private sector from any obligation to treat emergency cases,. Patient rights in this context appear to increase the potential for social conflict, and do not increase access to private health care providers.

Patient responsibilities and the rights of health providers have featured as an important elements of the discourse around patients' rights and have been central to acceptance of the Charter, even though the resources to implement these rights are lacking. Rights of access to health care through the Patients' Rights Charter are also bedevilled by human resource issues related to professional registration and scope of practice. For example, many services in Malawi are delivered in circumstances where resources are extremely constrained, as a result of which many personnel do not have formal training at the level they require, and may not have access to supervision by appropriate professionals. A rights approach has to balance recruiting lower level non-professional, health care workers, thereby increasing access, with withholding services until professional staff can be trained.

What agency has been conferred on communities through a human rights-based approach?

Can a patients' rights charter help to build social capital and organisation around health? The experience in Malawi to date has been equivocal. On the one hand, the Charter has provided the basis for a number of NGO projects' activities. For example, the Medical Association's participation in the MHEN is its only ongoing project, and the Patients' Rights Charter project has seen the Centre for Human Rights and Rehabilitation join the MHEN.

However, it not evident that the Patients' Rights Charter programme has directly helped the MHEN to develop its equity work. The Network carries out a wide range of activities unrelated to the Patients' Rights Charter, such as consulting to the Ministry of Health (HIV/AIDS) and working on the Essential Health Package, and the Poverty Reduction Strategy paper. In fact, the Ministry tends to see the MHEN as representing civil society's input into its policies, and calls on the MHEN to when it wants civil society inputs.

As for patient/community participation in overseeing health facilities (e.g. health committees), there has been relatively little involvement in the Patients' Rights Charter programme, despite the potential for the Charter to strengthen the community's say over how health services are delivered (see the Zimbabwean example, which follows). This may well be an area for future work. For example, the MHEN project to monitor the availability of drugs at health facilities may in future train community members to take on this role. By extension, committees could use the Charter to oversee the quality and nature of health care delivered.

However, the perception is that health committees, where they exist, are potentially tainted by the previous administration's use of civil society committees to lever political patronage, which compromises their ability to play a credible role on behalf of civil society. Governments tend to use health services for political mileage as proof of delivery. A patients' rights charter could serve to reduce the usefulness of health services as a form of patronage by attracting patients who would be less likely to accept the limitations of a flawed health service. On the other hand, it might work in the opposite direction, by attracting more articulate patients with greater political influence.

Current complaints mechanisms linked to the Charter are also very rudimentary. At the moment, complainants can only approach the Medical Council, and there are no channels for less egregious complaints. As a result, either nothing is done, or the Council is inappropriately used for the redress of complaints that require another less cumbersome mechanism. These complaints mechanisms cannot help to realise the provision of remedies for redress as contained in the Charter. Notably, the emphasis on working with parliamentarians in Malawi has also limited the capacity of the Network to work with structures outside Parliament. What may have been appropriate at one particular time may not always be so, given that the relationship to parliamentarians is a changeable and dynamic interaction.

South Africa

The Patients' Rights Charter in South Africa was launched in 1997 by the South African Department of Health as a component of its Quality Management programme. While the Charter appeared to emerge from groundwork conducted by a local health NGO, the National Progressive

Primary Health Care Network (NPPHCN), the government's final charter, bore little resemblance to the original NPPHCN's Health Rights Charter. The NPPHCN Health Rights Charter laid much greater emphasis on rights to health promotion and preventive measures than on curative services. The Charter was explicitly developed in a carefully conducted campaign in working-class communities, first by soliciting inputs from the public on their rights preferences, then by running workshops in communities to gauge how people viewed rights (NPPHCN, undated), and finally in a public launch of the Charter. In contrast, the South African government's Charter is entirely facility-focused, and, despite its notion of rights, has been implemented as a quality management strategy, with no element of accountability for meeting human rights standards. In that sense, it has been used in a similar way to the Patients' Rights Charter in Malawi.

The Patients' Rights Charter is held up by the South African government as representing a concrete expression of its commitment to the progressive realisation of access to health care, which is imposed by the South African Constitution (South African Human Rights Commission, 2003) and provisions of international human rights law. It contains a list of 12 rights held by health care users, but also a long list of responsibilities. Rights include access to health care (including timely emergency care), participation in decision-making, and typical consumer-like entitlements (choice of health services, information about treatment options, second opinions, etc). Ironically, the Charter refers to patients' rights to knowledge about their health insurance status, yet its applicability to the private sector is discretional. Much like the situation in Malawi, the Patients' Rights Charter in South Africa also addresses the rights of health providers and workers, and emphasises the responsibilities of patients, such as showing respect for providers, co-operating with the services and providing information when obliged to. Almost none of the rights and responsibilities cited conceive of the right-bearer in a group context (see the earlier discussion on group rights in Section 3.2), and the majority of rights imply attendance at a (usually curative) facility, representing user rights rather than health rights.

Evidence of the impact of the Charter is limited. A study in the informal settlement of Brown's Farm outside Cape Town in 2001 (Bloch et al, 2001) indicated that there was little awareness or use of the Charter by local community members, and that health care providers had limited engagement with the Charter. Most health workers see patients' rights as a threat, which has prompted the Charter's strong emphasis on patients' responsibilities. Unlike Malawi, the South African Patients' Rights Charter is not enforceable in the private sector, which is left to set its own standards.

Zimbabwe

The current Zimbabwean Patients' Rights Charter arose from interactions between patients and health workers, in the context of strong civil society organisation around health, rather than being a Charter imposed by government. The precursor to the Charter developed by government in 1996 was seen as too biased in favour of patients, and was revised by the Consumer Council and community groups, precisely to give greater recognition to patients' responsibilities, so as to balance patients' rights and health worker protection. For the Charter to be effective, civil society groups recognised the importance of making it workable, hence the importance given to patients' responsibilities.

Notably, government has not acknowledged community input into the Charter, particularly in the balance it brings to health care provider-client interactions. This reflects an ambivalent relationship between civil society and government around patients' rights. For example, the Community Working Group on Health or CWGH (see Section 4.3, which follows) was originally asked to distribute the Charter but now that responsibility has been moved to the President's Office, and distribution appears to have been blocked. Despite having developed the Charter, user groups now do not really have adequate access to it. However, the CWGH has contributed, with other organisations, to the production of two videos (*Take Charge* examining the relationship between health care providers and patients, and *Next is Not Enough*, aimed at improving interpersonal communication skills of health workers) for the Department of Health to support implementation of the Charter.

Nonetheless, the Patients' Rights Charter plays an important role at local level in relation to community organising around health. The CWGH has worked with communities to establish clinic health committees with diverse membership (typically including the nurse-in-charge, elected and traditional leadership, teachers, youth, women, traditional healers, etc). One of the key organising activities has been the development of local action plans, since most action plans usually have quality of care and access to health care as a priority. The Charter is used in workshops and for the training of health care workers, with the aim of establishing partnerships between the community and health care providers. To complement locally effective strategies, the CWGH has lobbied government to include the Patients' Rights Charter in the curriculum of health professionals.

Because the Charter is located within a programme in which communities and providers address problems (e.g. problems with drug supply) and draw up annual plans and budgets together, this removes suspicion and builds trust. The Charter gives both health workers and patients' accountability and rights, and there is a sense of ownership by the community. Its effectiveness at a local level is therefore far greater than at a broader policy level. Because of the way it has been used, the Charter plays a much stronger role in building social capital than is the case in either Malawi or South Africa.

Notably, the effectiveness of the Charter lies in its proactive role. Where rights are used as 'claims' for redress, the patient will do so through organisations because of the fear of victimisation. This is consistent with the general climate of 'soft' approaches to rights in Zimbabwe, because of the environment of severe repression.

Summary

Patients' Rights Charters, by their very nature, are both restrictive (for users of services) but also crosscutting, in that they link rights of access to health care to a range of other rights, usually civil liberties (such as autonomy, rights to second opinion, etc). Thus, they may have simultaneous strengths and weakness. For example, charters in South Africa and Malawi are applied predominantly outside the group context, and appear to have limited roles in terms of contributing to the realisation of health as a right, and to human rights approaches to health. In many aspects, they emphasise curative services at the expense of preventive measures or intersectoral interventions (Bloom, 1999), which is problematic. Yet they appear also to offer important avenues for redress, particularly for vulnerable populations. In particular, the use of a patients' rights charter in the context of community mobilisation in Zimbabwe indicates how group rights can be more easily linked to the use of human rights standards and norms to support advocacy and mobilisation.

In practice, patients' rights charters have been applied differently in each of the three countries, ranging from a 'top-down' application with a managerial focus (South Africa) to a 'bottom-up' grassroots application to facilitate community involvement (Zimbabwe). Notably, the progress of the Charter in Malawi has been constrained particularly by its detachment from any popular movement, and its reliance on government and politician motivation for progress.

4.3 Civic organisation around rights of participation in health policy: The Community Working Group on Health (CWGH), Zimbabwe

The Community Working Group on Health (CWGH) was formed in early 1998, as a network of membership-based civic organisations, in conjunction with the Zimbabwe Congress of Trade Unions. The CWGH was a response on the part of civil society to an ongoing decline in the quality of health services, increasing poverty, and industrial action by health workers facing declining conditions of service (CWGH, 2001) as well as resistance to the introduction of user fees in a context where free basic health services had been one of the major victories of the Zimbabwean revolution (Rusike, 2003). The gains made post-independence in health status and access to social services through heavy investments in pro-poor policies have been heavily eroded by the implementation of Economic Structural Adjustment Programmes (ESAPs) (CWGH, 2002a).

Moreover, civil society groups were concerned about how community participation was being framed in Zimbabwe (Loewenson, 1998). Communities perceived ‘participation in the health sector as being largely top-down (Loewenson, 1998; CWGH, 2001), intended to ensure compliance with state defined programmes (CWGH, 2001) and appearing to exclude many civil society actors. For example, none of the civic organisations in the CWGH were represented in existing ‘community’ health structures at the time, nor did they know what took place in them.

The CWGH was therefore formed in order to strengthen the capacity of civil society to engage with government in shaping policies for health through advocacy and networking around health issues. It aimed to address the need to strengthen mechanisms for participation, transparency, consultation and accountability within the health sector, at both local and national levels. It has established health committees in 21 out of 58 districts in Zimbabwe (Rusike, 2003). These committees provide local structures in which health care providers and civic/constituent organisations are able to interact on matters of health promotion, disease prevention and the management of health problems, so as to strengthen informed participation in local health planning. Complemented by research that shows declining budget allocations to preventive and outreach services, as well as to peripheral clinics, these structures have enabled advocacy to reverse or at least halt government’s relinquishing of its commitments to health equity.

How have human rights approaches been used by the CWGH?

In general, human rights approaches in the work of the CWGH are those constituting the ‘broad’ use of human rights (primarily to support advocacy and civil society mobilisation – see page 10), and not strictly as human rights law. This is largely because of the difficulty in challenging authorities in Zimbabwe, particularly relating to civil and political rights. Indeed, CWGH’s Advocacy work in Zimbabwe started with patients’ rights and health promotion (e.g. the slogan: ‘if we can pay for guns and war, why can’t we pay for health?’). Use of the courts to secure health rights would not be helpful in Zimbabwe, where, in any event, the government disregards the Constitution and routinely ignores court decisions. However, the CWGH and other health activists are increasingly being pushed to address the abuse of civil and political rights, such as denying medical treatment to victims of violence. ZIMRIGHTS, a leading human rights NGO in Zimbabwe, is a member of the CWGH, and has been able to assist by providing information that the CWGH passes on to its members, so as to raise community awareness of rights issues. The CWGH has also helped to pass on information to human rights lawyers, such as when health workers were put under pressure to refuse to treat certain patients who were suspected of being members of the opposition party. Transparency and access to information have therefore played an important role in CWGH rights work.

What have been the links between civil and political rights and socio-economic rights?

Ironically, it appears to have been less difficult for the CWGH to take up issues surrounding socio-economic rights (such as housing or clean water) because they can be taken up with the local authorities as an issue of service delivery, and not explicitly as a rights issue. In one area where the CWGH has an active district committee, farm workers have successfully claimed the right to protective measures when working with pesticides, and linked this to the right to attend their local clinic without fear of discrimination by its health workers (CWGH, 2001). The CWGH has also helped to distribute documentation and participated in outreach civic education on social and economic rights produced by the Civic Alliance for Social and Economic Progress (CWGH, 2002a), thereby placing advocacy for primary health care firmly in the context of broader socio-economic rights issues. It has also drawn on a strong tradition of monitoring social and economic rights in the country. At the same time, its work with human rights lawyers and ZIMRIGHTS have represented important interventions to protect the civil and political rights of its constituency.

What agency is conferred on communities by a human rights approach?

To the extent that users of health services have been empowered to be more assertive, or to demand improved conditions, awareness of health as a right has played an important role in conferring agency on them. However, more importantly, the membership of CWGH organisations links community issues to national policy, enabling communities to exert some say in health policies at both local and national level. More recent health system reforms, which have seen some degree of decentralisation and shifting of responsibility and ownership to local communities, have strengthened opportunities for community engagement. This form of social mobilisation goes some way to addressing the need for participatory and inclusive processes required for developing ethical public health policy (Section 3.1, page 8)

What has been the CWGH's relationship with the Zimbabwe government?

Given the level of ongoing political conflict in Zimbabwe, the degree to which government appears to accommodate the CWGH is surprising. For example, the CWGH is a regular participant in the Parliamentary Portfolio Committee on Health, and has provided this committee with technical input (CWGH, 2002a). CWGH staff members have also been appointed to important public health structures (such as the AIDS Council Board and the Public Health Advisory Board).

There are three possible reasons for government's favourable relationship with CWGH:

- Firstly, the work of the CWGH has been issue-based, is grounded in evidence (backed by research), and has a recognisable community base. This kind of advocacy may be difficult to ignore politically.
- Secondly, the Zimbabwean government is committed to decentralisation and could not do so easily without some degree of support at the periphery of the health system, a key role increasingly being played by the CWGH. Whereas the CWGH's primary objective is to maximise community involvement in health-related decision-making, it has been simultaneously able to play an important role in facilitating the decentralisation process consonant with the government's operational needs at this point.
- Furthermore, the CWGH has a strict non-partisan political position, emphasises transparency in its decision-making, and downplays politically partisan issues. As a result, government is less threatened. Were the CWGH to adopt an openly confrontational stance, such as the challenge of active civil disobedience which the TAC has been forced to take, it would be unlikely that government would be receptive to the extent that it has been to date (Rusike, 2003).

One of the key strategies that the CWGH has employed to achieve a degree of rapprochement with public health services has been to work with public servants rather than political heads. This has been done by inviting health services personnel and management to participate in, and give input into, CWGH-organised workshops. Much like the South African situation, civil society groups in Zimbabwe after independence were reluctant to criticise government because they regarded individuals in government as comrades. It is not clear if this perception is subject to change.

Nonetheless, government ambivalence to the increased involvement of communities and civil society in health planning can detected in its response to the Patients' Rights Charter, where the CWGH has been asked to assist in distribution but no budget to enable this has been provided.

Key to understanding the importance of civic involvement in decision-making in health is the role offered by the CWGH as a channel for community input into national health and social policies. In this way, social mobilisation processes are linked to formal processes, such as parliamentary oversight for securing rights, critical for dealing with the dialectic between constituent power and formal power.

How has the CWGH's rights work linked to health systems and equity?

The CWGH has structures in 21 districts (out of a total of 58) and where it is active, there have been reports of better care of patient-held records, better adherence to medication, the cessation of drug sharing between patients, guarantees of patient confidentiality by health services, and improvements in nurse attitudes (Rusike, 2003). Community members have become more open to discussing priority health needs, and communities have been able to place greater emphasis on preventive measures and to identify health needs that extend beyond a narrow conception of health service provision to include the range of intersectoral factors impacting on health. Civic groups are more confident of engaging managers and health planners, and dialogue between the users and providers of health services has improved (CWGH, 2001). In particular, rural residents have been able to benefit from the CWGH's advocacy. By linking community and civic groups to national policy debates, the voices of community groups have been able to pose questions and provide input into decisions regarding the distribution of important district funding sources, such as the AIDS levy.

5. FINDINGS AND CONCLUSION

What emerges from a consideration of the critical success factors in the cases above is the importance of addressing human rights across the full spectrum of rights, from civil and political to social and economic, as well as the need to locate rights in a group context, rather than in a consumerist mode, in which the individual is the active agent and rights holder. Human rights approaches have been particularly successful in achieving equity-promoting health goals when they link community demands at a local level to demands at national (in the case of the CWGH) and international (TAC) levels. However, the relationship between health equity and human rights is complex, and understanding the role of community agency is particularly important to understanding the equity-rights interface.

5.1 Findings

There are seven key themes that emerged from this paper.

Theme 1: Rights alone are not enough, but need to be coupled with community engagement

The relative effectiveness of the TAC can be clearly traced to its recognition of the fact that appeals to the courts would be ineffective without a strong and mobilised constituency behind it. Similarly, the different ways in which patients' rights charters have been applied in the region have illustrated how its most effective impact as a tool to promote equity has been where it has been integrated in grassroots organisation aimed at facilitating community involvement, even in environments of severe political repression (such as Zimbabwe). Failure to build on the Grootboom judgement in South Africa, which was not linked to an active civil society movement, can be seen as a validation of this hypothesis.

Furthermore, when we refer to 'human rights', it is the full spectrum of civil and political, and socio-economic rights that should be coupled to community organisation and social movement. For example, Sen (2000), in observing that no country with a free press ever suffered a major famine, cites respect for civil and political rights as being the essential preconditions for realising socio-economic rights. Also implicit in his observation is the recognition of the pathway whereby socio-economic rights may be realisable – a free press only has value when it is a vigorous component of an active civil society.

Evans (2001) makes the link directly to health equity: 'Systems characterized by the absence of democracy, pervasive corruption, violence, endemic racism, and gender discrimination are breeding grounds for inequities in health … In contrast, societies with flourishing democracies, respect for human rights, transparency *and opportunities for civic engagement – high social capital* – are more likely to be equity-enhancing.' [Author's emphasis]

Theme 2: Rights, appropriately applied, can strengthen community engagement

Not only do rights approaches require a degree of civil society mobilisation to complement legal strategies, but they can actually be used to open up a space for community engagement. In other words, there is a pathway from human rights to greater civic engagement. Court action has served as a focus for mobilising HIV+ persons for the treatment action movement, and rights education has played a key role in enhancing the vibrancy and confidence of HIV activists in confronting the South African government. Taking up issues of discrimination has also facilitated the recruitment of community members into treatment action campaigns. In this context, a rights claim has served to support community mobilisation in a context of confrontation with the State. In both Zimbabwe and Malawi, their patients' rights charters have enabled civil society groups to engage with policy makers and service providers in ways that would not have been otherwise possible. Unlike the TAC in South Africa, creating a space for civil society engagement in these countries has been non-confrontational. Moreover, rights approaches have allowed vulnerable groups to create alliances with other civil society formations so as to strengthen their activities and capacity. For example, TAC's appeal to academics, professionals, researchers and organised labour has been critical in its success at popular mobilisation.

Theme 3: Rights, conceived in terms of agency, are the strongest guarantors of effective equity-promoting impacts

Sen's observation (2000) that the opportunity to realise one's abilities (capabilities) is key to rights approaches resonates with much of the writing on the need to reinvigorate primary health care and public health with a return to the values of social justice and an emphasis on community participation. For example, Whitehead et al (2001) argue that social exclusion is the key pathway between social inequality and health inequities, and therefore that efforts to address equity require actions to build social structures that engender mutual support and provide opportunities to all people (not just the most vocal). In the case studies, mechanisms to reduce social exclusion include making popular participation in democratic processes possible, enabling people to work on the prioritisation of their health problems, and establishing inclusive health systems, all of which must explicitly be in favour of the marginalised.

Thus, in the same way that a human rights approach leads to better outcomes because it enables people to realise their potential, community mobilisation provides citizens with avenues to ensure access to the resources needed for their health. Moreover, in its prioritisation of the most vulnerable, a rights approach that provides these people with opportunities for agency will always be promoting equity.

A rights-based approach that focuses only on the redress of violations, or protecting victims from exploitative development, by using human rights standards and norms, while important, conceives of a very limited, even passive, role for people in the realisation of their rights (Paul, 1998). Rights to participation would include 'rights of association, assembly, advocacy, and access to information and decision makers … to influence policy making and administration …' (Paul, 1998). Participation and the space opened for civil society participation in policy development and implementation has been critical to the success of all three of the regional case studies in this paper. In the Southern African context, rights strategies offer the opportunity to shift governments' focus away from a preoccupation with their international allies (lending agencies) to local partners and to get governments to recognise communities. This conception of agency is also key to 'new' conceptions of public health outlined earlier ('Public health', Section 3.1).

Diderichsen et al (2001) construct a model for understanding the social basis of disparities in health, which identifies four mechanisms responsible for generating health inequalities: social stratification, differential exposure based on social stratification, differential vulnerability given an exposure, and differential consequences. The consequences (namely, ill-health) are thus differentially distributed, and exert a reinforcing effect on social stratification. The powerlessness of vulnerable groups in society can be traced to all levels of Diedrichsen's mechanisms, but are most evident in their incapacity to control their vulnerability to exposures, and to cope with the consequences of disease. This 'thinness of reserves' … leads to a higher probability of falling behind more fortunate groups' (Diderichsen et al, 2001). Conferring agency onto groups whose powerlessness is the root of health inequalities allows them to contest all four of the mechanisms mentioned above, but particularly the last two. This is most clearly illustrated by the treatment access movement in South Africa, where TAC's campaign work has been most successful at addressing the differential vulnerability of its HIV+ constituency and the need for comprehensive treatment for this vulnerable group.

Utilitarian approaches to resource allocation, which inevitably tend to allocate according to the capacity to benefit, can be counterbalanced if rights approaches prioritise the agency of those most affected by decisions regarding the allocation of resources. Gilson and McIntyre (2001), in discussing the monitoring of health equity, argue for a system that is 'open and transparent, engaging all sectors of society' and where 'wide-ranging ownership is as important as government leadership and action in developing an effective health equity monitoring strategy.' The model of the CWGH, in bringing community preferences to bear on national health policy, provides one example of how marginalised community groups can be brought into the overseeing and monitoring of health equity. Moreover, one of the strengths of approaches that incorporate human rights in the region lie in their ability to ensure that campaigns are not appropriated by 'experts' but remain ones where community members remain active agents and 'owners' of the process. The use of civil society-grounded 'shadow reporting' (reports by NGOs submitted simultaneously with government reports) at national level would be one example of how advocacy that is linked to human rights could increase accountability in the interests of equity.

Theme 4: Rights should strengthen the collective agency of the most vulnerable groups

However, notwithstanding the evidence that rights approaches that strengthen agency are good for equity, questions may well be asked about whose agency should be strengthened, and under which circumstances. According to the libertarian model, rights are concerned with developing the individual as the agent in his/her relationship to the state. In contrast, according to a communitarian model (or approaches that emphasise socio-economic rights), rights are tools for groups to challenge the imbalances of power that give rise to their dispossession or disadvantage. The most successful strategies emerging from the three case studies in this paper relate not to the consumerist notion of an individual exercising his or her rights (e.g. complaints mechanisms and civil claims), but to collectives of people in positions of vulnerability (HIV+ people, rural residents, users of public sectors health services, etc) taking action to redress their vulnerability. Indeed, in the absence of a firm location of rights in the socio-economic paradigm, rights-based approaches that individualise action run the risk of becoming appropriated in defence of privilege, and may even compound some people's vulnerability to HIV (Haywood and Altman, 2000).

Yet even when conceived of as a group characteristic, is agency alone sufficient to avoid the pitfalls of individualist claims that drive inequity in resource allocation? Gilson and McIntyre (2001) caution against the problem of 'a bias toward more organised and less disadvantaged communities' citing evidence from development research in South Africa that shows poorer outcomes amongst more vulnerable communities (Friedman, 1997; Marais, 1998). These are challenges that, for example, the treatment access movement in South Africa, is acutely aware of, and grappling with in its strategies to extend model HIV treatment sites to rural areas impoverished as a result of years of apartheid rule.

Theme 5: Rights should aim to address public-private and global divides in relation to human rights

Traditionally, human rights approaches have focused on the easily definable relationship between the citizen and the State. However, increasingly, civil society movements have been identified as critical to attaining progress in human development, principally through 'exerting pressure on the government *and the private sector* [authors emphasis] to focus policies and programmes on human development goals and human rights achievements alike.' (UNDP, 1998).

There are two responses to the problem of holding weak governments accountable to human rights standards. Firstly, there is the need to re-affirm government as the primary source of democratic legitimacy, despite a world order increasingly undermining the concept of the nation state. '[Human rights and health] activists must campaign to reassert the power of governments against non-accountable market forces and strengthen the ability of governments in developing countries to pursue the well being of all their citizens…' (Heywood and Altman, 2000). In its work on pharmaceutical access, the TAC has shown how it is possible to support the South African government's capacity to act in the best interest of its people (through regulations to enhance drug access), while still holding it accountable to human rights standards. At the same time, it has achieved this by using human rights arguments to foster and co-ordinate international alliances in support of treatment access demands, thereby successfully linking national health campaigns to the international debate on health equity.

Secondly, there is the option of extending accountability for human rights beyond government. Multinational companies are increasingly being targeted for their failure to honour rights, such as the right to participation by employees and communities affected by their operations (Paul, 1998). In extending the purview of rights language to claims against private sector players, we step strictly beyond the law. This approach to human rights represents a recognition of the role of rights standards and norms to support advocacy and civil society mobilisation (see Section 3.1), as exemplified in the work of TAC and its international allies.

However, it is not only in high-profile campaigns with international publicity that rights approaches can begin to tackle public-private inequalities. For example, the fact that the Malawi Patients' Rights Charter has chosen to include private providers in its stipulations for emergency care reflects how rights approaches, by using community agency and advocacy language, can begin to tackle public-private inequalities. However, once again, these strategies will only succeed if there is strong civil society action.

Theme 6: Transparency and access to information are key to human rights approaches that build equity

As both a right in itself and as an enabling mechanism for the realisation of other rights, access to information plays a key role in empowering civil society to drive the shifts in political will required for policy change (UNDP, 2000). This has emerged very clearly in the history of HIV treatment access and in Zimbabwe, with civil society there questioning sources of funding, such as those for the AIDS levy. Systems that maximise transparency and accountability offer the most likely opportunities for community engagement and meaningful input. Conversely, absence of information and transparency undermines community agency, and drives conflict and distrust that can potentially undermine efforts to redress inequity. In a sense, access to information is the backdrop against which other rights operate, and facilitates agency on both individual and group levels.

Notably, the TAC have mobilised their own 'experts' to develop positions on key HIV-related debates, so that information is made available to all members in media and workshops, and disseminated through campaigns to the public. The CWGH have enlisted researchers to access information on health conditions and services to help support active campaigning on health equity in Zimbabwe. Use of research has taken place dialectically, strengthening civil society's ability to engage with the State and the private sector in the pursuit of health equity goals.

Theme 7: Human rights approaches provide additional opportunities for mobilising resources outside the health sector

The strongest evidence that a human rights approach can facilitate mobilisation outside of the health sector emerged from the CWGH case study in Zimbabwe, where health, housing and sanitation issues were relatively easily combined in the organisation's advocacy agenda. In terms of Diderichsen's model (2001), 'higher-level' policies that address social stratification, the antecedents of vulnerability, are typically policies that lie outside the health sector. There was insufficient evidence from the case studies to tease out the role played by civil society mobilisation in relation to these 'higher-level' policies. However, it is evident that this is a key question to address in the assessment of how a rights approach can fit in with equity-oriented public policies.

5.2 Conclusion

This paper has travelled a deliberately long route. From its starting point of asking whether human rights can promote or necessarily will promote equity in resource-poor developing countries, this paper has examined both the theoretical literature and empirical evidence from three case studies in Southern Africa, to identify key themes for policy makers concerned about equity.

Inasmuch as the term 'public health approaches' belies a vast diversity of strategies, so the notion of 'human rights approaches' to health problems includes a range of interpretations, with vastly different implications of health equity. This lack of definition potentially bedevils analysis. However, where it is clear that rights approaches are predicated upon casting units as groups, specifically vulnerable groups, where the operationalisation of rights is conceived of in terms of agency on the part of those most affected, and where rights are conceived of as the complete spectrum of civil and political, through to socio-economic rights, human rights approaches appear to offer powerful tools to support social justice and institutional transformation. Public health concerns for equity then become entirely consonant with human rights-based strategies and tactics. The synergy between public health and human rights in relation to equity lie less in the setting and mechanisms for pursuing individual rights but rather in social processes and consciousness, and the interface with the State that secures collective rights.

Empirical evidence from the preliminary review of three Southern African cases supports this by suggesting that:

- Rights alone are not enough, but need to be coupled with community engagement.
- Rights, appropriately applied, can strengthen community engagement.
- Rights, conceived in terms of agency, are the strongest guarantors of effective equity-promoting impacts.
- Rights should strengthen the collective agency of the most vulnerable groups.
- Rights approaches should aim to address the public-private and global divides in relation to human rights.
- Transparency and access to information are key to human rights approaches that build equity.
- Human rights approaches provide additional opportunities for mobilising resources outside the health sector.

Can human rights serve as a tool for equity?

However, further work is needed to deepen these case studies, and to test out these preliminary findings by extending the analysis to other case studies. For example, what are the critical strategies that make a rights approach successful at opening the space for community engagement, and how sustainable are such strategies? How do health equity initiatives reinforce the potential mutuality of the relationship between rights and community agency, and what strategies ensure that the agency of the most marginal are prioritised in the development of such initiatives? Can equity approaches help to develop a better theorisation around group rights and the role of collective agency in ways that benefit the people of the developing countries? How best can rights approaches support equity initiatives that address both national and global health inequalities?

Lastly, health systems analyses need desperately to muster stronger rights arguments to ensure equity promoting transformation. By drawing on human rights theory and the empirical lessons of local case studies, we can begin to explore the synergies between human rights and public health to advance the health and well being of all the peoples of the Southern Africa region.

GLOSSARY

Agency	Capability of individuals, groups and communities to take action to achieve individual and collective objectives.
Alma-Ata Declaration on Primary Health Care	Declaration of the World Health Organisations setting out the elements of the Primary Health Care approach.
Autonomy	Right of individuals to choose their own courses of action.
Civil and political rights	Legitimate, valid, justified claims on society to various freedoms deemed essential for dignity and well being.
Civil liberties	Liberties, privileges and immunities of citizens that are protected by law.
Civil society	Groups of people who contribute to change in their communities through activities that are not part of formal political governance or commerce.
Clinical medicine (biomedicine)	Clinical medicine and biomedicine are used interchangeably to signify health care activities involving the diagnosis and treatment of illnesses.
Communitarianism	Contextual and community-sensitive approaches to policy making and programming that take priority over liberty and equality.
Communicable disease	Illness due to specific infectious agent transmitted directly or indirectly from an infected person to another, or from an animal or arthropod.
Consumerist approach	Approach to realising entitlements or services where the user of the service is viewed as a buyer whose powers and rights should be strengthened in relation to a seller of a service.
Economic structural adjustment programmes	Policy of reducing government expenditures, lowering inflation, limiting imports, devaluing currency, and increasing economic efficiency, as required by the IMF of countries as a condition of debt restructuring.
Effectiveness	The extent to which an intervention, treatment or service, when deployed in the field, does what it is intended to do for a defined population.
Efficiency	The extent to which resources used to produce an intervention or treatment or service, are minimised. A measure of the economy with which a procedure of known effectiveness is carries out.
Equity	Absence of unnecessary, avoidable and unfair differences between individuals, groups, communities or countries with respect to economic potential, educational status, living conditions, access to health care and health status.
Ethical codes	Documents produced by professional or statutory bodies that set ethical standards, and which enjoy a degree of professional standing.
Ethical framework	Norms for conduct of individuals and institutions based on religious, cultural and social factors, involving reflection on the complexity of a moral choice. Frequently draws explicitly or implicitly on pre-existing philosophical traditions dominant in a particular society.
Globalisation	Policies of deregulation and external trade liberalisation by national and international economic policy makers.
Health care systems	Resources, organisation, administration, management, and systems of financing of health care needed to promote health.
Health equity	Absence of differences between individuals, groups, communities or countries with respect to health outcomes that are unnecessary, avoidable and unfair.
Health system	Resources, organisation, administration, management, and systems of financing of health care and services outside the health sector needed to promote health.
Health system reform	Policies and measures aimed at effecting changes in the existing system of resources, organisation, administration, management, as well as systems of financing of health care and services outside the health sector needed to promote health.
Horizontal equity	Treating equals as equals, for example, by ensuring the equality of resource availability per capita.

Can human rights serve as a tool for equity?

Human rights	An internationally agreed-upon set of principles and norms embodied in international legal instruments that take the form of legitimate, valid and justified claims to various goods and benefits deemed essential for dignity and well being.
Indivisibility of rights	All human rights are equally important and cannot be separated.
Intersectoral	Actions required for health that take place outside of the health care sector, for example, water, housing, education and the environment.
Justiciability	The ability of the courts to pronounce on matters relating to policy.
Libertarian	Tradition that views society working best when each person is responsible for their own future no matter what happens.
Macro-economic	Related to the overall working of a national or global economy.
Market-orientated	Economic policies that emphasise the importance of the free market as the most important (sometime only) framework in terms of which implementation should occur.
Maximisation of utility	Choices that result in the largest benefit quantitatively.
Neoliberal economic paradigms	Models for economic development based on the theory that competition among businesses in market with limited state regulation best fosters growth. More specifically, they believe competitive global markets and the movement of goods and capital should be deregulated.
Non-communicable disease	Illness caused by an agent that is not infectious or transmitted through biological media, usually a chemical or mineral toxin. Typically causes a chronic health condition.
Operational policy	Policy that seeks to establish the logistic framework for implementing new health policies.
Principalist ethics	Based on four principles: beneficence, non-maleficence, autonomy and justice. Clinical choices are based on considering which principles apply in a given situation.
Procedural justice	Fairness and transparency in the processes by which decisions (e.g. resource allocation) are taken.
Progressive realisation	The concept whereby the realisation of specific rights may be accomplished in stages as resources permit.
Pro-poor policies	Preferential policies explicitly for the benefit of the poor.
Resource allocation	Process of distributing money, capital, human and other resources in order to meet health policy objectives.
Resource-poor environments	Settings where health care and health-related interventions are constrained by low aggregate measures of available resources.
Social capital	An aggregate of measure of the cohesiveness of communities arising from networks, norms and social trust that facilitate coordination and cooperation for mutual benefit and enables health interventions to be more effective.
Social spending	Government spending on measures that represent social goods and that benefit large groups or whole populations, such as welfare, health, education, etc.
Socio-economic rights	Legitimate, valid, justified claims on society to various social, cultural and economic rights deemed essential for dignity and well being.
Sustainable development	Development that meets the needs of the present without compromising the ability of future generations to meet their own needs.
Upstream causes	Factors in a causative pathway that operate before the disease or consequence is manifested in an individual, and that are usually not evident during the clinical encounter.
Utilitarian	Utilitarianism is an approach that bases morally correct decisions on whether the decision or policy brings the greatest happiness for the members of a given society.
Value-driven	Choices based upon implicit or explicit recognition of social priorities based on human values.
Vertical equity	Treating unequals differently by giving more to those in greater need.

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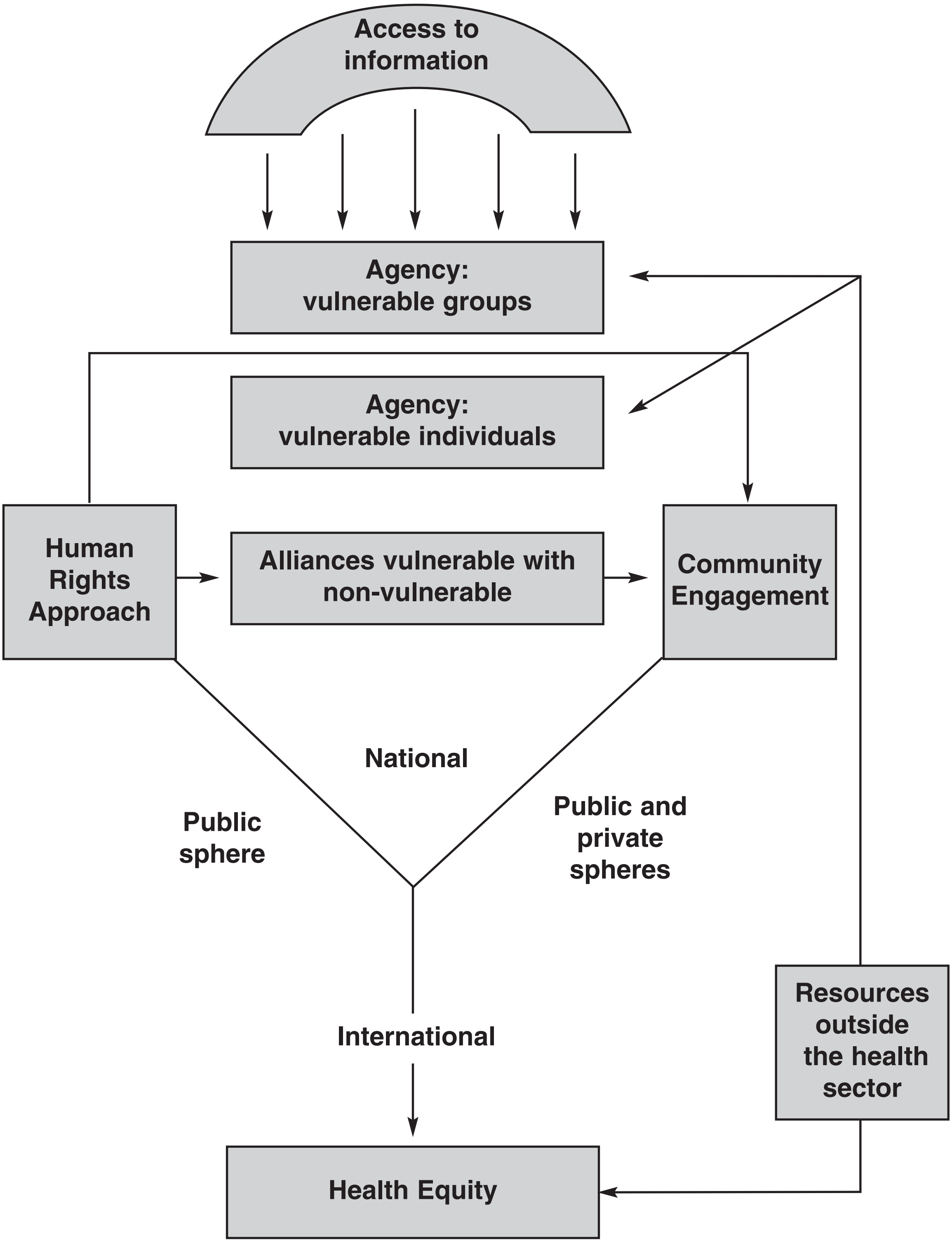
Figure 1: Human Rights approaches, Agency and Health Equity: A Model



Web addresses used

Treatment Access Campaign - URL: http://www.tac.org.za
EQUINET – URL: http://www.equinetafrica.org
People's Health Movement – URL: http://www.phmovement.org/
Community Working Group on Health – URL: http://www.tarsc.org/prog2.html
AIDS Law Project – URL: http://www.alp.org.za
Canadian HIV/AIDS Legal Network – URL: http://www.aidslaw.ca/

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Equity in health *implies addressing differences in health status that are unnecessary, avoidable and unfair. In southern Africa, these typically relate to disparities across racial groups, rural/urban status, socio-economic status, gender, age and geographical region. EQUINET is primarily concerned with equity motivated interventions that seek to allocate resources preferentially to those with the worst health status (vertical equity). EQUINET seeks to understand and influence the redistribution of social and economic resources for equity oriented interventions, EQUINET also seeks to understand and inform the power and ability people (and social groups) have to make choices over health inputs and their capacity to use these choices towards health.*

EQUINET implements work in a number of areas identified as central to health equity in the region:

- Public health impacts of macroeconomic and trade policies
- Poverty, deprivation and health equity and household resources for health
- Health rights as a driving force for health equity
- Health financing and integration of deprivation into health resource allocation
- Public-private mix and subsidies in health systems
- Distribution and migration of health personnel
- Equity oriented health systems responses to HIV/AIDS and treatment access
- Governance and participation in health systems
- Monitoring health equity and supporting evidence led policy

EQUINET is governed by a steering committee involving institutions and individuals co-ordinating theme, country or process work in EQUINET: Rene Loewenson, Godfrey Musuka TARSC Zimbabwe; Firoze Manji Fahamu UK/SA; Mwajumah Masaiganah, Peoples Health Movement, Tanzania; Itai Rusike CWGH, Zimbabwe; Godfrey Woelk, University of Zimbabwe; TJ Ngulube, CHESSORE, Zambia; Lucy Gilson, Centre for Health Policy South Africa; Di McIntyre, University of Cape Town, HEU, South Africa; Gertrudes Machatini, Mozambique; Gabriel Mwaluko, Tanzania; Adamson Muula, MHEN Malawi; Patrick Bond, Municipal Services Project; A Ntuli, Health Systems Trust, South Africa; Leslie London, UCT School of Family and Public Health, South Africa; Yash Tandon/ Riaz Tayob, SEATINI, Zimbabwe.

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