

# **Health Care: A Right and a Responsibility**

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## Health care: A right and a responsibility

### INTRODUCTION

This literature review was commissioned by Soul City for the purposes of providing an overview of the issues relevant to community participation and empowerment in preparation for the development of *Soul City Seven*.

### BACKGROUND

The review will focus primarily on health care inequities in South Africa, specifically in relation to rural-urban and public-private disparities. It will present health as a human rights issue and highlight the importance of public 'participation' in the health care system to enact positive change.

Legislative processes, upcoming legislation, models for community 'participation' and possible stakeholders that could be used in an advisory capacity during various parts of production are also included.

#### ***Role of Community Action in Promoting Equity***

To rehabilitate and develop a health system that meets health needs in a time of scarce resources demands difficult choices on how national resources are to be shared, where to spend public resources and on how to motivate and direct private health spending. To that end, participation of communities is widely argued to be an important aspect of improving health outcomes and the performance of health systems as it is the community that often knows its own priorities and needs. Therefore public participation and input is not only important, it's necessary.<sup>i</sup>

#### ***Terminology and definitions relating to equity***

Equity in health and health care has received considerable attention not only at a national level but also at an international level and there is a worldwide drive towards measuring and advocating for equity in health systems to ensure greater social justice.

Equity means "fair shares" and "fair opportunities" in the distribution of and access to resources and provision of services. Equity does not mean equal shares or equal opportunities. Instead it implies that greater resources (in the case of health care these would be financial, human, drugs, buildings, infrastructure etc) are distributed and made available to the most vulnerable and needy groups in society and in under-resourced areas, especially rural areas.<sup>ii</sup>

#### ***Terminology and definitions relating to community action***

Throughout the literature a number of different terms are used to describe various levels of public involvement.

For the purposes of this review, unless otherwise stated, the term 'community participation' will be used to relate to all three of these – basically the community doing *something*.

According to Myezwa and Mkumbuzi, the terms "community involvement" and "community participation" are often used interchangeably. Their meanings, however, are not the same.

The World Health Organization (WHO) suggests the use of the term "involvement" because "to participate may be simply a passive response."<sup>iii</sup>

Participation is generally seen as being 'in relation to something – an external agent or other sections of a community.' For example, the community participates in a project, event or process organised by someone else. To this degree, external agencies control the resources that are used for the community's benefit.<sup>iv</sup>

Community involvement involves the community being involved in some aspects of the event, project or process but not having full accountability or complete self-reliance.<sup>v</sup>

Meanwhile, empowerment gives people the tools and knowledge to create change themselves. "To empower communities, strategies must be developed to allow people the knowledge needed to make real choices, and the skills necessary to understand the implications of these choices and to control the implementation of development." Effectively, the community takes control of its own destiny.<sup>iv</sup>

### **THE RIGHT TO HEALTH**

The right to health has been codified in a variety of national and international instruments. The International Covenant on Economic, Social and Cultural Rights provides for the "enjoyment of the highest attainable standard of physical and mental health conducive to living a life of dignity". This means that health care facilities, goods and services have to be available in sufficient quantity; must be physically and economically accessible to everyone, must be ethically and culturally acceptable, and must be of a medically appropriate quality.<sup>v</sup>

The South African Constitution has been internationally acclaimed for its inclusion of a range of justiciable (courts may be approached to enforce these rights if they have been violated or not adequately provided for) socio-economic rights. Included in these rights, which are enshrined in the Bill of Rights, is the right to have access to health care. The Constitution provides for access to health care services including reproductive health and emergency services; basic health care for children, and medical services for detained persons and prisoners. If the state is unable to provide for these rights due to insufficient resources, it is required to take reasonable legislative and other measures to making progress in the realisation of these rights. It is worth remembering however, that the Constitution does not guarantee the right to health but the right of access to health care services.

Great effort has been put into raising public awareness around civil and political rights (the right to life, right to equality, human dignity etc). However, the widespread meaning, content and implications of socio-economic rights have not received the same attention and resources. Subsequently, the rights that have the most potential to transform the quality of people's lives remain shrouded in legal terminology and academic rhetoric. In light of this, it is crucial that information around the existence and meaning of socio-economic rights, aimed at ordinary citizens who would not normally have access to this information is disseminated as widely as possible. In particular, the existence of the right to access to health must be highlighted as improved knowledge of this right and community activism and participation around the enforcement of this right has the potential to have various ramifications in quality of people's lives.

In addition, the Constitution strives to ensure equal access to health care facilities provided by third parties; to ensure that privatisation does not constitute a threat to the availability, acceptability and quality of services provided; and to control the marketing of medicines by third parties.<sup>v</sup>

For the right to health to become a reality in the South African context, it is critical that a rights based discourse around health is developed among those sectors of society that rely on the state to deliver this right. People do not, as a rule, engage the state or government on its duties to provide this right and generally exhibit low levels of activism in accessing and claiming this right. Relationships between health care service users and providers are frequently an unequal one, with power and control largely vested in the health care provider.

Too often, patients are not advised of their nature of their illnesses, nor are they consulted or informed of their proposed treatment, its side effects or its consequences. The reasons for this power imbalance are diverse and stem in part, from society's tendency to exalt the status of health care providers - in particular doctors. Other reasons for this unequal relationship between patient and health care provider are related to a lack of time to adequately consult with patients, and other resource constraints.

The Department of Health has developed the 'Patients' Rights Charter' – as a set of norms and standards to govern the relationship between themselves and users. Widely displayed in state health care facilities, the contents of the charters are neither known by patients nor practised by health care workers.

Anecdotal evidence suggests that many people's experience of the public health system has been an unpleasant one where health care workers are brusque or worse, do not speak to patients and prescribe treatment without consultation. This leaves beneficiaries feeling disempowered, vulnerable and unsure of what steps they need to take to improve/control their health conditions.

This culture of meekly accepting poor treatment from health care workers needs to be challenged and that a new paradigm where there is a healthy, reciprocal relationship between service provider and seeker needs to be developed. In order to develop an ethos in which healthcare is delivered and accepted as a right and not a privilege, it is necessary to publicise the provisions of the charter and well as the Bill of Rights.

Intrinsic to developing a new approach to delivering and accessing healthcare, is popularising the idea that rights also come with responsibilities and obligations.

In this regard, the Patient's Charter sets out the rights and responsibilities of the patient. The aim of including both the rights and responsibilities of the patient is to foster the development of a culture in which people accept that the delivery of rights is not a one sided concept and that there is a positive duty on citizens to respect, promote and facilitate the delivery of rights. Responsibilities of the patient are also included in the National Health Bill. The inclusion of patient responsibilities in official Department of Health documents and legislation suggests that the department is keen to create awareness around the symbiosis that is needed between itself and its beneficiaries. It is within this context then, that community participation and the can make a qualitative difference to healthcare delivery. Community engagement with the prevailing health issues of the area can facilitate a strong sense of empowerment and social activism. 'Empowerment is the process by which disadvantaged people work together to take control of the factors that determine their health and their lives. By definition, one cannot empower someone else: empowerment is something that people do for themselves. However, sometimes, concerned health workers or facilitators can help open the way for poor people to empower themselves'.<sup>ii</sup>

The Global Equity Alliance (GEGA) suggests that supporting the empowerment of poor and disadvantaged communities would logically lead to demands for a fairer distribution of health affecting resources and greater accountability of the health system.<sup>ii</sup>

GEGA further suggest that while equitable health polices may exist in theory, these do not necessarily always or fully translated into improved or more equitable services or conditions at local levels. They suggest that communities that are empowered with an awareness of a legal, moral or human right to a service are better placed to persistently demand that these rights are delivered and that policy is translated into practice.

### **INEQUITIES IN THE HEALTH CARE SECTOR**

According to Braveman, "equity in health status refers to the attainment *by all people* of the highest possible level of physical, psychological and social well-being that biological limitation permit."<sup>vi</sup>

Braveman continues: "Equity in health care implies a commitment to ensuring high standards of real (not only theoretical) access, quality and acceptability of health services for all...(Real access) can only be determined by measuring the quantity, nature and quality of the services people actually receive."<sup>vi</sup>

To that end, a number of "indicators" are chosen to illustrate disparities between different groups. The number and type of indicators that can be chosen is vast but in this review we will attempt to isolate those that are the most pertinent to two areas of disparity: public-private inequities and rural-urban inequities.

In addition, the impact HIV/AIDS has had on those already facing severe inequities will be highlighted.

### **Public-private inequities**

The population of South Africa is estimated to be about 44 million. Of those, approximately 37 million –more than 80% – rely on public health care for their medical needs.<sup>vii</sup>

Various studies put the unemployment rate between 29.4 and 40.9 per cent, depending on the definition.<sup>vii</sup>

A government study indicated that just over 50 per cent of the population was described as poor and 27 per cent is “ultra-poor.”<sup>iii</sup>

It also showed that:<sup>iii</sup>

- *Race*: 61 per cent of the black, 38 per cent of the coloured, 5 per cent of the Indian and 1 per cent of the white population were poor.
- *The household head's gender*, with 60 per cent of female-headed households being poor compared with 31 per cent of male-headed households.
- *Rural residence*, in that 71 per cent of the rural population is poor compared with 29 per cent of the urban population; urban households, however, are significantly poorer than those in metropolitan areas (such as Cape Town, Durban and Johannesburg/Pretoria). In addition, households in the former homeland states face especially high probabilities of being poor.
- *Provincial residence*, with 3 of the 9 new provinces having poverty rates of 60 to 70 per cent and being home to only 36 per cent of the population.

People do not get sick at random; they do so in relation to their living, working, social and political environments. Poverty and ill-health combine to form a vicious cycle where the existence of one pre-disposes vulnerability to the other. As a result ill health can easily drag families into poverty, while poverty creates conditions that are conducive to ill health and inhibits people from seeking health care. This is particularly relevant in the context of the HIV/AIDS epidemic where more and more families are descending into poverty due to the burden the disease has placed on them

The joint World Health Organisation (WHO) and World Bank report, *Dying for Change*, chronicles the views and health needs of poor people in over 60 countries.<sup>viii</sup>

The report found that poor people most frequently describe ill health in multidimensional terms which include hunger, pain exhaustion, social exclusion, insecurity, fear, powerlessness and anger.

Most of the people interviewed spoke of the devastating consequences of ill health rather than particular illnesses. People also viewed good health in a holistic manner, citing good health as a ‘balance of physical, psychological and community well-being’.<sup>viii</sup>

In most countries, poor people identified hospitals and clinics as the most important state institution. Barriers and deterrents to accessing health care include the travel time to the health care centre, waiting time to get treatment, rude and humiliating treatment from health care workers and inability to afford user fees.

The report makes a strong case for the right of poor people to participate in processes that affect their lives. The report further suggests that ‘strategies are needed to involve poor people and their representatives in the design, implementation, monitoring and evaluation of policies and programmes that affect health. These will not only provide valuable information about the problems facing poor people, thereby helping to ensure that projects are appropriate, but also, and more fundamentally, they will help to empower the poor and alleviate feelings of shame and isolation-themselves causes of ill health.’ The report cautions that ‘poor people’ cannot be treated as a homogenous group and identified factors such as gender, culture, and ethnicity as significant variables in perceptions of health and ill health and access to and experience of health workers. The report also indicates that poor people’s values, networks and support mechanisms are being eroded by the strain of increasing poverty and urbanisation which affects the way in which poor people cope with and

experience ill health which in turn has implications for community participation and social activism around health issues.<sup>viii</sup>

In addition to providing free primary health care, the South African government has introduced a variety of free health care services to 'vulnerable' sectors of society. Pregnant women, children under six years old and, as of July 2003, people with disabilities are entitled to free health care. A simple means test is administered with most people paying an average amount of R13 per visit to hospitals. This user fee deters some from accessing health care as competing priorities and scarce resources might dictate that the money be spent on food for the family rather than on individual medical care.

However, some reports indicate that the payment of a user fee creates a sense of ownership and responsibility over the process. The following comment illustrates this point: "In the past when chloroquine was free I used to stop taking it once I felt well and would throw away the rest of the tablets. Now, however, I finish drinking them all because of the (price) I paid for them."

Conversely, user fees might also result in medication such as antibiotics and antiretroviral being spread through families and other extended support structures which nullifies their effect as the entire course has to be taken for it to be effective.

The largest equity problem in health care continues to be the differential in resources available to service the poor – who are dependent on public sector care – and higher-income individuals.<sup>ix</sup>

In 1998/99 South Africa as a country spent R70.2 billion on health care.<sup>ix</sup> That number is estimated to be around R80 billion today.

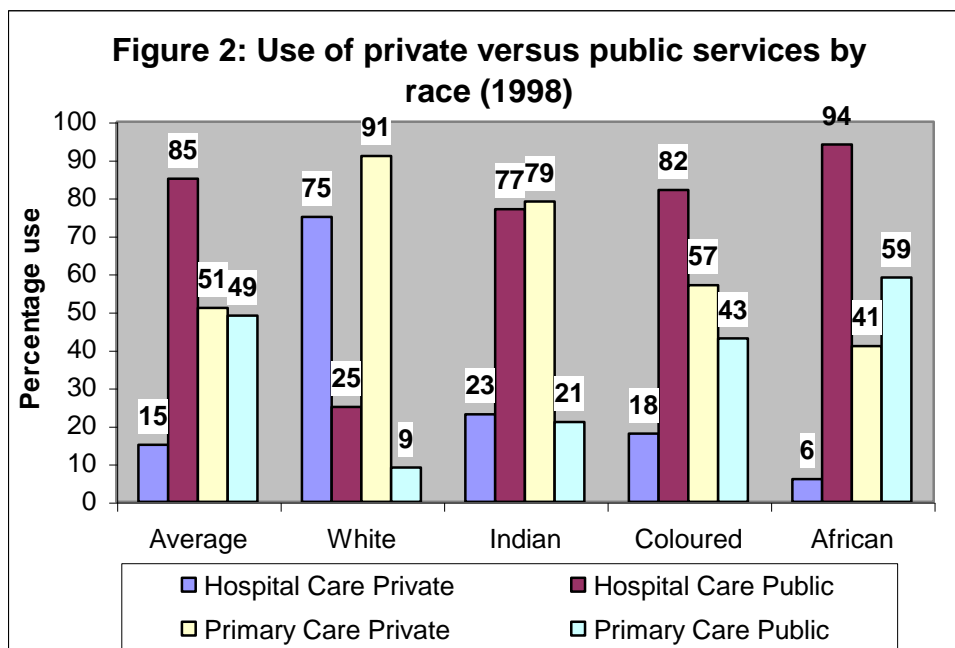
When the numbers are broken down, South Africans spent approximately R42 billion on private health care – which again services only 17% of the population – versus R29 billion on public health care. And while the amount of money being spent on private health care is increasing, the total percentage of the population that is covered is decreasing.<sup>ix</sup>

A number of factors including cost, physical distance and perceived quality of care influence whether patients use private or public services. More people can afford to use private services for primary health care (PHC). However, private hospital services may be out of reach financially. It may also be that public services are non-existent or non-functional forcing individuals to use private services.<sup>ii</sup>

Most South Africans cannot afford medical aid as the prices are too high. "Even the lowest-cost options still cost between R600 and R800 for a family of four. This is still probably not affordable for families earning less than R3 000 a month."<sup>ix</sup>

Those with more money are more likely to choose private health care as a first option. In addition, the wealthier sectors of the country's population almost all belong to a scheme whereas the poorest cannot afford this coverage.<sup>ii</sup>

Due to the legacy of apartheid, public-private disparities can be broken down into race as well, which is not surprising considering economic situations per household follow the same pattern.

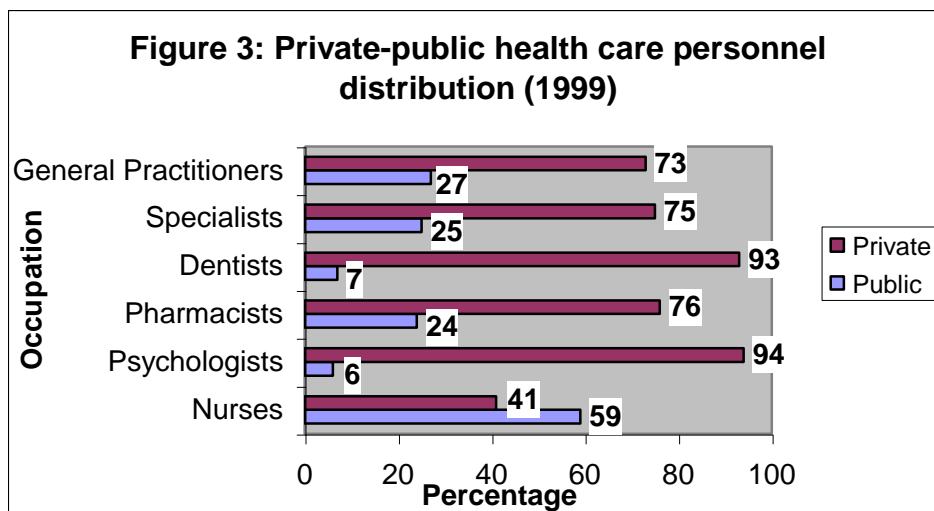


Source: Equity Gauge, 1999

In 2000, per capita health care spending was R779 in the public sector compared to R4 396 in the private sector, almost six times as much.<sup>ix</sup>

This translates into more resources for a small segment of the population. For example, the ratio of available beds to population served in the public sector was 1:349 in 2002. In comparison, the ratio was 1:186 in the private sector.<sup>vii</sup>

However, the biggest difference is the distribution of personnel.



Source: Equity Gauge, 2003

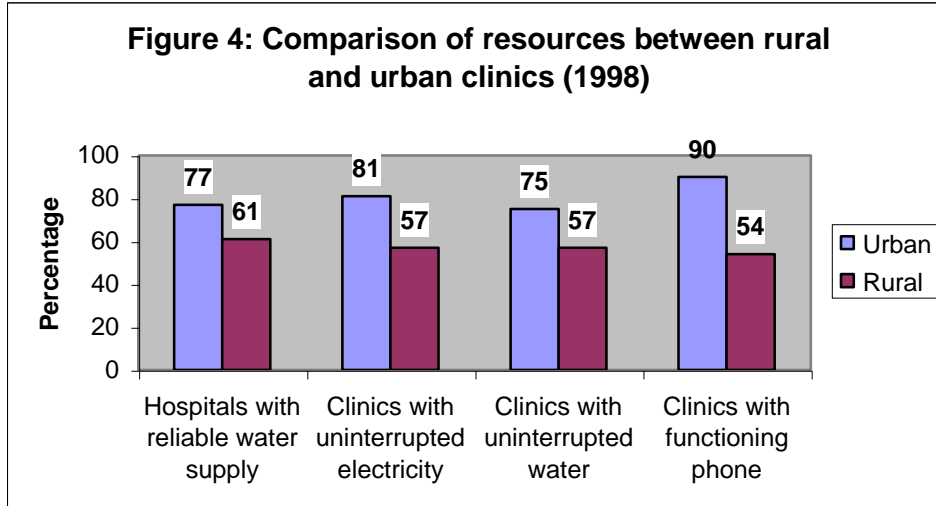
This is one of the clearest demonstration and starkest indictment of the inequity in the current health care delivery system given that the private sector treats a smaller number of people than the public sector. The relative oversupply of health professionals in the private sector seems to be one of the most intractable problems facing the South African health system.<sup>x</sup>

#### **Urban-rural inequities**

In 1996, 46.3% of the population lived in non-urban areas, which include commercial farms, small settlements, rural villages, and other areas that are further away from towns and cities.<sup>x</sup>

The definition also includes semi-urban areas that are not part of a legally proclaimed urban area.

In general rural areas have the least access to services and resources for a variety of reasons including poor infrastructure – electricity and water services – and shortages of equipment.

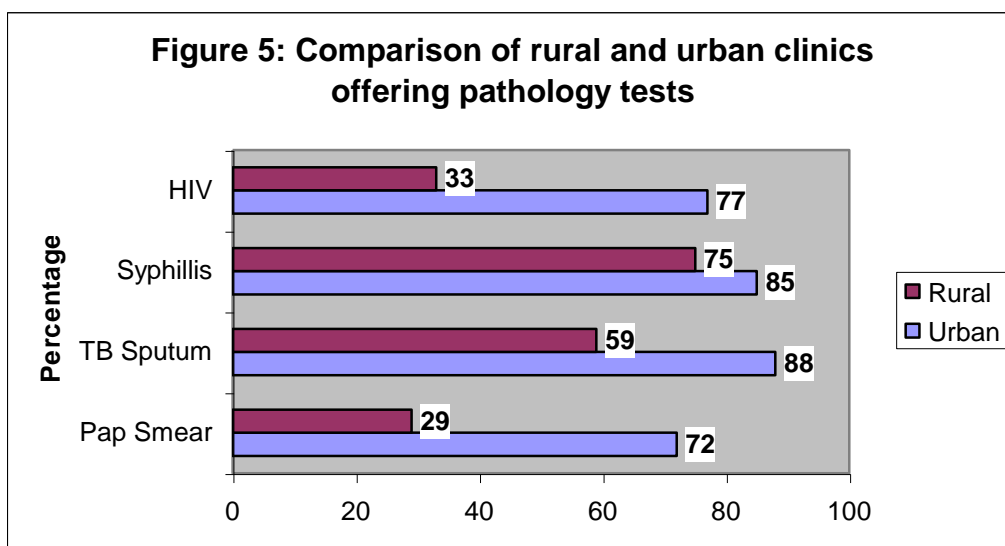


Source: Equity Gauge, 1999; National Primary Health Care Facilities Survey 2000

Insufficient water and electricity can cause severe problems in clinics and hospitals. Electricity shortages mean that equipment doesn't work, proper lighting is not available and medications that need to be kept in refrigerators are not stored properly.

According to the National Primary Health Care Facilities Survey, in almost every single category rural clinics did not receive the services or resources on a par with their urban counterparts. The categories included functioning refrigerators, laboratory tests availability, turn around time for test results, ambulance response times and availability of medication and other drugs.<sup>xi</sup>

In addition, the percentage of rural clinics offering HIV testing and PAP smears is less than half the percentage of urban clinics.



Source: Equity Gauge, 1999



As is the case between the private and public sectors, personnel distribution differences are also a major cause for concern. About 88% per cent of public sector doctors in the country are serving urban areas while the other 12 %per cent serve the rural areas.<sup>ii</sup>

Poverty prevalence in the country has been listed at 40% and unemployment, according to various definitions, ranges from 29.4 to 40.9 %.<sup>vii</sup>

According to one government study, 71% of the rural population is poor compared with 29% of the urban population. In addition, urban households are significantly poorer than those in metropolitan areas like Cape Town and Johannesburg.<sup>iii</sup>

When taken in context, all of these shortages and differences have a direct impact on health care service in a rural setting compared to an urban setting. Most concerning, is that in many cases, people living rural areas have a greater need for good health care than those living in urban areas

### ***Impact of HIV/AIDS***

HIV/AIDS has had a significant impact on communities, families and individuals throughout South Africa and the households trying to cope with the epidemic are being deeply affected.

“It is the poorest South Africans who are most vulnerable to HIV/AIDS and for whom the consequences are inevitably most severe.<sup>xii</sup>

In South Africa the disease has resulted in the burdening and rationing of health care services and their inability to cope with late and end stage HIV disease.<sup>xiii</sup>

In 2002 researchers conducted a survey the impact of HIV/AIDS had on 771 households from across the country.<sup>xii</sup>

The findings included:<sup>xii</sup>

- 22% per cent of children under 15 years in households included in the survey had lost a parent.
- 64% of AIDS-sick individuals in the survey were female. The average age was 33.
- Almost half the households reported having insufficient food at times and that children in these households often went hungry.
- More than 12% of households had sent their children away to live somewhere else, usually with a grandparent or other relative.

According to the survey, those households that were hardest hit by HIV/AIDS were usually the most underserved in terms of basic public services like sanitation and piped water. Only 43 per cent of households in the survey had a tap in the dwelling and nearly a quarter of rural households didn't have a toilet at all.<sup>xii</sup>

Almost half the respondents needed assistance with walking while 10 – 20% needed help with daily tasks like dressing and washing. The most common symptoms were weight loss and pain but chronic diarrhoea was also very common (52 % of cases).<sup>xii</sup>

To this end, doing even the simplest jobs would be almost impossible if a person has difficulty with the most basic of daily tasks. In that context, the household already loses a potential breadwinner.

In 68% of the households a caregiver provided full time care for the ill person and 22% of respondents said there was someone available some of the time.<sup>xii</sup>

More than 40% of caregivers took time off from work or school to care for the ill person, adding to the loss of household income and under-schooling.<sup>xii</sup>

The average AID-sick person was chronically ill for a year before dying.

The households in the study spent an average of 34% of their monthly income on health care. Households spent between R8 and R4 000 per month per household on care, with a median of R250.<sup>xiii</sup> This is significantly higher than the amount spent on health care by non-AIDS households, which spent an average of 4% of monthly income on health care.<sup>xiii</sup>

Overall rural households spent a greater proportion of monthly income – 54% – on health care than urban households – 29%.<sup>xiii</sup>

Rural households utilised local clinics extensively. However, almost 50% of urban respondents had used a doctor in the private sector and 40% used a traditional healer, often with a high degree of satisfaction.<sup>xiii</sup>

Most patients were satisfied with the service they received at public clinics due to the type of care received, health worker attitude and treatment provided.<sup>xii</sup>

Satisfaction of public hospitals was significantly lower, as was general usage of public hospitals. Respondents said the type of care and treatment was the reason for the low rating.<sup>xii</sup>

Respondents were also generally dissatisfied with traditional healers due to the lack of effect the treatment had.<sup>xii</sup>

The researchers concluded that the long-term ramifications of the HIV epidemic are:<sup>xii</sup>

- Deepening poverty among the already poor;
- Disruption and premature termination of schooling for children, especially girls;
- Increasing early childhood malnutrition;
- Increasing strain on extended family networks;

### **PUBLIC PARTICIPATION IN HEALTH - A Theoretical Overview**

Participation of communities is widely argued to be an important aspect of improving health outcomes and the performance of health systems. Despite this, participation is often loosely designed and hardly evaluated for its contribution to health outcomes. Participation takes many forms and reflects varying degrees of community control over decision-making in health systems.<sup>xiv</sup>

**Table 1: Levels and Forms of Community Participation**

<b>Degree</b>	<b>Community Participation</b>	<b>Example</b>
High	Has control	Organisation asks community to identify the problem and make all key decisions on goals and means. Willing to help community at each step accomplish goals.
	Has delegated power	Organisation identifies and presents a problem to the community, defines the limits and asks the community to make a series of decisions which can be embodied in a plan which it will accept.
	Plans jointly	Organisation presents a tentative plan subject to change and open to change from those affected. Expect to change plan at least slightly and perhaps more subsequently.
	Advises	Organisation presents a plan and invites questions. Prepared to modify plan only if absolutely necessary.
	Is consulted	Organisation tries to promote a plan. Seeks to develop support to facilitate acceptance or give sufficient sanction to plan so that administrative compliance can be expected.
	Receives information	Organisation makes a plan and announces it. Community is convened for informational purposes. Compliant is expected.
Low	None	Community told nothing.

**Source: Loewenson, *Putting Your Money Where Your Mouth Is: Participation in Mobilising and Allocating Health Resources*, 2000**

These different levels of community authority depend also on where authority is located within health systems planning, resource allocation, etc., and how far health workers and managers are willing to widen the inclusion of different social groups in decisions that have often been under their control.<sup>xiv</sup>

Despite participation having been accepted in policy for some time, it has not been completely realised, particularly in relation to participation in decision-making. Constraints include:<sup>xiv</sup>

- Poor health worker appreciation of the value of participation
- Poor health worker skills in facilitating community involvement
- Weak methods for re-orienting health workers towards community involvement
- Weak political commitment towards community involvement
- Lack of stable planning structures for joint planning between communities and health services

In addition, communities often lack the 'language', information, cohesion, organisational structures and capacities for effectively engaging in these competing spheres of authority and can become disempowered and distrustful in the process.<sup>i</sup>

It is not uncommon that those with the greatest health needs have the least control over health resources. Therefore, participation should not simply mean more activity within a social group but activity aimed at enhancing control over health resources.

**Table 2: Roles of Participatory Structures within Key Health Processes**

<b>Health Process</b>	<b>Roles of Participatory Structures</b>
Health promotion; prevention and care of illness	Promote primary health care, health awareness and goals Co-ordinate health providers and sectors on agreed health goals Identify and mobilise community inputs in health interventions Oversee the administration of health programmes, including staffing, supplies
Information gathering and exchange	Gather and organise community information for local govt and health system Report to communities and different providers on health policies and programmes Investigate and report on specific health problems
Policy, priority and standard setting	Assess health and health development needs Propose, review and monitor policy goals and strategies Identify and communicate health system and public health priorities, targets and standards Review equity impacts of health strategies
Mobilisation of resources	Raise health revenue (cash, taxes, levies, fees) and resources (food, supplies, labour) for investments in health sector Identify household resource contributions to health and exemption mechanisms Mobilise co-financing and in kind inputs to agreed health programmes from sources outside the health sector Negotiate and propose incentives and subsidies for co-financing inputs Call for tenders for specific areas of work
Allocation of resources	Prepare health development and budget plans Allocate available health resources to health plans and programmes Monitor health expenditure against agreed allocations Monitor resource allocations in relate to equity and efficiency goals Ensure contractual standards are met in private purchasers Negotiate agreements and codes of conduct with health personnel Ensure accounting and independent audit of finances

Monitoring quality of care	Review service performance against health standards and plans Monitor and report on quality of care Review and make recommendations based on client inputs, feedback and grievances on health services Convene public debate and input on health system performance
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**Source: Loewenson, 1999**

In general it has been noticed that partnership between health services and communities depends on an organised demand and contribution from communities that matches their own perceived priorities and a responsive or facilitating health system that is capable of responding to this demand or facilitating this contribution and matching it with meaningful levels of service delivery. Sustained primary health care is essential for building community participation.

**FACTORS IN PARTICIPATION**

A study by Roefs and Liebenberg<sup>xv</sup> found that only 8% of South Africans felt they fully understood the stages of policy making and the legislative process. “With less than one out of 10 respondents saying he or she felt confident about his or her knowledge concerning crucial aspects of policy formation, it seems that the ability to participate in contemporary democratic South Africa is seriously undermined by lack of knowledge.”

Roefs and Liebenberg also found that there is a stated intention to participate in democratic and political processes, actual knowledge of opportunities and process around these are alarmingly low.

**Education**

The study did not show any significant difference between levels of awareness of the policy making process between respondents from rural and urban areas. There were however, provincial differences between levels of understanding and information about local councils, parliament and policy-making processes.

Respondents from Gauteng, the Free State and the Eastern Cape had higher levels of understanding of local councils and parliament than counterparts from other provinces. Northern Province respondents displayed the least amount of knowledge of policy-making processes, parliament and local councils, followed by the Northern Cape.

**Participation**

Participation in policy-making processes was studied in two ways.

Respondents were polled about their intentions to participate in public hearings at various levels of government. In addition, their actual participation in policy-making processes and community activities were also measured. The results showed that there was a general willingness to participate in public hearings, but that incidences of reported actual participation were not as low as expected.

Intended participation and reported participation varied significantly between provinces. Respondents with a better understanding and knowledge of policy-making institutions and processes were more likely to participate. Furthermore, respondents who had relatively more trust in the government reported higher levels of participation. Disparities in living standards were not related to the intention to participate and were only marginally related to reported participation.

Respondents in the Eastern Cape and Mpumalanga showed greater willingness to participate at the various levels. Northern Cape and Western Cape residents seemed to be the least interested in participating. Participation in KwaZulu-Natal was relatively low as well, but this only pertained to provincial and national levels. The intention to join at local level was relatively high among the respondents in KwaZulu – Natal.

The willingness of residents in the Eastern Cape and Mpulanganga residents is a significant finding of the study as these are two of the more under-resourced provinces in the country with high levels of inequity within them.

### **Race**

The intention to participate at local and provincial level was higher among black respondents than among coloured and Asian respondents. White respondents showed the least willingness to participate. The differences between black, coloured and Asian respondents were insignificant regarding participation in national bodies.

### **Participation, Standard of Living and Trust in Government**

Results of the study confirmed that participation in policy-making processes is more likely among South Africans who trust the government than among citizens who do not feel they can trust the government. Results also indicate that political participation is far from an élitist endeavour. A rough categorisation into lower, middle and higher standards of living reveals that those worse off tended to participate more often than those who had a higher standard of living.

### **Issues**

At a national level, the three most often reported issues that respondents would raise at a public hearing were services, the economy, and safety and security. More than 25% of the respondents indicated that services had the greatest priority, followed by economic issues and then by safety and security.

The authors of the report suggest that since respondents most frequently mentioned services when asked about issues to be raised at public hearings indicates a concern over the responsibility of local and provincial government to provide, sustain and enhance basic services in the community.

### **Information**

As knowledge and participation seem to be linked, the survey attempted to establish how respondents and thus presumably the citizenry in South Africa obtained most of their information.

Respondents were asked where they got most of their information relating to political decisions that affected their community. More than half of the respondents (58%) mentioned the media (radio 20%; television 18%; newspapers 85%; other media 16%) as their primary source of information about political affairs affecting them. One-quarter (25%) said that the community was their main source. A further 7% mentioned political parties and 4% local government.

The community played a more important information role in the Northern Province, the Free State and Mpumalanga than elsewhere. Respondents in the Eastern Cape and KwaZulu-Natal, on the other hand, mentioned the media as their most important source of information than other provinces.

The percentage of respondents relying on or receiving information through the Internet was minimal – less than 0,5%. Posters and billboards were only mentioned by 1% of the respondents.

The survey also attempted to establish what people perceived to be the most important organisation/institution to address problems in their community was. The results indicate that community is thought to play an important role in assisting people with problems in their immediate surroundings (30%). Local government came second with 24%.

### **OPPORTUNITIES FOR PARTICIPATION**

Community participation does not have to be confined to one particular area or intervention but can occur at various levels and fulfil a multitude of functions. Community involvement in health can be conceived of as a spectrum ranging from physically assisting to upgrade local infrastructure, to monitoring delivery of health care to engaging in lobbying and advocacy initiatives with political representatives and decision makers.

## **Community Action at a Local Level**

### **Contributions**

Communities have done a variety of things to take action and improve health care in their areas:

- Contribution of labour and building materials to construction of health facilities, waiting mother shelters, etc.
- Contributors of voluntary time to health activities, e.g. care givers, volunteer care workers, community based workers, peer educators, counsellors, etc.
- Contribution of food, transport and other inputs to care giving activities
- Contribution of monthly payments to hire security staff to guard clinics
- Contribution of materials and in kind inputs from businesses to clinic/hospital needs
- Contribution of time and inputs to communal food plots for vulnerable groups
- Contribution of time and household resources to orphan fostering
- Savings for health needs through burial societies and other savings schemes (Loewenson 1999, Loewenson et al 1999a)

### **Community Health Workers (CHW)**

Community-based health workers are community members who participate in health care by providing some limited services within their community.

There are an enormous variety of CHWs, which have been recognized as an important part of many countries' health sectors since 1978. Some CHWs are paid and have been able to make their work a career, but many more are unpaid and have worked as volunteers, driven by their willingness to provide community service.<sup>xvi</sup>

CHWs are important to the health care sector for various reasons, including accessibility by community members, their ability to conduct home visits without abandoning vital functions in a formal health care setting and their ability to link communities to vital resources and services. They also provide a vital service in educating communities about health problems, mobilising communities in identifying community needs and priorities and can also act as agents for change at the same time as carrying out special activities in areas such as HIV/AIDS, tuberculosis, malaria, chronic conditions, nutrition, etc.<sup>xvi</sup>

Some believe that CHWs have not been implemented to their fullest potential and that lack of consistency, lack of coherence and lack of a good CHW model have reduced the effectiveness of these personnel.<sup>xvi</sup>

The creation of a solid and consistent model and standards to make sure that effectiveness is maximized, especially considering how important these people are to the system has been recommended.<sup>xvi</sup>

However, community health workers should not be seen as an alternative to formal health care services but rather as complementary to the formal health care setting.

In the context of scarce resources, the HIV/AIDS epidemic and the limited impact of health services in the most needed areas, it is submitted that CHW have a significant role to play in raising the health of poor communities.

### **Monitoring**

Communities also have an important role in monitoring the delivery of health services in their areas. This could take the form of ensuring that opening and closing times are adhered to, unauthorised user fees are not charged and that provisions of the Patients' Rights charter are complied with. Results of such monitoring actions could either be fed to clinic/hospital committees, high ranking departmental and ministry staff, MEC's and other members of parliament. The use of the media (local newspapers) in highlighting poor delivery can also be explored.

### **Community Action at the Legislative Level**

Community groups have a vital role to play in contributing to the legislative process. Too often, policies and legislation are created with little consideration of how these could operate at a practical level. Community input in the form of how proposed legislation and policy would affect them is vital if the current chasm between policy development and implementation in South Africa is to be bridged.

Policy, legislation and implementation need to be distinguished.

Policy is a stated commitment to a course of action. All laws must be based on public policy. However, not all policies require a law. According to the 2002 Health Review<sup>ix</sup>, health policy, legislation and implementation should be guided by efforts to:

- Take steps to progressively realize the rights of everyone to have access to health care services;
- Promote and protect the right of children to basic health care services;
- Ensure that no-one is refused emergency medical treatment;

The following steps usually occur in policy making.

If the problem is health related, the health department will come up with a proposal for policy on the issue. The department may draft a Green Paper and publish it in the Government Gazette for the public (if the Bill is being introduced at the provincial level it appears in the Provincial Gazette). The Centre for Public Participation describes this as the “thinking aloud.” Stage. The Green Paper is also circulated to specialist interest groups for their input.

After it has received submissions from the public and consulted those who have an interest in the policy, the government will often publish a White Paper, which is essentially a statement of intent. This is the final policy from government on the issue or problem. Again the paper is published in the Government Gazette and distributed for comment. Once again, there is debate and consultation between the department concerned and interest groups.

The Green and White paper stages are considered the most important stages for lobbying as they come early in the legislative process. Between the Green and White Paper stages public hearings are normally held.

If the White Paper suggests that new laws should be drafted or existing laws amended, a draft Bill will be developed to this effect.

Bills are drafted by the Minister of Health (or her representatives) before being submitted to Cabinet. If Cabinet agrees to the Bill it is introduced to Parliament where it is referred to a Committee in the National Assembly (NA) or National Council of Provinces (NCOP) for consideration – depending on whether the Bill will affect provinces or not. In the case of a Bill relating to health matters, it will go to the Health Committee.

Meetings of the Health Committee are open to the public and press. If there is a lot of interest in the Bill, the Health Committee will hold public hearings or ask the public to make submissions. However, even if the Committee does not actively involve the public, everyone has the right to write to the Chairperson of the Committee or any of its members.

The Bill will also be published in the Government Gazette while it's before the Health Committee. People wishing to make submissions have three weeks from the date the Bill is published in which to do so. This is a critical stage for public involvement.

The public can also make presentations and submissions at committee meetings. The procedure of the meeting is as follows:

- An introductory discussion takes place;
- Public submissions are heard;
- The principle of the Bill is debated;
- A clause-by-clause debate follows;

After the Committee has finished its work the Bill goes to the National Assembly to be debated by all political parties. If there are any changes that need to be made it goes back to the committee for further consideration and to deal with the proposed changes. This can occur several times.

When the NA has no further changes it wants made the Bill is voted on. If passed it goes to the NCOP where a provincial Health Committee follows the same process. Again the public has the chance to comment on the bill while it is in front of the Committee.

If both the NA and the NCOP agree, the Bill is passed and goes to the President for signing. If the NCOP disagrees with the NA, a mediation committee must try to solve the disagreement. If this fails, the NA can send the Bill to the President for signing if two-thirds of NA members vote in favour of it. Otherwise it falls away.

A Bill becomes law when it is signed by the President and declared official in the Government Gazette.

The Centre for Public Participation<sup>xvii</sup> urges that the earlier interested parties get involved the better so it's important to be aware of policy changes. It suggests trying to influence the process as soon as government starts to consider the idea since it is hard to get policy changed when the issue gets to parliament as the majority party will usually have already made up its mind on the subject.

### **Green Papers and Discussion Documents**

This is the time to undertake serious research, to formulate an alternative position, make a submission to government, plan a media campaign, ask the Minister responsible for a meeting and to begin networking with like-minded individuals and organisations.

### **Committee Process**

When a Bill is tabled, a public hearing should be sought in which the parliamentary committees dealing with the issue hear submissions. This is probably the last chance to get a law or policy changed. In preparing a submission it is important to be familiar not just with the committee as a whole – especially its style and way of doing things – but also with the key people within the committee. Most of the parliamentary committees have an inner group of experts who are particularly interested in the portfolio covered by the committee. It is essential to keep in touch with them so that they are clear about your arguments and proposals.

### **Parliamentary Debates**

Snap debates offer a unique point of intervention. Parties that want a snap debate on a current issue may ask the Speaker to allow this. Any MP may introduce a motion for a snap debate in the House. If you can identify an MP to 'champion' your cause and you brief him or her effectively, getting that MP to initiate a snap debate can raise the profile of the issue. Such a debate is a useful instrument in attracting public and media attention to an issue.

### **Parliamentary Questions**

Asking ministers questions or summoning them to appear before committees can be a powerful way of keeping them accountable. Interested parties should request MPs to ask questions of ministers during parliamentary sessions.

One thing to consider is the fact that more than 50 per cent of South Africans live in rural areas. Historically these areas have been neglected by government and as a result are marked by low levels of literacy, skills and scarce resources. In addition, transportation and communication problems hamper lobbying and advocacy efforts for residents in these areas.

However, there are several NGOs and university-based legal service providers who can be approached to help rural-based communities participate in consultations on legislative processes. They can also help rural communities make representations to parliament.

In addition, NCOP is planning on holding sittings on a rotating basis in each of the provinces in a variety of venues in an attempt to drive up awareness and accessibility.



Monitoring government processes is just as important as influencing policy development. The purpose is to measure the performance of government against its stated policies and the needs and interests of the public.

The best way to do this is include:

- Asking questions;
- Writing letters to and arrange meetings with elected representatives;
- Litigation;
- Analysing trends that monitoring exposes;
- Listening, making input and seeking feedback wherever there is an opportunity for participation;
- Recording the key points and decisions at all meetings;
- Keeping a record of all the key people who are in a position to influence the outcome of the campaign;
- Reporting and publicising poor service delivery and policy problems;

### **COMMUNITY ACTION AND ADVOCACY**

While taking part in clinic committees, working as a community volunteer and participating in the legislative process in government are all viable ways of enacting positive change, active advocacy in the form of protest and lobby groups and campaigns are another usually much more visible way of initiating change or calling attention to an issue.

Lobbying and advocacy is generally seen as the preserve of well educated, politically connected organisations. However, decision makers generally take heed of advocacy and lobbying initiatives that are more rooted in the practical experiences and realities of ordinary people than by organisations and grouping driven by donor or political agendas.

Lobbyists need three things: a few basic facts, a belief in a cause and some common sense. The lobbyist does not have to be an expert, he or she simply needs to know the objective, the content of the law or policy being proposed or opposed, and needs to be clear of its importance.<sup>xvii</sup>

Lobbyists need to contact people in power and:<sup>xvii</sup>

- Identify what should be changed and why
- Offer alternatives
- Gather information to support demands
- Join with others who share the same view
- Seek the support of people who might be able to influence policy
- Identify organisations that are likely to support and oppose the idea
- Draw up and carry out plans of action

In contrast there are several steps to forming such an advocacy group. There are no strict rules for advocacy and the best step depends on the group's objective, on the people the group wants to influence and on the political and cultural environment. The approach to an MEC in the Western Cape will not be the same as to an iNkosi in KwaZulu-Natal.<sup>xvii</sup>

The Centre for Public Participation's *Advocacy for participation in governance* training manual says (2003) there are a number of stages that can be followed:

#### **Stage 1: Issues and goals**

The process begins by identifying issues that require policy change. The next step is to decide on a goal or objective for the campaign. This must be clear before deciding on how to advocate. The objective must be specific and measurable.

#### **Stage 2: Developing solutions**

Rather than simply complaining about a policy or law it is better to provide alternatives. It will make the case stronger. NGOs, CBOs and religious bodies often feel their cause is just so

they do not need facts and figures to support it. This makes it easy for those in charge to dismiss them.

Facts and figures are needed to provide proof for what the group is trying to do. Voices from those affected are also needed. Sometimes expert or specialist evidence is required to make the case stronger. However, this is not always necessary.

It is also important to identify people or organisations who may be against the group. Efforts may be made to try to persuade them to change their views or arguments against them will need to be prepared.

### ***Stage 3: Building political support***

Once issues have been identified and an objective is chosen it's time to get people to join the group. There are many ways to do this:

- Building coalitions
- Meeting with decision-makers
- Building awareness among anyone who can help influence decision-makers

It is also important to identify who the group is trying to influence. While it is important to have wide support, the purpose is to target the people and organisations or groups that can influence the decision in the way the group wants.

### ***Stage 4: Turning support into action***

There is a huge range of possible campaign strategies, all of which will depend on the group's objective and audience. For example, if the main obstacle to policy change is ignorance or lack of awareness, an information campaign using media and public forums may be necessary.

Steps to begin:

- Writing to an MP or local councillor
- Placing a newspaper advertisement or writing a letter to the editor
- Holding a public meeting

If this does not garner a positive response alternatives include:

- Asking for a private meeting with the relevant stakeholder
- Persuading the opposition party MP to ask a parliamentary question
- Sending a written submission to parliament
- Asking for a public hearing in parliament

If broader support is needed people could consider:

- Selling t-shirts supporting the campaign
- Getting the support of the NGO Coalition
- Getting public commitments from support of high-profile people
- Organising letter writing or post card campaigns
- Submitting petitions
- Holding rallies

If the issue is becoming urgent and the government is about to make a decision that rejects the case, the following could be tried:

- Organising mass pickets, boycotts or demonstrations
- Organising a strike in support of the campaign
- Civil disobedience – breaking the law in a non-violent way in order to attract attention to the case.

Advocacy and lobbying are not once off activities. They are processes designed to build up long-term relationships with people who make and influence policy. Feedback and reports on the effect of new legislation or policy is also useful to give government an idea of the (positive) effects of the change.

### ***Stage 5: Evaluating policy action***

It is important to monitor progress and achievements of the advocacy process. In addition, celebrating victories and understanding defeats is an important component of the advocacy process.

### **COMMUNITY ACTION AND LITIGATION**

As previously indicated, the justiciable nature of the South African Bill of Rights means that people can always turn to the courts for assistance in claiming their rights. While legal recourse is an excellent vehicle for accessing rights, legal victories have their limitations and might not necessarily result in the immediate change of circumstances that people are looking for. Rather, decisions coalesce to form a cumulative body of case law over long periods of time and communities who turn to the law might be disillusioned. For example, the people of Wallacedene (Grootboom case) are still living in poverty and very little has changed for them despite their legal victory.

In addition, the courts have emphasised that the state has a progressive duty to provide rights within its available resources and generally assess governmental initiatives within the framework of whether these are reasonable or not. Since 1994 there have been several court cases which have served to add to the normative content of the right to health care. These have thrown light on the concepts of "available resources" and "reasonable measures" as named in the Constitution.

In the *Soobramoney* case, the Constitutional Court held that the scarcity of resources available to the government was a constraint to the enjoyment of the right by the appellants, given the socio-historical context of South Africa.

In the *Grootboom* case the Constitutional Court defined the parameters of what constitutes "reasonable measures". In addition to these, it concluded that measures that do not include meeting the needs of the most vulnerable groups in society, were unreasonable. Furthermore, it was stated that implementation plans that failed to be "reasonable" would not meet the government's obligations.

Another important case dealt with the prevention of mother to child transmission of HIV in which the Treatment Action Campaign (TAC) requested that the anti-retroviral drug, Nevirapine be made available to all HIV positive pregnant women in the public health sector. In this case the Constitutional Court upheld the High Court order to make Nevirapine available to all HIV positive pregnant women. This judgment is of great significance given the high prevalence of HIV/AIDS in the country and the growing number of AIDS orphans. Despite this ruling, Nevirapine is still not provided in all state hospitals – highlighting once again the limitations of litigation as a legal strategy.

Notwithstanding the limitations of litigation, under the right circumstances, this can be a highly effective strategy. There are many human rights organisations offering technical and legal assistance to communities wanting to resort to court action (eg: Legal Resources Centre, Black Sash) that can be approached for advice, guidance and representation.

### **FACILITATING COMMUNITY ACTION**

Roefs and Liebenberg<sup>xv</sup> made a number of recommendations relating to what the government can do to improve participation in the legislative process.

#### ***Access to Proposed Legislation***

The public should be provided with executive summaries of each bill and policy paper in an easily accessible and crisp format to enable them to grasp the contents and practical implications of the proposed legislation.

The findings of this survey suggest that such information should be communicated primarily through the radio (local, provincial and national), followed by television (preferably national television), and newspapers. The findings of the study suggest that these media are far more effective than posters and websites. Posters and the Internet seem to be unattractive options for respondents. The multitude of posters that still adorn South Africa's streets, often illegible

and poorly designed, may cause information overload and reader aversion. Moreover, whereas state officials and academics may have access to the Internet and websites, few citizens have access to them. The survey also suggests that provincial differences in knowledge and information sources need to be taken into account. This implies that provinces and provincial stakeholders should adapt their communication and information (education) strategies to the citizenry in their particular region.

### ***Formal Education***

Various theorists and observers regard education for the citizenry on the functioning of the state and state processes, inclusive of public institutions, as very important. Education increases awareness and understanding of state structures, institutions and processes. It is suggested here that education around the composition and functions of such structures should be included in secondary school curricula. Citizen education, if formalised within the educational system, is likely to advance understanding as well as knowledge, and will foster the will to participate in state functions, which may ultimately manifest in active participation in and the sustainment and deepening of democracy in South Africa.

### ***Involvement of Civil Society***

Civilian organisations should be drawn into the law-making process at national, provincial and local level at an early stage so that their inputs have a bearing right from the start. Early and timely invitations to participate are crucial.

### ***Responses to Submissions***

Previous reports suggested that protocols be established to guide national and provincial legislatures in responding to submissions from the public. This study showed that there was a strong overall intention to participate in policy processes among the respondents, regardless of the political parties to which they belonged. This strong interest should be translated into active involvement to add value to public participation in democracy in South Africa. Apart from giving written feedback to organisations, groups, civic structures or institutions on whether their submissions have made an impact upon the legislation (and to what extent), broader feedback should be given to the public in general by means of the radio, the print media and television. Talk shows and phone-in programmes on radio and television could be used to good effect in addition to more formal feedback via news and/or actuality programmes. National, provincial and local authorities (elected representatives) should also ensure that communication is thorough and effective by evaluating their feedback to their constituencies.

### ***Focus on Issues***

The survey showed that an issue-based approach was effective in attracting people's interest and involvement in the law-making process.

Respondents provided information about the issues uppermost in the public's mind. It follows that they would rather participate in activities that address and resolve such issues, than in those that they do not consider important. Therefore legislatures at various levels should be aware of the concerns of their constituencies when providing feedback and/or inviting participation.

### ***Constituency Offices***

The role of constituency offices is to inform the citizenry about political parties and law-making processes. The opinions and "street wisdom" of elected representatives to national and provincial parliaments suggested that parliamentary constituency offices were important. However, only 9% of the respondents in this survey indicated that they made use of constituency offices.

Parliamentary constituency offices should therefore be redefined as vehicles for improving public participation in governance. This would include setting standards for the training of staff, defining the functions of constituency offices, and getting clarity about who is served by these offices. It may be best to centralise the development and management of such offices as well as the training of staff. Constituency offices need to provide links with the communities in their particular areas. They need to be seen as forums where the public can

articulate local interests, and where the general public is being exposed to information about legislation and government policy at national, provincial and local levels.

To fulfill their purpose, constituency offices should embark on effective communication on their role and how this role relates to the needs of their constituencies. This should be done through the relevant media.

The media, especially the radio, should be used more effectively in public participation programmes, e.g. the broadcasting of parliamentary deliberations, and phone-in radio programmes. Newspapers could have dedicated columns to inform and educate the public about new legislation and the process of participating in policy formulation and the legislative process. Moreover, regular feedback is essential. Constituency offices can be a useful information and communication tool. However, this study seems to indicate a need to popularise constituency offices and enhance their efficiency through benchmarking and performance evaluation, although the approach may have to be adapted to the particular province. It is perhaps also appropriate to consider the regulation of constituency offices through legislation. Their exact roles need to be defined to ensure that they serve their constituency as a whole and that the resources are optimally utilised. Training programmes and refresher courses for staff in such offices should become an entrenched practice.

### ***Disadvantaged Groups***

The recommendations so far can primarily be realised among so-called “literate” people, i.e. people able to read, and people who have access to the radio and television. People with little formal education however not be excluded from public participation. The survey revealed that the intention to participate in political processes was high overall, thus including poor and rural dwellers, - those sectors who are most likely to be illiterate and without access to radio and television. Other means of communication should therefore be employed to reach such groups, for example, audio-visual media, theatre and creative workshops. More resources should be allocated to the arts, for example street theatre, to overcome language and literacy barriers in communication between communities and government. The popular media can assist in highlighting, explaining and debating complex issues around governance. “Road-shows” by government departments, political parties and other stakeholders may also enhance communication — especially in rural areas or smaller towns.

### **VOICES OF THE HEALTH CARE WORKER**

Health care workers are the first line of the health care system and as such are exposed to a variety of experiences and environments. The South African health care system has a cadre of dedicated individuals who are energetic and enthusiastic about their responsibilities and motivated by a commitment to the public sector and the desire to serve people.

One of the most crucial aspects of health care provision is the relationship staff have with patients and communities. Patients respond positively to attention and encouragement. Good interaction between health care workers and patients/communities improve user satisfaction, utilisation, patient compliance and willingness to participate in service delivery. In addition, health worker morale is boosted by appreciation, and recognition. However, for many reasons doctors do not have the time, energy or desire to form close relationships with patients and communities and this has the opposite affect. In addition, relationships between colleagues are important to maintaining a common vision and improving service delivery. Effective service delivery depends on how well the health staff and users are operating as a team.

While it is important to listen to the concerns and complaints of frontline health care workers, such initiatives should guard against portraying these people as adversaries rather than partners. Health care workers work under extremely difficult conditions and do not have control over the allocation and distribution of resources they need to execute their jobs effectively. Anger at decisions taken by high-ranking government officials and poor management of the health care system is sometimes directed at frontline health care workers who have no power or avenues to challenge or change the situation.

In an attempt to chronicle the experiences of frontline health care workers, the Health Systems Trust staff conducted interviews with 11 nurses, six doctors, nine pharmacists, eight administrative clerks, and eight environmental health practitioners in 2002.<sup>xviii</sup>

Although the views expressed cannot be generalised to health workers in the country, by interviewing real people the idea was to bring to life the variety of subjects, concerns and stories that these people experience every day.

The main themes outlined were: training; working environment; facilities, infrastructure and resources; HIV/AIDS.

### ***Training***

The initial training of PHC workers, particularly nurses, does not address real day-to-day needs and challenges such as: cultural diversity; community mobilisation and participation; community data collection analysis; interpretation and utilisation; problem solving; integration of PHC services; inter-sectoral collaboration; co-ordination.

Workers also cited restricted access to training and the failure to fully utilise their skills due to lack of resources, heavy workload and poor facilities. In addition, many health workers are experiencing stress because their training has not prepared them to perform the tasks that their jobs entail. A heavy workload also prohibits workers from being able to participate in training opportunities.

### ***The Working Environment***

A number of areas were cited as areas of concern for health care workers.

### **Transformation**

The government and the health care sector are constantly changing in an effort to battle inequities and create a viable system for the country. While these changes are usually necessary, continuous and ongoing transformation has sometimes impacted negatively on quality of care and staff morale and knowledge. It is not uncommon for staff to be confused on what practices are being followed and what regulations have been put in place.

### **Roles**

Due to the shortage of other health professionals, nurses are expected to perform multiple roles. They can work in any number of capacities including social worker, pharmacist, administrator, and physiotherapist and even do some of the duties of a doctor. The multiplicity of roles can be a source of job dissatisfaction and curtail professional growth.

### **Workload**

Due to severe doctor shortages throughout the country, the brunt of the workload is placed on a smaller number of staff. A common consequence of unmanageable workload is stress, which results in low morale, rapid turnover of staff, and worsening of service delivery. It also impacts on interpersonal relationships.

### **Security**

The South African health sector is amongst the highest incidence of violence in the world. Recent research indicated that 61 per cent of surveyed health sector personnel had experienced at least one form of violence in the past year. Women are especially vulnerable. Nurses are three times more likely to experience violence in the workplace than any other occupational group.

### ***Facilities, Infrastructure and Resources***

Since 1994 a vast number of facilities, specifically clinics, have been built and infrastructure at many clinics has been improved. However, frequent breakdowns of equipment, electricity interruptions, lack of transportation and lack of sanitary water create huge problems. In addition, lack of space and shortages of medicine and even basic equipment like gloves and stethoscopes were highlighted.

### ***HIV/AIDS***

Surprisingly many health workers were silent on the issue of HIV/AIDS. This could be because of feelings of hopelessness, lack of skills in counselling and palliative care, stigma

and burn out as a result of having seen too much suffering. However, some worried that their efforts weren't making a difference.

### **Other staff**

Besides the interviews with health care workers, HST staff interviewed service users, policy makers and public health managers for the 2001 Health Review. While parliamentarians and managers were optimistic and dedicated, the sheer number of challenges facing them as they struggle to transform South Africa's health care sector into a viable system has created its own problems.

Users complained of overcrowding, long waiting times and limited hours of service, which are symptoms of under-resourcing.

For managers, job satisfaction was associated with factors like teamwork, good staff relationships, accessible management, recognition and affirmation of efforts and peer support. Sources of frustration were understaffing, heavy workload, limited physical space, poor remuneration, inadequate support from respective districts and arbitrary and unexpected summons to attend meetings.

In light of the above, it is crucial that any portrayal of the public health care system also reflects the difficult and challenging circumstances under which frontline health care personnel work.

### **COMMUNITY INVOLVEMENT – A survey**

In a survey of the dynamics surrounding community involvement in health, Friedman and Hall<sup>xix</sup> found that there was no single or uniform way in which community involvement evolved at the various clinics involved. Rather, 'every clinic reported some form of community involvement. In understanding this it was important to explore how community involvement started.'

The following is an excerpt of the survey findings.

"The most common way in which community involvement started was when nurses began to encourage the community to volunteer. They began to create roles within the health service for voluntary workers of different types. Some volunteers helped in the clinic, others in the community with providing support for example with the DOTS programme. One of the special groups of volunteers, the Village Health Workers were recruited to work with communities. They themselves started community projects in the communities in which they were volunteering. An important element was the involvement of the leadership in the community, both the traditional leaders as well as elected councillors. It also involved recognition of some important roles that people were already playing in the community, such as that provided by traditional birth attendants.

Not all initiatives for community involvement came from health personnel. In a few clinics it was the people themselves that recognised the need for a service closer to them, combined with their willingness to raise funds for the erection of a clinic or the extension of a service. In one community there was even the willingness of a community member to transport nurses for outreach activities. The recognition of the need for additional services in the community was sparked by various issues, but not least because of concern with the poor nutritional status of children and increasing HIV/AIDS in the community. In one case it sprung from dissatisfaction with the lack of medicines at the clinic.

Community involvement activities in its own right created further interest. This occurred in various ways, including holding meetings with the community, for example to create increased awareness about TB to engaging youth days which led to much greater involvement. A further useful strategy was to determine priorities, and thereby securing their support and involvement.

<b>How community involvement started</b>	<b>%</b>
Village Health Workers recruited who then worked with communities	20
Nurses wanted to teach self-reliance/encourage community	20
Creating roles for voluntary workers e.g. in the clinic; DOTS support etc	20
Involvement of counsellors and traditional leaders	20
Recognition of the value of traditional birth attendants who were supported	13
Need for a service closer to the people; community wanted a local service	13
Fundraising for the erection of a clinic/provision of the service	13
Establishment of a clinic committee elected by the community	13
Concern with increasing HIV/AIDS in community led to interest	7
Concern with poor nutritional status of children	7
A community member was willing to transport nurses for outreach	7
Engagement with key figures who helped identify priorities and gave help	7
Holding meetings with the community	7
Youth organised health awareness days	7
Nurses need for people to be more aware of PTB	7
Dissatisfaction with the lack of medicines at the clinic	7

**Source: Friedman I, Hall, W *Evaluating Community Participation in Health in Mount Frere – a rural area of the Eastern Cape* [unpublished paper]**

#### **Factors contributing to success**

About a third of the participants thought that the most important factors contributing to the success of community involvement was the motivation and encouragement of the community by nursing staff. Important in this was both a good attitude and approach in engaging with the community. Other important service factors included offering health education sessions, providing information, using the clinic as a venue for community meetings and allowing the community to hold their own health meetings at the clinic.

The provision of a free service, readily accessible medicines and the government's building a clinic were also felt to be important.

Some of the participants mentioned specific aspects of the how the clinic provided its services as instrumental in achieving successful community participation. For example when the staff of one clinic showed their willingness to share their problems with the community rather than hiding them. Or in another example, when the commitment of the staff to improving the service showed through their willingness to make small sacrifices such as working through lunchtimes or even overtime. Offering privacy and immediate referral if its was needed was felt by at least one of the participants as a critical factor.

Active health promotion, both in regard to HIV/AIDS, immunisation through campaigns and health awareness days also helped to develop community participation, and so also did publicising the Patient's Charter and encouraging feedback by means of a suggestion box.

<b>Factors contributing to success</b>	<b>%</b>
Motivation/encouragement of nursing staff	33
Good attitudes/approach of the nursing staff	33
Providing health education/information	27
Providing a venue/holding meetings at clinic	20
Providing free services/medicines	20
Government's building of a clinic	13
Community volunteers	7
Free availability of drugs made accessible	7



Staff sharing their problems with community	7
Promotion of an HIV/AIDS programme	7
Campaigns, e.g. EPI where VHWs helped	7
Health awareness days	7
Improving service; privacy, immediate referral	7
Willingness of staff to sacrifice. Egg lunchtimes, overtime	7
Publicising Patient's Charter; providing suggestion box	7

**Source: Friedman I, Hall, W *Evaluating Community Participation in Health in Mount Frere – a rural area of the Eastern Cape* [unpublished paper]**

#### **Community factors contributing to success**

More than a quarter of the nurses participating in the study felt that the most important community factor contributing to success was good human relationships, and a willingness to participate.

A range of other factors were also involved

- Leadership for example was important, both formally from traditional leaders mobilising their community to use services as well as from the informal enthusiasm and high motivation of ordinary community members.
- Community willingness to provide venues for outreach services or to transport nurses, to provide funds, to look after the clinic, to attend regular meetings, to volunteer as VHWs or DOTS supervisors and to motivate other members in the community. Direct participation of community in health promotion activities that contributed to success was participation in organizing or talking at the clinic or using entertainment such as drama or music as vehicles for health education.
- Understanding patient's rights and having pride in the heritage of their area and clinic were important. Participation by stakeholders from outside the area was often a source of inspiration
- Some of the success factors related to community members own need to generate income or produce, particularly after seeing other community members as being successful

<b>Community factors contributing to success</b>	<b>%</b>
Good human relationships	27
Community willingness to participate.	13
High motivation of some community members	7
Seeing other members with communal gardens	7
Great priority to generate income	7
Willingness to transport nurses to outreach clinics	7
Using entertainment for education. Egg. Drama, music	7
Community participate in organising and talking at clinic	7
Participation of stakeholders from other areas	7
Regular meetings; willingness to attend	7
Community willingness to provide venues for outreach services	7
Community willingness to provide funds for outreach services	7
Community willingness to look after their clinic	7
Community willingness to volunteer eg.VHWs, DOTS supervisors	7
Traditional leaders mobilising community to use services	7
Pride in the community about its heritage and clinic	7
Understanding of patient's rights	7

**Source: Friedman I, Hall, W *Evaluating Community Participation in Health in Mount Frere – a rural area of the Eastern Cape* [unpublished paper]**

***Obstacles hindering success***

As with many other aspects of primary health care, forty percent of the participants felt that the long distances of people from the clinic or poor access due to roads or unfavourable geography combined with a lack of transport or an inappropriate vehicle were the greatest obstacles to achieving successful community participation.

Some of the obstacles related to the state of the services, such as shortages of medicines in the clinic, being short-staffed and hence staff being unable to attend community meetings, telephones being out of order in the clinic and generally inadequate channels for communicating with the community.

Other obstacles related to physical difficulties in the community, which as already mentioned included geographic barriers such as rivers being flooded in summer months, but also included poverty, inadequate communication facilities and the need to attend to ploughing or hoeing in the growing season.

Besides these several other more social and psychological factors were involved such as lack of confidence, misinterpretation of health rights, illiteracy and adults not wanting to talk about sex.

<b>Obstacles hindering success</b>	<b>%</b>
Long distances from clinic; poor access	40
Lack of transport/ appropriate vehicle	40
Bad roads	27
Lack of incentives for VHWs	20
Community lacking knowledge, information or interest	20
Hoeing and ploughing season	13
Shortages of medicines/drugs in clinic	13
Lack of motivation of some community members	7
Physical barriers e.g. Rivers often flooded in summer	7
Adults not wanting to talk about sex	7
No communication facilities within the community	7
Illiteracy	7
Misinterpretation of health rights	7
Poverty	7
Lack of confidence	7
Telephone out of order in the clinic	7
Poor communication	7
Clinics being short-staffed; unable to attend meetings	7

**Source: Friedman I, Hall W. *Evaluating Community Participation in Health in Mount Frere – a rural area of the Eastern Cape* [unpublished paper]**

***Benefits of community involvement***

Nearly half of all the participants saw the good rapport between community and clinic nurses as the main benefit of community involvement. But many also saw benefits in the increased range of services that could be offered, as for example in traditional birth attendants (TBAs) delivering some babies, improving the DOTS programme, or VHWs following up TB defaulters, providing education, transferring people to clinic, improving geriatric care and finding additional children to be immunized. This led to increasing rates of immunisation.

There was the view that this was leading to decrease in deaths among the under 5s from diarrhoea and measles as well as a decline to malnutrition. The more appropriate use of medicines was leading to fewer shortages of drugs at the clinic.

As a result, the community feel part of the health system and staff feel that they can appeal to the community to solve problems, such a break in at the clinic.

People were feeling much more free to talk to staff about HIV/AIDS, with better reporting of problems, improved dissemination of information. Condom use was increasing amongst the youth. With greater community awareness, disease outbreaks were reported.

A clinic had been built. There was a faster service at the clinic and the quality of people's lives was improving."

<b>Benefits of community involvement</b>	<b>%</b>
Good relationship between community and nurses - good rapport	47
TBAs. Egg. deliver some pregnancies	20
VHWs egg. To follow-up on TB defaulters, find additional children to be immunised	13
Improved awareness of and use of use condoms, especially among youth	13
Improved access to services & care e.g. immunisation	13
Identification of DOTS volunteers	13
Decrease in deaths among under 5s from diarrhoea & measles	13
More appropriate use of drugs – fewer shortages	13
People feeling free to talk about STDs, HIV/AIDS	7
Improved geriatric care	7
Dissemination of information on health	7
Community feel free to report problems	7
Gradual improvement in the quality of life	7
Greater community awareness - disease outbreaks reported	7
Building of a clinic	7
Decrease in malnutrition e.g. kwashiorkor	7
Community feel part of the health system	7
Clinic staff can appeal to community to solve problems; e.g. Break-in at clinics	7
Faster service	7
VHWs provide education and help to transfer people to clinic	7

**Source: Friedman I, Hall, W Evaluating Community Participation in Health in Mount Frere – a rural area of the Eastern Cape [unpublished paper]**

## **SOME EXAMPLES OF COMMUNITY ACTION AND SOLUTIONS**

### ***The Mntwana Clinic***

The Mntwana Clinic initiative in Mount Frere<sup>xx</sup> serves as an example of how community action can improve health services at a local level. The Mntwana Clinic serves 9 locations which comprises approximately 20 000 people - the area is characterised by deep poverty and severely underdeveloped infrastructure. Most communities live in small villages or locations scattered over the hillsides. Access to health care is obfuscated by poor roads, lack of suitable vehicles and long distances to the clinic.

Supported by the Health Systems Trust (HST), a clinic committee comprising political structures, key community members, non governmental and community based organisations, traditional and spiritual leaders was formed. Members identified the key health needs of the area served by the clinic and developed a plan of action to address these needs.

The clinic committee collected R10 per annum from every household which was invested in a savings account and used to purchase equipment like a Blood Pressure (BP) machine,

paying an honorarium to voluntary night watchman who watched over the clinic at night. Funds were also used to build a waiting room at the clinic, buy benches and to pipe water to the clinic. The latter proved to have been a fruitless exercise as the local reservoir is out of order.

The committee also articulated the community's need for a mobile health service. Monies (ranging from 50c to R2 per person) were collected from the area to be visited which was then used to pay the transport costs (a hired van or bakkie) of the nurses to the area. Voluntary community/village health workers assist the nurses by taking temperatures, blood pressures, weighing children, urine testing and other routine tasks for which they have been trained.

As a result of the community's initiatives, the quality and coverage of health services were improved.

The Mnwana example however, does provide a few important caveats. Firstly, while community donations/contributions might have played an important role in upgrading the quality of the health service provided, this model must not be seen as completely desirable especially in contexts where people live in grinding poverty and the contribution of even a minimal amount of money might be prohibitive. Secondly, while community donations might play a crucial role in delivering basic services to a (usually poor) community, the state should not be simply absolved of its responsibility to provide such necessities. There needs to be a balance between communities taking short term measures to ensure that they contribute to an improved health service and sustained action and monitoring to ensure that the state delivers on its responsibilities.

### ***Clinic committees***

In 2001 the people of Chesterville decided to establish a clinic committee to meet bi-monthly or when an urgent need arises and discuss problems together with the clinic's management. As Sizwe Shezi, an HST member who recently joined the committee as an advisor, said<sup>xxi</sup>, the community felt the clinic was not rendering a good service to the public and they, as the community, needed to do something to correct that.

According to Shezi, the committee has managed to: raise awareness about health and health care delivery; bridge the gap between the clinic as the service provider and the community as the consumers; establish good working relationships with community structures and leaders; open communication channels between all clinic stakeholders; empower community members to ask questions about their health rights.

There were some significant challenges to getting the committee up and running including the following: convincing the community of the need to play a role in their health care delivery; convincing clinic management and staff that the committee is not there to police them; finding suitable dates and times for meetings where everybody was present and securing support from community leaders like councillors and leaders of community structures. In addition, there are no clear guidelines or regulations for the make up, responsibilities and powers of a clinic committee or hospital committee. Provincial governments are responsible for drafting these guidelines but most, with the exception of the Limpopo Province, are waiting for the national government to pass its long awaited National Health Bill so that it does not supersede the guidelines.

In Limpopo draft guidelines have been drawn up and are being examined to see how well they will work.

Despite the lack of regulations and guidelines, the clinic can investigate complaints from the public about the clinic, work with clinic management to address problems like crime at the clinic, building and staff safety and security, and shortages of medicines, act as a link between the clinic and community, assist the clinic to monitor TB patients on treatment and encourage community members to become community health workers and help at the clinic.

In Chesterville the community plays a central part in the committee's work. The community gives the committee its mandate and also keeps the committee accountable. The reasons for

such a level of commitment, according to Shezi, is that the committee realized that they are there to serve the interest of the community and the community, after many meetings, started to see the important role the committee was having in improving health care delivery in their area.

So far the committee has: identified the need for an induction workshop for the committee on their functions and responsibilities; identified the need for a partnership between all stakeholders to address problems facing the community and clinic; agreed to set up regular meetings to monitor progress; held a workshop to discuss guidelines and committee's role; met with department of health officials to discuss the functions of the committee and establish a good working relationship with the district health management and the city health department. It has also increased access to information and co-operation between those involved.

However, according to Shezi, community participation is not optimal - there are political differences within the community, a lack of collective leadership and a lack of trust amongst all role players which creates difficulties on their own.

The committee is made up of several community representatives (who make up the majority of the committee), a clinic representative (the senior sister) and ward councillors and Members of Parliament residing in the community. The community representatives were elected in a community meeting called by a CBO and the others were invited to serve.

The eventual goal is to have a clinic committee for every clinic in the country. Some of the challenges to achieving this goal include the following:

- There is no national representative to spearhead the effort from the highest level
- There are no national or provincial guidelines on how to set up committees
- Communities are not aware that they are supposed to take an active role in running their clinics and hospitals as per legislation
- Communities don't want to get involved
- In some cases the environment is not conducive for such initiatives to take place

Shezi recommend that strong political leadership advocating the establishment of clinic committees and participation in health, clear guidelines, and strategies to teach communities the importance of playing a role in improving their own health service delivery and their constitutional rights and how to claim those rights will help to address the situation.

### ***Advocacy Groups***

#### **The Treatment Action Campaign (TAC)**

The TAC Web site<sup>xxii</sup>, which includes a plethora of applicable research and documents, clearly outlines the group's objective and strategy:

TAC was launched on 10 December 1998, International Human Rights Day. Its main objective 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 campaigns against the view that AIDS is a 'death sentence'.

TAC's objectives are to ensure access to affordable and quality treatment for people with HIV/AIDS; prevent and eliminate new HIV infections; improve the affordability and quality of health-care access for all.

It aims to do this by:

- Promoting treatment awareness and treatment literacy among all people.
- Campaigning for AZT and Nevirapine for pregnant women to prevent mother-to-child transmissions.
- Campaigning against profiteering by drug companies and other bodies.

- Building a mass TAC membership.
- Building networks and alliances with unions, employers, religious bodies, women and youth organisations, lesbian and gay organisations and other interested sections of the community.
- Maintaining TAC visibility through posters, pamphlets, meetings, street activism and letter writing.
- Targeting pharmaceutical companies to lower the costs of all HIV/AIDS medications and maintain pressure on the government to fulfil its HIV/AIDS obligations.

The group has gained public prominence through its controversial strategy in which it has brought a successful court case against the South African government that required the government to provide anti retrovirals to people with AIDS. It has also used civil disobedience campaigns and the media to raise awareness of the issue and the group's objectives.

### **Massive Effort**

The Massive Effort Campaign (MEC) is a global non-profit organisation established to organise the social movement against AIDS, tuberculosis, malaria and other diseases of poverty.<sup>xxiii</sup>

The group was established on 10 September 2001 with a board of directors and group of founding members representing the private sector and NGO community. The Massive Effort team functions as a network with a small group of professional staff supported by a wide range of experts giving inputs when required.

The group's goals are:

- To mobilise society against diseases that keep people in poverty.
- Using state-of-the art advocacy, communication and marketing strategies - to create and sustain an effective global movement committed to improving the health of the world's poorest people through ensuring TB and malaria deaths are reduced by half
- Reduce HIV infections by 25%, by the year 2010
- Save further lives by preventing childhood diseases and maternal and prenatal conditions.

In April the group co-ordinated a campaign to fight the tax on malaria nets. Hundreds of school children sent post cards to the national government in Pretoria asking for the tax to be removed as the government had said it would several years ago.

The group is funded and sponsored by several organisations and companies including Medvantis and Winteruther.

### ***People's monitoring of the health system***

The following is a useful example from India of the role that communities can play in monitoring delivery of health care at a local level.

'If people could monitor the health services that they should rightfully get, then they could also play a responsible part in making the public health system work. A step towards this was the implementation of the 'health care calendar programme' in over 100 hamlets of Dahanu *taluka*. The activity was based on people's monitoring of village-level healthcare services. A healthcare calendar is hung in the village depicting the timetable of the auxiliary nurse midwife (ANM) and multi-purpose worker (MPW) in the form of pictures. The health personnel are asked to sign on the respective dates when they visit the village. If they do not come as planned, the villagers mark their absence. This enables the village health committee to raise the issue of erring health personnel in joint meetings with the medical officers.

An interesting survey was done in 56 hamlets about the effect of this programme on the functioning of the health personnel. It was seen that the village visits of the ANM had almost doubled since the programme was started. 78 per cent of hamlets reported ANMs now completed their work, but only 32 per cent hamlets reported signing on the respective calendars. 46 per cent of ANMs completed their work but refused to sign on the calendar.

However the health personnel do not seem to like this idea. Their resistance to signing on the calendars offers a glimpse of the difficulties on the path' ahead.<sup>,xxiv</sup>

## CONCLUSION

Community participation in development of health services and delivery of effective, quality health services to the community is essential.

As has been outlined, community participation and involvement can take many forms. A group can be formed to influence policy-making and the legislative process or take a more confrontational role in the form of protest and lobby groups. Additionally, individuals can write politicians to raise their concerns and keep tabs on government processes.

Either way, something must be done to provide the public with the tools and knowledge they need to influence the decision-making process or have their concerns addressed. As things stand not enough of the population can take an active role because they don't know how the government works. Many do not even know they *can* take an active role.

Just as importantly, the public needs to realize that they have rights when it comes to health care in South Africa. While those rights, if the highlighted court cases are any indication, aren't universal but are constrained by limited resources, they are there to some degree and should be pursued by the public.

Ultimately the public must take care of itself and protect its rights. It can't rely wholeheartedly on politicians and the health care sector to do it for them.

Helping to transform the public health system may seem like a massive and sometimes insurmountable obstacle. As a result, many chose to accept the situation as it is, rather than to actively engage with the system. In reality, it is the small battles and little pockets of activism and community participation that eventually help to transform the system. "Social activism will always be about hard struggles to wage, often impossible to win, at least in obvious ways, so often every battle appears lost but over time, consciousness shifts and suddenly society shifts and the day is won."

## STAKEHOLDERS

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