

ART Treatment access and effective responses to HIV and AIDS - Providing new momentum for accessible, effective and sustainable health systems

Southern African Regional Network for Equity in Health (EQUINET)¹

Issues and Options Briefing

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The Regional Network for Equity in Health in Southern Africa (EQUINET) and Oxfam GB with government and civil society partners initiated in 2003 a programme of research, policy analysis and intervention on equity in health sector responses to HIV and AIDS. The programme commissioned review papers on equity in health sector responses to HIV and AIDS in Malawi, South Africa, Tanzania , Zimbabwe, southern Africa and in relation to health personnel and nutrition.

This briefing outlines the major findings and issues from work carried out in southern Africa on equity in health sector responses to HIV and AIDS, particularly in terms of access to antiretroviral treatment. It presents options drawn from the evidence and experience in the region of how to strengthen equity and include low income or more vulnerable communities in treatment access programmes.

This paper is intended to be a summary: The full papers referred to and evidence referenced are available at <u>www.equinetafrica.org</u>

- EQUINET and OXFAM GB (2003) Report of A Review Meeting On Equity Issues In HIV/Aids, Health Sector Responses And Treatment Access In Southern Africa, EQUINET and OXFAM GB, Harare
- Kemp. J, Aitken JM, LeGrand S, Mwale BI (2003) Equity in Health Sector Responses to HIV/AIDS in Malawi, EQUINET Discussion Paper Number 6, EQUINET and OXFAM GB, Harare
- 3. Ntuli, A Ijumba P , McCoy D , Padarath A, Berthiaume L (2003) HIV/Aids And Health Sector Responses In South Africa Treatment Access and Equity: Balancing the Act, EQUINET Discussion Paper Number 7, EQUINET and OXFAM GB, Harare
- 4. Semali, I and Kimambo, A (2003) Equity in Health Sector Responses to HIV/AIDS in Tanzania, EQUINET Discussion Paper Number 8, EQUINET and OXFAM GB, Harare
- 5. Ray, S and Kureya, T (2003) Zimbabwe's Challenge: Equity in Health Sector responses to HIV/AIDS in Zimbabwe, EQUINET Discussion Paper Number 9, EQUINET and OXFAM GB, Harare
- 6. McCoy, D (2003) HIV Care and Treatment in Southern Africa: Addressing Equity, EQUINET Discussion Paper Number 10, EQUINET and OXFAM GB, Harare
- 7. Chopra, M, (2003) Equity Issues in HIV/AIDS, Nutrition and Food Security in Southern Africa, EQUINET Discussion Paper Number 11, EQUINET and OXFAM GB, Harare
- Aitken, J.M and Kemp, J (2003) HIV/Aids, Equity And Health Sector Personnel In Southern Africa, EQUINET Discussion Paper Number 12 EQUINET and OXFAM GB, Harare

¹This briefing paper has been prepared by the EQUINET Secretariat (R Loewenson, TARSC admin@equinetafrica.org) with input from the authors of and drawing primarily from the papers written for EQUINET listed above. These papers are shown in full in the EQUINET website (<u>www.equinetafrica.org</u>). Reviewer comments on this brief are gratefully acknowledged. The work in the Equinet - Oxfam GB programme was carried out with support from DfID and IDRC.

1. PUTTING HIV, AIDS AND TREATMENT ACCESS IN CONTEXT

1.1 **The epidemiological context:**

Adult HIV prevalence in southern Africa is estimated at 13,7%, with upper ranges of over 30%. This translates into approximately 15 million adults and children currently infected. Of these an estimated 700 000 - 1million currently have AIDS. Such data indicate the significant burden of the disease in the region and the scale of response required. With only one eligible person in 25000 currently on treatment with antiretroviral therapy (ART), the shortfall is enormous.

This scale of need for treatment cannot be met by scattered programmes and projects. It requires a comprehensive approach that embeds treatment within an effective and accessible health system.

HIV infection, morbidity and mortality is concentrated globally in southern Africa and in other poor regions, while treatment access is concentrated in high income counties, with notable exceptions, such as Brazil. While 1million people have AIDS in the region, up to a further 125 mn family members are affected, and there are about 7mn orphans. The region experiences high levels of malnutrition, and preventable diseases of poverty and poor environments². Many HIV positive people are thus at risk of under-nutrition and other communicable diseases. The epidemic has a long duration, with 20 years from rising infection to plateauing mortality and effects across generations.

HIV infection is an outcome of risks in the macro-environment (economic, social, political); in the microenvironment (eg: housing, health care and education access) and more proximal behavioural and biological determinants. There is evidence of growing inequalities in the distribution of these risks. These inequalities exist between different areas and communities within southern African countries, across the region, and globally between southern African and high income countries. They are associated with widening disparities in health. Mortality reductions have paradoxically been lower in recent decades in low income sub-Saharan African countries than in higher income OECD countries, despite higher mortality levels in the former. There is also evidence of a vicious spiral of HIV related morbidity and mortality leading to new risk environments in orphans, female adolescents, poor households etc.

HIV, nutrition and food security interact at a number of different levels – biological, individual and community. Good nutrition plays a critical role in the ability of the individual's immune system to withstand and respond to infections, including HIV. Poor nutritional status (especially from a young age) leads to reduced physical and intellectual capacity, ultimately leading to reduced earning potential. Poverty is well recognised as an important factor in increasing vulnerability to HIV, especially for poor women. Communities with poor food security are more likely to be engaged in high risk strategies such as increased migration, and have decreased access to health care services. They are therefore at increased risk of spreading or contracting HIV. Similarly, HIV erodes social capital and traditional coping mechanisms within

² Regional data cited can be found in McCoy (2003) Equinet discussion paper 10

communities, thus increasing food insecurity For example, one common coping strategy is to grow and consume foods that are easier to cultivate and cheaper to purchase but these also tend to be nutritionally poorer foods (such as starchy foods)³.

HIV is spread in risk environments that have social, economic and political determinants. The epidemic also has profound social, economic and political impacts. HIV and AIDS adds to other structural determinants of ill health and malnutrition in the region and exacerbates disease and mortality outcomes, deepening major economic, environmental and political shocks. Evidence links AIDS to a deepening of household poverty and to famine and chronic food insecurity. Economic survival strategies like migration have been associated with increased risk of HIV transmission. AIDS has led to significant losses in social networking and cohesion and to excessive demands and weakening capacities in essential public services. The evidence from southern African countries indicates that AIDS has led to school dropout in affected families, reduced agricultural production outputs, threatened small enterprise survival and increased costs to the business sector⁴. These effects and the burdens of the epidemic are concentrated in low income households and communities, but there is also evidence that AIDS has caused declines into poverty even in middle income households⁵.

In contrast, education, employment, access to social security and housing and improved household food security have been shown to reduce risk of HIV transmission and mitigate against AIDS impacts.

Knowledge of the determinants of HIV infection has grown and has informed approaches for prevention. This has, however, had limited impact on reducing risk at national level, because provision of, access to and uptake of prevention measures has remained limited. A worsening risk environment itself challenges the sustainability of health interventions, including treatment.

Social and economic inequalities and poverty are thus central to the AIDS epidemic in southern Africa: They shape the risk environments for HIV transmission and the household and community vulnerability to AIDS. Household incomes, education, employment and food security not only impact on susceptibility to HIV and impacts of AIDS, they are important determinants of health status and of the uptake of health care. Health sector responses to AIDS thus need to build positive synergies between prevention and treatment of AIDS and to ensure that ill health and mortality does not undermine provision of health promoting inputs like education and household food security.

1.2 The public health context:

A public health strategy for HIV and AIDS demands a continuum of promotion and prevention strategies, clinical medical and community care and counselling; backed by social welfare services. In southern Africa these inputs are provided through a mix of social, environmental, medical and welfare strategies; through modern and traditional systems; and through

³ For a full discussion of food security – HIV links see Chopra (2003) Equinet discussion paper 11

⁴ See for example Ray et al 2003; Semali et al 2003 and McCoy et al 2003

⁵ Ibid

community, state, profit and non profit sectors. They involve a range of disciplines, sectors and skills.

There has been significant effort at policy development and planning of the public health response to AIDS in southern Africa. All SADC member states have policies on AIDS and treatment guidelines and some are developing explicit treatment access policies⁶, Policy implementation and access to services varies considerably however. Preventive interventions of proven effect still do not reach many at risk, for example. Policy implementation has been influenced by a range of factors. These include the level and cohesion of political and public health leadership; the capabilities and resources in the public sector; the extent of private sector contributions; the quality, consistency and relevance of development assistance and the extent of civil society engagement and community inclusion. The variability of the national response in the region is an important factor to take into account in designing any global or regional response.

Country level processes need to drive strategies. This needs to be based on the real capabilities and demands of national health systems and the means they have to implement strategies⁷. Within countries, the conditions and voice of those working in under-resourced areas and services need to be taken into account in designing strategies.

Scarce resources and shortfalls in skilled staff, medical equipment and transport have undermined delivery and led to uneven access to HIV and AIDS interventions. For example Prevention of parent to child transmission (PTCT) and Voluntary Counselling and Testing (VCT) programmes (for which drug costs are not a barrier) still do not widely cover the region. Even in a country like South Africa, with significantly higher levels of resources, the availability of such services remains low and access to PTCT is often inequitable, benefiting those in mostly urbanised provinces where there is better infrastructure, better distribution of human resources and fewer social and cultural constraints⁸.

Evidence indicates that these shortfalls are most evident in the lower and peripheral levels of health services and in poorer communities (rural and urban). The shortfalls reduce access and value for money in low income communities, implying that they have to wait longer for treatment, receive fewer drugs and pay higher shares of their incomes for care. This bias leads to poor households benefiting less from services for HIV and AIDS prevention and care and taking on larger burdens of care for people dying of AIDS. This further worsens the economic and health status of these households.

There are also significant social and community barriers to address to accessing prevention and care. These include lack of information on services options, fear of

⁶ The South African Government has for example launched in November 2003 a comprehensive policy on making ART treatment available in South Africa

⁷ Hence for example treatment guidelines, measures for procuring storing and distributing selected drugs, ensuring quality assurance and monitoring treatment need to be set in the context of the current operations of district health systems to balance clinical excellence and quality standards against available health resources. Deficits need to be addressed in necessary laboratory services, drug procurement, distribution and dispensing within health services and for making treatment regimes accessible across different levels of service and types of communities.

⁸ See Ntuli et al 2003 Equinet discussion paper 7 <u>www.equinetafrica.org</u>

disclosure of HIV positive serostatus, stigma attached to being HIV positive, community, family or partner rejection (especially for women), health worker labelling and mistreatment, economic and social insecurity and gender imbalances. Hence, while VCT is a crucial entry point for many HIV and AIDS interventions, including treatment, women from low income communities still face information and stigma barriers to using VCT services⁹.

Explicit measures need to be taken to provide information and to deal with social barriers to enhance uptake of services. In relation treatment access, for example, if information and treatment literacy are not provided, it is likely that more educated, more informed and higher income groups will have greater uptake of services providing treatment. If this happens then the positive effects of treatment on reducing stigma will be totally lost to more marginal groups.

Limited services and cost of treatment in the face of desperate need and huge demand can result in clinical and financial short-cuts being taken by clinicians and patients alike, with adverse clinical and public health outcomes. Monotherapy, dual-therapy regimes or intermittent and interrupted regimes may end up being common, especially in poor communities. This, together with problems in treatment compliance can lead to ART resistance. This undermines use of available therapies and leaves countries exposed to high priced new and patented medicines¹⁰.

Public drug regulatory systems are weaker in some countries in the region than in others. Donor financing has influenced choices of drug regimes, while private sector procurement and informal household measures being taken to secure drugs are bringing drugs into countries without going through public regulatory systems.

Treatment access programmes should strengthen national policies, programmes and institutions for regulating, managing and monitoring drug procurement and use. National capacity shortfalls can be supported by regional approaches to standard setting, quality testing, regulation and procurement. Treatment literacy, including on drug compliance should complement drug management systems.

1.3 The health systems context:

The current health sector responses to HIV and AIDS in southern Africa are taking place in the context of weakened public health infrastructures with absolute shortfalls in healthcare funding, health personnel, materials and recurrent financing. This is the case in all but a few countries. It is particularly severe in the public sector, at lower levels of the health system and in services in rural areas. Aggregate annual per capita expenditure on health in the public sector (\$10/capita) falls short of minimum levels for basic services, and is significantly less for all health services than the estimated monthly per capita costs of introducing ART for those who need it (about \$30 /capita).

Significant new resources for the health sector will need to be made available to facilitate the infrastructure and systems needs for widening treatment access.. This level of investment calls for review of public budget

 ⁹ See Kemp et al 2003; Ray et al 2003 Equinet discussion papers 6,9 <u>www.equinetafrica.org</u>
¹⁰ See McCoy 2003 Equinet discussion paper 10 <u>www.equinetafrica.org</u>

commitments to health in southern Africa, increased ODA commitments to meet the UN and G8 commitment of 0.7% GDP (currently not met), renegotiation and cancellation of debt and review of finance institution constraints to increased health financing¹¹.

Beyond absolute resource shortfalls, health services in southern Africa continue to face challenges to equity. Despite all SADC countries having health equity policies, there are significant disparities in per capita financing and in human resources, infrastructure, coverage and access. These disparities exist between private and public sectors, between urban and rural areas, between higher and lower income groups and countries in the region. These disparities are avoidable, but are widened under situations where there is a shift away from risk pooled tax or budget and insurance financing towards out of pocket and vertical project financing¹².

In the context of existing inequities that undermine access to care in a population majority who are poor, treatment access programmes should at least not worsen inequities.

Country experience indicates that current ART access is concentrated in private sector providers and users of services, and that planned ART programmes are largely urban-based, centered around big hospitals with the infrastructure to manage the programmes. Where ART is introduced in large hospitals immediate beneficiaries are likely to be the urban educated population, and more likely to be men¹³.

The provision of ART in rural and under-resourced areas is more limited, and largely dependent on mission hospitals and NGOs with external donor funding. The significant new resource inflows brought into pilot donor programmes and concentration of public resources in urban hospital facilities mean that treatment access has not yet been tested in the real health system conditions of most southern African countries to determine the required inputs for effective and equitable roll out.

Human resource shortfalls, attrition and out-migration are now a significant limit to any resource flows reaching poor communities¹⁴. Human resources currently flow from public services serving low income communities to urban private services, from low income to higher income countries in the region and from the southern Africa to UK, Canada, Australia and other high income countries.

HIV and AIDS has further impacted on healthcare staff, with estimates of up to 14% of health workers HIV infected. Factors such as poor infection control, poor work environments, inadequate pay and benefits, new demands with inadequate supportive inputs and high job stress push personnel out of health systems. The

¹¹ For example, the IMF/World Bank Medium Term Expenditure Frameworks (MTEFs) identified in PRSPs have been noted to place fiscal constraints on the public expenditure levels needed for widening treatment access.

¹² McCoy (2003) Equinet discussion paper no 10 <u>www.equinetafrica.org</u>

 ¹³ McCoy 2003, Kemp et al 2003; Ray et al 2003, Equinet discussion papers no 6,9,10
<u>www.equinetafrica.org</u>
¹⁴ In Malawi, for example, over half of government health posts remain unfilled; as a result,

¹⁴ In Malawi, for example, over half of government health posts remain unfilled; as a result, 90% of public health facilities do not have the capacity to deliver even a minimum package of healthcare for all. See further information on health personnel issues in Padrath et al, EQUINET discussion paper number 4 2003 and Aitken J, Kemp J (2003), Equinet discussion paper number 12 <u>www.equinetafrica.org</u>

pull of higher resources in the private and NGO sectors or overseas is fuelling attrition and reduces service capacities, including to absorb new resources¹⁵ Weaknesses in management capacities in peripheral services can undermine abilities to use new resources. There is also a real danger that the introduction of new services will be done at the cost of redeploying staff from existing services unless new personnel are made available. There is a long time gap between enrolling students in training and the availability of new health personnel, calling for creative strategies to widening skills around ART management.

Widening ART access should not exacerbate public sector HR losses, nor divert resources from wider health programmes. It should, in contrast, use the new resources for health to strengthen the retention, capacities of and support for personnel for wider health system gain.

1.4 **The public policy context:**

Public policy on equitable treatment access in the region has been driven by two streams: The first is a longstanding national commitment to equity and universality in meeting population health needs that has expression in building public health systems and financing, primary health care and in efforts towards redistribution of resources for health. This has been compromised in more recent decades by market led macroeconomic and health reforms but remains a fundamental value in the region.

The second policy stream is a groundswell of social and legal activism around HIV and AIDS and the rights of people with HIV and AIDS, and in the last decade, activism around the treatment of AIDS (therapeutic activism).

Policies to expand treatment access would need to be consistent with both of these policy streams for their stability. They would need to balance the social rights and public health obligations that inform equity in health and the individual rights of people with AIDS to access treatment.

All countries in the region have national policies on AIDS and a SADC regional strategy exists on AIDS. Some countries have declared AIDS a national emergency to facilitate the importation of low-cost generic medicines under the provisions of the WTO Doha Declaration. SADC countries are now beginning top develop explicit policy guidelines on effective and equitable treatment access. Although clinical guidelines are available for ART, there are no specific ethical and public health guidelines for managing treatment access, rationing and integration of treatment within health systems. Even for the available clinical guidelines, knowledge of and uptake amongst both providers and communities is variable.

SADC regional co-operation in health provides an opportunity for policy review and development, for standard setting and for promoting knowledge and uptake of policies across communities, sectors and health providers¹⁶.

¹⁵ Evidence from pilot programmes indicate significant additional personnel inputs brought to district level services to implement ART programmes, sometimes drawing from public to NGO sectors and from already underresourced districts to pilot districts, to the cost of wider health services.

¹⁶ This has already begun to be explored by SADC through standardising protocols for ARVs in the region

There is a policy opportunity in accessing new treatment resources to significantly impact on the burden of mortality, improve morale in health services, reduce stigma due to availability of treatment and strengthen health care systems. There is a risk that new treatment resources could medicalise AIDS (excessively shifting policy focus to treatment as the dominant response to the epidemic); and lead to conflict between claims for treatment resources and claims for wider health systems resources.

There are national organisations, processes and forums through which wide debate and social organisation around treatment access can be organised, including for poor communities. While the voice of the most marginalised is weak in these mechanisms, they have been successful in the past in organising and implementing primary health care policies and public health campaigns. In contrast there is evidence that the policy choices around treatment access have so far generally been made without adequate public consultation and dialogue.

Given the nature of the choices being made around treatment access, the many communities and sectors involved and the political nature of the choices there needs to be stronger mechanisms for informed social participation in and transparency of policy formulation on treatment access.

Many of the most important policy constraints to treatment access do not exist at national level, they exist at global level. These include trade constraints, such as in the World Trade Organisation GATS and TRIPs agreements, constraints imposed by current policies on research and development of new drugs, on drug prices and regulation of pharmaceutical markups, on METFs, aid levels and mechanisms, on debt relief and on intellectual property rights.

The primary challenge to addressing these policies is at global level, and particularly for global institutions that have a constitutional mandate to protect public health and security such as World Health Organisation (WHO). The countries of the SADC region have greater negotiating influence and capacity when there is regional networking and coherence around global policies, and where they build regional policy coherence.

The public health and health systems issues arising around treatment access and their resource, trade, economic policy, legal and political implications indicate that providing for sustainable solutions calls for broader, multi-sectoral responses to enable the health system responses. Pressure from southern Africa and other low income regions has led to stronger protections for public health in the TRIPS agreement, as reflected in the Doha declaration. Pressure has also led to a review of global drug pricing systems, proposals for differential pricing systems, the formation of new funding resources for AIDS in the Global Fund on AIDS, TB and Malaria (GFATM) and the declaration of a global public health emergency and direct commitment from WHO as a global agency towards action. These commitments serve to galvanise energy and focus attention.

Sustainable treatment access means using this energy and the commitments to goals to interrogate the changes needed in policy, financing and institutional arrangements at global, regional, national and subnational level for their achievement, within the context of building strengthened health systems¹⁷.

¹⁷ For example the 'Drugs for Neglected disease Initiative' provides an alternative model for vaccine and medicine development in the non profit sector

2. A HEALTH SYSTEMS APPROACH TO TREATMENT ACCESS

"People in bad economic situations have more difficulties, but we can overcome them if we provide good services"

P Teixera, Brazil¹⁸

The epidemiology and current response to the HIV and AIDS epidemic and the state of health systems in southern Africa provide a context for responding to the opportunity for new treatment resources for AIDS, and for confronting the unmet need to prevent HIV and mitigate its impacts. The policy choices made now have ramifications for the long-term configuration, equity, effectiveness and sustainability of health systems in southern Africa.

Figure 1 below exemplifies the range of issues drawn from one country in southern Africa to be addressed in an equity oriented health sector response to AIDS. This signals the spectrum of responses, from addressing the negative impacts of AIDS on staff and other resources for health, strengthening general health and health care interventions that impact on the disease, to putting in place specific measures explicitly for AIDS.

Figure 1: Conceptual Framework for equity in health sector responses to HIV/AIDS in Malawi; Source: Kemp et al 2003



¹⁸ Quoted in Rosenberg T (2001)

The scale of mortality and suffering, the pressure from treatment activism, the declaration of AIDS as an emergency and the pooling of significant resources in the GFATM has had and *should* have a galvanising effect¹⁹. There is a moral imperative to treat people with AIDS that must be addressed. The impetus around expanding HIV care and treatment can be used to reduce inequities, reach poor communities and systematically uplift the health care infra-structure of the most under-resourced areas in the countries of the region. It can do so in a way that ensures that treatment is not just the privilege of a minority, but reaches the majority of vulnerable households living below the poverty line in southern Africa. It can be done in a manner that secures rights and that is just and fair.

How can this be done?

There are lessons from countries like Brazil, that have expanded treatment access to significant levels. They indicate that effective responses to AIDS build synergies with the wider prevention and care continuum; are based on strong public sector health services; draw on civil society and private sector resources and capacities; and reach through district services to primary care levels²¹.

The scale of infection and the level of poverty in southern Africa give additional (not less) impetus to that approach.. Where 60% or more of the population live below the poverty line, approaches that are pro-poor and that direct resources to those in need have high overlap with those that aim for comprehensive, universal access based on solidarity financing. Experiences within southern Africa and globally suggest some of the essential features of how this should be done.

2.1 Locating treatment within the prevention and care continuum

This brief does not debate the cost-benefit comparisons of prevention and treatment interventions. This is discussed in more detail elsewhere²² Studies indicate high health gains of standard HIV prevention interventions²³. Prevention is widely recognised as being a more effective and equitable approach in controlling disease than treatment oriented strategies, and especially in resource-poor settings²⁴.

It cannot, however, be a case of *either* prevention *or* cure. Primary health care approaches that achieved high health gain in southern Africa did so by

¹⁹ For example Kemp et al (2003) note that the prospect of injecting \$196 million from GFATM to AIDS had a galvanising effect on policy responses to AIDS in Malawi. Several rounds of planning and widening consultation changed initial proposals focussed mainly on ART provision towards more comprehensive proposals covering the continuum of HIV and AIDS prevention, care and support, and making explicit attempts to support the HIV and AIDS services through the essential health programme of the public health system and general health system strengthening.

²¹ See for example Ministry of Health Brazil (2000) The Brazilian Response to AIDS: Best Practices, Mimeo, Brazil

²² McCoy (2003) discusses this and notes the limitations of these analyses in relation to the variation in different contexts and different prevalence levels, in relation to knock on effects etc. They also do not take into account non cost issues like staff morale, the value of life or wider public good

 ²³ Noted to be higher in terms of cost per year of life gained than treatment interventions
²⁴ Ntuli et al 2003

making accessible and improving coverage in *both* prevention and treatment for priority conditions²⁵.

Despite this, in many countries, proven HIV prevention interventions continue to have low coverage and thus low impact on the epidemic.

The momentum for treatment should thus enable, not discourage prevention.

Preventive interventions of proven impact (targeted condom distribution, blood screening, nevirapine for the prevention of mother-to-child transmission and STD treatment) and certain treatment interventions (e.g., co-trimoxazole prophylaxis for patients with HIV, TB treatment) should be protected in terms of institutional and financial resources and policy visibility in any process that expands treatment access.

Treatment policies need therefore to be located within continuum of strategies for prevention, treatment, care and mitigation of AIDS. This is critical as there are important potential synergies to be gained between prevention and treatment, particularly for poor households. Treatment can reduce the stigma of AIDS, and strengthen social factors that enable prevention, such as womens status. Bringing people through prevention programmes can, on the other hand, facilitate treatment access in groups who may otherwise be excluded.

For example, when Anti-retroviral therapy (ART) is introduced through Voluntary Counselling and Testing (VCT) services that link to Prevention of Parent to Child Transmission (PTCT) at Antenatal care (ANC) services, this more explicitly address female access as a point of entry, particularly given that they are often excluded from formal workplace or research centred programmes²⁶. It helps to deal with social stigmas around AIDS in women. It provides a better opportunity for treatment -prevention links than provision of ART at central hospitals. PTCT programmes are a good entry point for women to learn about access to other programmes and resources, such as support groups, nutrition, home based care, and for bringing in their partners and children who may also be HIV positive. Women identified as clinically eligible through PTCT could be referred to treatment programmes, while those who were still relatively healthy would be followed up through community outreach, advice given for child health including vaccinations, and providing ongoing support for them to stay healthy 28 .

²⁵ Equinet steering committee (2000) Turning values into practice Equinet discussion paper 7, Benaby printers, Harare

²⁶ Ray et al 2003

²⁸ Some countries are considering PTCT+ that involves providing triple therapy for HIV positive mothers for 6 months over the pregnancy and breast-feeding period, to provide more effective protection for the baby and to preserve the mother's health over this vulnerable period. The programme also involves monitoring CD4 counts and continuing triple therapy for those women whose immunity is falling. These women and their partners (if their immunity were also falling) would then enter treatment programmes.

Wider public health programmes such as TB control, when effectively delivered, also provide useful experience for expansion of ARV treatment and possible entry points for better care for HIV. Working through effective TB programmes provides gains in widening access to district level and poor populations. It utilises the same nursing staff that are administering TB drugs. In some southern African countries TB programmes are well established nationwide. In Zimbabwe, Botswana and Malawi for example, TB services are available at district level, with good structures, despite resource shortages affecting the public health service Where such services are not well established, and where multi-drug resistant TB is a sign of poor TB control, the introduction of ART provides an opportunity to strengthen systems to improve *both* TB control and treatment access.

The positive dimensions of TB programmes also provide lessons for approaches to ART access: they have systematic protocol-led approaches, register clients; carry out follow-up and community outreach and train staff in dealing with stigmatising conditions. They have experience of record keeping, direct observed medication, and drug supplies management.. Staff are trained to advise patients on taking medication over long periods, although the course of treatment for AIDS is significantly longer than for TB²⁹. There are potential synergies for the management of both diseases: Reciprocal screening for TB and HIV when clients present for one or other service, would assist with case-finding and support education of individuals. Contact tracing and home-based care for TB can be extended to following up family members that need HIV testing and education.

For such synergies to be tapped, however, TB services need to be sustained at district level, and additional resources applied to support ART provision, otherwise both services will be compromised. Further community and civil society outreach is important to ensure coverage and effective uptake of health service interventions.

There is a further lesson from the achievement of national coverage of TB control. It is noted to have been achieved, even in relatively under-resourced health systems, through strong leadership from the public health services, accompanied by training, supervision and monitoring implemented at all levels of the health system, with an uninterrupted drug and commodity supply, sustained over years³⁰. Directing resources towards sustained strengthening of the public health system is a proven route to achieving national coverage, in terms of widening treatment

- A well established policy framework and five-year development plan supported by national standards and guidelines
- strong planning, implementation and reporting cycle
- GOM leadership to support the policy framework, which has engendered joint donor/GOM partnership to implement programme and basket funding by GOM, DFID, NORAD, KNCV and USAID, with supplementary funding from WHO
- training, supervision and monitoring implemented at all levels of the health system
- an uninterrupted drug and commodity supply, over years
- national guidelines implemented by all CHAM (private, not-for-profit facilities) and larger private health providers, with reporting integrated into the national database
- well established programme of operational research which, coupled with strong leadership, has allowed the programme to respond to the changing context of the HIV and AIDS epidemic, and (currently) policy changes such as the national decentralisation policy (Kemp et al 2003).

²⁹ Kemp et al 2003; Ray et al 2003

³⁰ The National TB Programme in Malawi for example using the WHO-recommended international framework and programme for TB control is noted to have been able to reach national coverage though

access³¹. Similar approaches have been used in strengthening management of Sexually Transmitted Infections. National guidelines provided the framework for non government organisation (NGO) and private sector co-operation, sector wide support enabled public funded training across the health system and drug management approaches aimed at service integration at all levels³². The lessons from TB and STI programmes indicate that mainstreaming care involves strengthening standard treatment guidelines for each service level, augmenting skills of staff, providing a continuous supply of drugs, ensuring effective referral systems and district monitoring.

Not all AIDS related prevention and care approaches have used this framework. While guidelines have been developed in some countries for behaviour change communication, Voluntary Counselling and Testing (VCT), and blood safety, implementation has often depended on specific donor inputs, with limited geographical coverage. This has led to 'islands of excellence', within an overall a fragmented response. In Malawi and South Africa this was noted to apply to PTCT and VCT³³.

These experiences indicate that approaches integrated within wider public health systems enable sector wide funding, which itself provides for sector wide inputs that widen coverage. While NGO interventions do successfully reach underserved communities, they do not reach the same levels of coverage. There is evidence that when VCT programmes are run vertically or as separate facilities they are less able to act as entry points for prevention, treatment and care services and cost more in time and opportunity costs, discouraging use in poor communities. (Ntuli et al 2003). At the same time NGO input in public sector programmes contributes to the information flow, outreach, community organisation, innovation, social dialogue and social support needed to make better use of these programmes.

Strong public health service leadership is thus critical to ensure co-ordination of state, private and NGO initiatives³⁴. Reaching *district* levels of public health systems is important, but may still not be adequate to reach marginalised groups. There is evidence that services need to reach community and primary care level, to be responsive to community planning and needs and to take account of community

³¹. That aggregate resources alone do not determine coverage is evident in the fact that more highly resourced countries like South Africa have a TB cure rate reported as 64%, below the national and WHO accepted target of 85% (Ntuli et al 2003).

³² In Zimbabwe, by locating PTCT sites in district and mission hospitals, the programme was able to rapidly scale up to 155 centres, supported by guidelines, Nurse training, manuals and protocols to standardise implementation. Some facilities are using trained lay counsellors to decrease the work burden on nurses (Ray et al 2003). ³³ Kemp et al (2002) pote that PTOT

³³ Kemp et al (2003) note that PTCT services are partial, offered only in selected sites and at district hospitals rather than all health facilities limiting potential beneficiaries. While all hospitals offer VCT, these are not fully staffed and do not all offer testing. Stand alone VCT centres, even within hospital groups were not socially accepted for possible stigma, especially by women. Given the 'gateway' VCT provides to treatment exclusion for any reason is important. Ntuli et al (2003) note in South Africa that access to secondary prevention such as VCT and PMCT, is currently inequitable. In 2001, only 7 of the 18 pilot PTCT sites achieved an HIV testing rate of more than 60% (a site achieving a 60% or above testing rate can be considered to be doing reasonably well) and of these, six are urban or peri-urban and situated in the three historically best resourced provinces (Western Cape, Gauteng and KwaZulu-Natal).

³⁴ Even within these approaches barriers to access to care remain for the poorest and most vulnerable, relating to longer pathways to care; and the time, income and opportunity costs of seeking care. To some extent these relate to the poorer quality of care and can be dealt with by service improvements. NGOs can also provide supports to enhance health seeking behaviour or health outreach to complement and enhance uptake of public health systems.

and social norms if they are to reach poor communities and be used by women and other vulnerable groups³⁵.

2.2 Beyond clinical criteria for rationing

Clinical criteria for patient eligibility are well established, even for low resource settings without access to CD4 and viral load tests. 'Universal access' for clinically eligible people is an explicit policy objective in South Africa. In most other countries in the region the policy aims at expansion of treatment access. Currently, resources for treatment provide for about 4% of those eligible, including funds from the GFATM.

Rationing (formal or informal) thus becomes an issue, and an area where equity can be compromised. The criteria for rationing amongst those who are clinically eligible are less well established. There is evidence that beyond defining the point of care, those who access will be on a 'first-come, first-served' system. That will favour the city or town-based, higher educated non-poor population, often men. It also puts the burden onto healthcare workers to decide who gets access. At best these criteria will be inconsistent across health workers and sites, and at worst will open up the possibility of corrupt practices (Kemp 2003).

Several options are suggested to make rationing more equitable:

- The first is to seek universal access within selected districts or catchment areas of points of entry. If these districts are selected for their poverty levels, for public health reasons, to address gender equity concerns, etc then the rationing can be linked to social and equity goals.
- The second is to select particular subgroups of the population, such as health workers and teachers, for their contribution to wider epidemic control and poverty reduction³⁶.
- The third is to locate at points of health services used by low income groups and operate a first come first serve basis, but put in place explicit measures to overcome barriers to access, such as income and travel support or female empowerment. This can include specific measures for tracing and follow up of people on treatment, as it done with TB, to enhance compliance.
- In the fourth, the community participates in ratifying and legitimising decisions about patient selection, to prevent the development of patronage or corrupt practices.

Each of these, depending on how they are applied, can be argued to have pro-poor, equity impacts. They are not mutually exclusive and can be applied in tandem.

There are no easy answers to which approach is more equitable, and the choices made are as political as they are technically motivated. Hence the choices should be brought into the public domain, ensuring social dialogue, debate and transparency around them.

It is important to remove this responsibility from front-line health providers and to avoid selection being 'informal' to provide greater policy direction to the issue. There is an assumption that this will enhance equity. It will not,

³⁵ Such as indicated by the level of application and use of PTCT services in Malawi ³⁶ In light of the bottleneck to wider treatment access that could arise from inadequate health workers, healthcare workers have been frequently singled out as a group that should have early access to treatment

however, if the choices around rationing are made at central level by people with specific interests as clients or providers, or if the debates and information over choices only reach urban middle class people. Such information often does not reach rural, female or urban low income communities. This means that 'treatment literacy' and information on ARVs and treatment options should be actively disseminated, by state and civil society³⁷.

2.3 Integrating treatment within health services

The discussion on the continuum of care, the positive lessons learned from TB and STI and the negative outcomes of fragmented interventions highlighted the opportunities to be gained both for coverage and for reaching poor communities through the public health services. This has resource implications, and additional inputs may be needed to ensure that these services reach the most vulnerable.

Costing the provision of treatment has been done in South Africa. While the absolute figures are changing as input costs change, estimates from the South African Health and Treasury Departments estimated that covering 500,000 people with a full package of healthcare and nutrition support *including* antiretroviral treatment by 2008 would cost approximately double the same services and care excluding ARVs³⁸. For countries with lower prevalence rates, smaller populations **or** higher incomes (eg, Mauritius, South Africa), aggregate cost is not the significant barrier to treatment access. For lower income countries with high HIV prevalence, while domestic resources may be limited, there are now significant resources through the GFATM. This raises new issues of wider impacts in public employment and spending and on changes needed to enable the health system to absorb and manage these funds.

This implies strengthening, for example,

- the human resources to implement programmes
- the managerial skills needed to procure and manage antiretroviral drugs
- the clinical skills required to diagnose and treat opportunistic infections
- Community education and mobilization, supported by NGOs, CBOs.

Many countries in southern Africa have initiated new ART treatment services in academic and urban centres⁴⁰. There have been pilot programmes through mission hospitals and international NGOs at rural district level, often working with public sector health services and providing additional resource

³⁷ In South Africa, TAC has been promoting treatment literacy as a good way of families living with AIDS finding out what they need to know about treatment so that they can ask health workers the right questions about their care, without feeling intimidated and undermined.(Ray et al 2003)

³⁸ Ntuli et al 2003 present costs of between R13.4bn and R15.7bn (US\$2.3bn) for health services and care including ARVs, and R6.7bn (US\$1bn) for HIV services and care excluding ARVs

⁴⁰ Urban central hospitals have been justified as entry points based on clinical capacities and their roles as referral centres.

support. The latter have proved the possibility that prevention, treatment and care can be integrated into the lowest levels of the health system, provided that the resources are made available⁴¹. Without wider resource strategies, applying new treatment resources in urban hospitals or providing primary care pilot projects that use high levels of staff, finance and management inputs can both draw staff and skills from less well resourced levels of the health system, to the cost of poor communities.

There are examples of treatment located within less resource intensive services, at district levels with community outreach. For example, mission hospital provision of ART includes features of health worker and community identification of beneficiaries, linkages between treatment and broader health services, provision of VCT, PTCT and Home based care (HBC) services, health outreach and longer term external funding (+5 years).⁴² These less resource intensive approaches within district health systems provide evidence that treatment can be widened to poorer communities, but that additional inputs are needed. The mission services and pilot interventions at primary care level by NGOs give an indication of what the resource and policy gap might be⁴³. They include personnel, staffing norms used in such services, a basic level of health care services, specific prevention and care services for AIDS, community outreach and involvement and sustainable funding (for at least 5 years).

District based approaches, extending out reach to primary care and community level (like the mission hospital model) appear to combine coverage and equity and have the greatest likelihood of being replicable within the reality of health systems in southern Africa. This approach uses the resources of the hospital and primary health care outreach for improving treatment access, and uses treatment resources to strengthen the health system.

Kemp et al (2003) note 'For the many people living with HIV/AIDS and for the health workers providing general health services, it is important that the message of hope and that 'we can do something' is not limited to the provision of ART alone, but extends to all components of an integrated response. This will be achieved if ART is delivered within the context of a continuum of care for HIV/AIDS. A continuum of HIV/AIDS care will prevent further infections and provide services for those who cannot access treatment and for those for whom treatment fails.'

2.4 Investing in health personnel

Health personnel are a critical factor in both extent and quality of coverage. Across southern Africa countries coverage and quality of outcome in AIDS related services are associated with the availability of personnel, training and skills, and the level of technical and managerial support. Skilled health personnel have used their

⁴¹ The MSF-led HIV responses in Malawi provide examples of how the continuum of HIV prevention and care can be offered within a district-based system with sufficient financial resources (Kemp et al 2003)

⁴² For example there are two church hospitals providing ART in Zimbabwe, one in Chiweshe district and one in Mutoko district (Ray et al 2003).

⁴³ Pilot sites at primary care level such as Thyolo in Malawi offer the possibility of identifying the *minimum* staff complement to provide ART services, and to develop guidelines for mainstreaming comprehensive HIV care and support across the district health system

experience from other diseases to managing AIDS⁴⁴. Pilot programmes for treatment access have made deliberate efforts to reduce staff losses and to increase staff management, motivation and performance. The programmes have included measures to protect health workers job safety through infection control. They have involved non-clinically qualified staff in conducting non-clinical activities like VCT and health promotion to relieve staff pressure and provided additional performance-related incentives to health staff. (Kemp et al 2003).

The gap between such pilots and the reality of health systems is still wide. Successful pilot projects can pull personnel out of public health systems to pilot districts and to NGOs⁴⁵. In a number of countries in the region, expanding treatment access calls for significant and sustained investments in human resources, at the service level (district and primary care) and in management roles. This is an area where private sector contribution can and has been made⁴⁶.

Aitken et al (2003) propose a range of policy responses to respond to the human resources for health crisis in the longer and shorter term.

- 1. Making better use of the staff currently available through:
 - redeployment to reflect utilisation patterns and fill priority posts
 - upgrading existing staff through sandwich and distance learning courses
 - speeding up public service placement and promotion procedures
 - effective performance management strategies.
- 2. Producing more staff through:
 - increasing training capacity
 - regrading jobs and entry requirements downwards for faster production
 - creation of new cadres appropriate to actual working situations.
- 3. Recruiting and retaining more staff through:
 - streamlining public service appointment procedures
 - investigating reasons for attrition and developing targeted incentives
 - improving pay and terms and conditions
 - developing 'return to work' packages targeted at those who have left the sector
 - flexible working schemes for positive living for those who are HIV positive
 - occupational health schemes and antiretroviral therapy (ART) for health workers.

4. Protecting the institution from the negative effects of attrition through:

- strengthening institutional memory and knowledge management
- improved succession planning
- monitoring and predicting attrition
- encouraging staff to know and reveal their status

⁴⁴ For example, health workers trained in looking after cancer patients have knowledge about management of pain and other symptoms (Ray et al 2003)

⁴⁵ Ntuli et al (2003) cite Dr Gustaaf Wolvaardt, executive director of the Foundation for Professional Development (FPD), observation that 'relatively few' of the estimated 31,480 doctors and 202,000 nurses in southern Africa have received training in the clinical management of the disease, or in counselling and testing their patients and families. The majority of professional nurses, who are also charged with supervision of PHC facilities, are not trained in clinical use of ARVs.

⁴⁶ For example, Eskom, Africa's largest electric utility company, has joined with the FPD, the Southern African HIV Clinicians Society (SAHCS) and Development Communication Associates (DCA), a US-based development organisation, to train doctors and nurses in the southern African region.

• skills development and sharing through an emphasis on team working.

Addressing these health personnel issues is central to the response to AIDS, and calls for policy shifts and significant new resources, including from bilateral support. SADC provides opportunities for regional co-operation in policy development, training and negotiation on health personnel issues. Beyond the health service personnel needs, the demands for prevention, accessible treatment and care related to AIDS places new attention on the role and support of community health workers as a bridge between communities and health services. Research on home based care programmes indicates that where households face burdens of caring without effective community and health service support, both quality of care and household wellbeing can be compromised. Significant further focus thus needs to be given to both policy and resource mobilisation for this.

2.5 Intervening beyond health services to enhance treatment access

There are a range of factors outside the health services that have relevance to the effectiveness of treatment uptake. Where poverty levels are higher and health services poorer, the barriers to access are greater, as is the need for effective intervention. While education, employment, public infrastructures, social welfare support, womens empowerment, safe water and other wider inputs all have positive health impacts, two are discussed here.

The social dimensions of health programmes (information, networking, coplanning, community involvement) are important for enhancing both use and outreach of services, particularly to less vocal groups. At the same time providing effective health care can have a positive impact on social cohesion and awareness. Making effective services available at primary care and district level has a positive impact on stimulating health service use and gives greater value for money to low income users. Making treatment accessible has spillover effects in reducing levels of stigma and denial, improving morale of health staff, encouraging use of VCT, and generally giving people hope. This makes the social dimension of health sector responses and particularly of treatment programmes central to wider public health benefit⁴⁷

The economic conditions that influence treatment also need to be considered. For example, as discussed earlier, nutrition and food security have direct relevance to both risk and vulnerability⁴⁸. Food intake affects response to and compliance with treatment, reduced morbidity enables people to work to produce food and improves ability to eat. These effects have greatest impact

⁴⁷ Projects providing treatment – such as through the AIDS Support Organisation (TASO) in Uganda and the Khayelitsha project in Capetown – have demonstrated that provision of treatment gives hope, and this has a positive effect on dispelling stigma and denial. The Khayelitsha project has shown how provision of treatment significantly strengthened prevention efforts by providing an incentive for people to seek VCT, promoting openness about HIV and reducing stigma (Ray et al 2003).

⁴⁸ Improved food security reduces risky behaviour; improved nutritional status enhances the strength and resistance of individuals allowing them to function productively for longer (Chopra 2003)

in the poorest with worst nutrition. This makes community, household and individual nutrition an important aspect of pro-poor interventions.

Nutrition and food security can play a critical role in mitigating the impact of AIDS. Improved nutritional status can directly improve the strength and resistance of individuals allowing them to function productively for longer, and improved food security reduces risky behaviour. Furthermore, food and nutrition programmes can provide valuable experience of engaging communities in participatory processes that support other health interventions. For example, an integrated approach involving home-based caregivers, orphan committees, agricultural extension agents and health workers can ensure that food, school fee relief, home gardens and health care go directly to families that most need them⁴⁹.

Experience from food and nutrition programmes provide valuable experience of mechanisms for engaging communities in identifying beneficiaries, for using participatory processes within the health system and for building strong local partnerships among organisations with complementary skills to support health⁵⁰ interventions (agriculture, health, education, social protection, and so on).

2.6 Ensuring fair financing

High levels of inequality were observed in many southern African countries between private and public sectors, and greater private sector contribution could be levered in the interests of equity⁵¹. Options for this include private sector contributions towards health personnel training through training programmes, ensuring that private health insurance scheme funds cover AIDS interventions and flow into public health systems and to primary and district facilities, and direct prevention and treatment provision at workplaces. While more direct service provision widens coverage, as noted by Ray et al (2003) this is often restricted to the male worker, and not their wife or children, particularly for migrant workers. Resources paid into wider public and community programmes would better reach families. The ability to lever and use such contributions depends on capacities within the state.

Fair financing in the context of the wider global inequities however goes beyond the national private sector. There has clearly been a shift globally in what is considered fair financing around AIDS. It is no longer fair for high income countries to withhold resources or for pharmaceutical companies to charge high prices and control patents while millions of people die. The accumulation of resources in the global fund and massive reductions in drug prices through generic production are visible signs of this shift. These changes have now produced a new tension in what is fair. This has led to initiatives such as the monitoring of drug prices that identify unfair differences

⁴⁹ Further evidence on food and nutrition strategies is given in Chopra 2003 Equinet discussion paper 11 <u>www.equinetafrica.org</u>

⁵⁰ For example, an integrated approach involving home-based caregivers, orphan committees, agricultural extension agents and health workers can ensure that food, school fee relief, home gardens and health care go directly to families that most need them (Chopra 2003).

⁵¹ Several large-scale employers were noted to provide ART to employees through workplace schemes. Through these schemes companies pay for ART at cost.

or markups. Opportunities exist for regional co-operation in such monitoring, particularly given SADCs existing role in regional bulk purchasing of drugs.

At global level, the question remains, if the mindset has changed, treatment access is now recognised as an imperative, funds are available and drug prices not the major barrier, why are poor people still dying? The challenge of the WHO 'global emergency' indicates that the health system factors that undermine drug access now need to be called into focus, and new activism applied to building health systems to meet the aspirations for treatment access.

There may be efforts to contain this tension – to introduce drugs through parallel or 'piggy back' NGO systems, to import and move personnel around to support programmes, or to simply restrict programmes to areas where health system resources are already found. There are even suggestions of adopting an 'emergency relief' approach to ART and setting up a separate NGO distribution channel from global funding headquarters in Europe to female peasant in southern Africa. These approaches go against the evidence: the approaches used in Brazil, the role of the state in successful southern African programmes like TB, and the importance of sector wide approaches to organising training and personnel needs. In contrast are the fragmented (even if exceptional) outcomes of NGO programmes and the growing debates around the impact of emergency relief on long term food patterns and social institutions.

The inability to absorb even available funds and to use them to reach communities in need implies that the health system constraints described earlier need to be addressed as a priority⁵². Systems of 'fair financing' and 'fair trade' need to be developed (as has been done with drugs) for structural problems, like the loss and migration of health personnel⁵³.

The funding arrangements for new resources should explicitly enable the goals of building national health systems. The modalities of Global Fund for AIDS, TB and Malaria (GFATM) funds identified in the country work in southern Africa indicated some problems around using GFATM funds for support of public sector health systems: ie where funds were held by a fund-manager and dispersed on a grant basis (project-by-project), where system strengthening aspects of applications were cut, where it was not made clear that GFATM funds could be used for basket support for the Ministry of Health through sector wide approaches, or where GFATM drugs were to be procured and distributed to districts through parallel systems.

It was also noted that GFATM funding is output driven and the release of further funds will be based on performance. Although this provides an imperative to provide an effective response quickly, it does not allow sufficient time for the wider public health system to respond, and further promotes isolated 'islands of

⁵² For example, in South Africa specific problems have been experienced with the HIV/AIDS conditional grant, impacting upon provinces ability to utilise the monies. These problems have included poor timing of the delivery of funds, and poor communication or planning as to provinces' needs. ⁵² Already disadvantaged provinces are least able to find the necessary resources to overcome these problems. (Ntuli et al 2003).

⁵³ The gains in prioritising public health within trade reflected in the Doha declaration on TRIPS need also to be obtained for example in reversing or limiting negative effects of GATS commitments on governmental authority in public health.

excellence' (Kemp et al 2003). This undermines the comprehensive systembuilding approach adopted by governments in southern Africa, necessary for propoor interventions, and essential for sustained treatment access.

2.7 Turning windows of opportunity into sustainable systems

After decades of macroeconomic measures and health reforms weakening health systems, there now needs to be an explicit global and national refinancing of health services, particularly in Africa, even if this does contradict fiscal and medium term expenditure frameworks. The capacities lost to public systems need to be systematically rebuilt to plan, manage and use resources, including new global resources for treatment of AIDS. Treatment activism has opened a real window of opportunity for meeting rights of access to treatment and overcoming unjust barriers to ART. It now needs to join with health activism to ensure that these goals can be realised for all through sustainable, effective and equitable health systems.