“Strengthening Community Voice and agency”

Abstract Book

Regional Meeting

January 26-28 2005

Kafue Gorge, Zambia

Regional Network for Equity in Health in Southern Africa (EQUINET)
in co-operation with
Centre for Health and Social Science Research (CHESSORE) and Training and Research Support Centre (TARSC)

CHESSO

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With support from: IDRC (Canada) and SIDA

CHESSO RE ZAMBIA

Southern African Regional Network on Equity in Health (EQUINET) in co-operation with TARSC, CHESSORE

STRENGTHENING COMMUNITY VOICE AND AGENCY IN HEALTH

Regional Meeting January 26th to 28th 2005
Kafue Gorge, Zambia

Objectives

The meeting will:

⇒ Present and discuss evidence to date to identify key findings on community involvement and social roles in health and their implications for health policy and practice

⇒ Review and recommend policy and practice options for strengthening community involvement and roles in health systems

⇒ Outline areas for follow up research, training, policy and programme support and publication for EQUINET on community voice and agency in health

Process

The meeting will:

⇒ Involve presentation and discussion of presentations (strictly no presentation of more than 20 minutes)

⇒ Include participatory reflection sessions to build collective and shared analysis and proposals

⇒ Include working groups to discuss issues in more depth

⇒ Provide for demonstrations of training, research and monitoring tools

⇒ Be focused on producing practical outcomes that we can act on rather than recommendations that others should act on

⇒ Aim to build participation from everyone and value the different experiences and inputs of all delegates

⇒ Aim to be enjoyable!!!

Programme

Wednesday January 26 2005		
9.00 am	Opening Introduction to the meeting objectives and to delegates	TJ Ngulube, CHESSORE
9.30am	Overview: Strengthening community voice and agency: review of the issues and the EQUINET programme to date Discussion	TJ Ngulube CHESSORE R Loewenson TARSC
10.30am	Tea/coffee break	
11.00am	Mapping the issues and areas of work Participatory exercise on the major issues and on the scope, focus and levels of work of the delegates	B Kaim, R Loewenson TARSC
12.30pm	Lunch	
	I Community roles and district health systems	
2.00pm	Session Introduction (5 min) - Effectiveness of DHBs in Zambia - Role of DHBs in Kenya - Involving communities in district health planning - Role of committees on patient care Discussions (15-20 min)	Chair: M Macwangi A Ngwengwe, M Macwangi A Odacha S Mbuyita C Mwandingi
3.45pm	Tea	
	IIA Community roles and primary health care	
4.00pm	Session Introduction (5 min) - Effectiveness of HCCs in Zimbabwe - Effectiveness of HCCs in Zambia Discussions (15-20 min)	Chair: C Mbili R Loewenson, I Rusike TJ Ngulube, C Njobvu
5.05pm	Rapporteurs on issues and actions	Rapporteurs
5.30pm	Day ends	

Thursday January 27 2005		
8.15-9.15	Participatory Training session	Ifakara
	IIB Community roles and primary health care –Communicable diseases	
9.15pm	Session Introduction (5 min) - Voluntary health workers in AIDS management - Community monitoring of ART programmes - Involving communities in malaria management - Lessons for HIV and AIDS prevention and control Discussions (15-20min)	Chair: G Musuka Z Sibiya A Mafuleka F Kaona F Banda
10.00am	Tea/Coffee (during the session,30min)	
	IIC Community roles and primary health care – family and social environments	
11.45pm	Session Introduction (5 min) - Privatisation of water and community roles - Community forums for involvement in water and sanitation Discussions (15 -20min)	Chair: B Chebundo H Dedat N Dayile, R Stern
12.45pm	Lunch	
2.00pm	Rapporteurs on issues and actions	Rapporteurs
2.30pm	Working groups on strengthening voice and agency in i. district health systems ii. primary health care What policies and programmes? What capacity/ skills gaps to be addressed? What knowledge gaps to be filled?	
3.30pm	Tea	
3.45pm	Plenary report back on working groups and discussion	Chair: R Loewenson
4.45pm	PRA review session	B Kaim
5.15pm	Close of day	

Friday January 28 2005		
	IID Which 'community'? – voice and agency of youth	
8.15am	Introduction to the issues (5 min) - Strengthening youth voice in adolescent health Discussions (15 min)	Chair: A Mtukula B Kaim
	III Brining community voice to National level	
9.00am	Introduction to the issues (5 min) - Community voice in monitoring access to essential drugs - Equitable access to ART - Fair financing: community voice in the community health fund Discussions (15-20min)	Chair: F Goma B Amailuk P Jones P Kamuzora
10,.30am	Rapporteurs on issues and actions	Rapporteurs
10.45am	Tea/Coffee	
11.15am	Working groups: 1: How to bring community voice and agency to national level 2. How to ensure social inclusion of vulnerable groups ? What policies and programmes? What capacity/ skills gaps to be addressed? What knowledge gaps to be filled?	
12.15pm	Plenary feedback and discussion	Facilitator TJ Ngulube
1.00pm	Lunch	
2.00pm	Follow up programme of work Lessons learned Areas for follow up action EQUINET follow up and resources	Facilitators: R Loewenson, B Kaim TARSC, TJ Ngulube CHESSORE
3.15pm	Closing remarks and views MP District health worker Community activist National state institution CHESSORE and EQUINET	 S Sikota I Mtitu H Dedat C Mbwili TJ Ngulube
4.15pm	Tea and depart	

P1: **Community roles and district health systems**

1.1 Assessing the Effectiveness of Health Governance Structures in Interceding the Community in Zambia.

Alasford Ngwengwe and Mubiana Macwangi INESOR, University of Zambia

In 1992 the government of Zambia introduced major health reforms (HRs) in the public health sector. The vision the HRs is to "provide Zambians with equity of access to cost effective and quality health care as close to the family as possible". Within the HRs context. The community is viewed as an important stakeholder and available resource. To facilitate community involvement in health care delivery and to ensure equity in health the government through the act of parliament established health governance structures. However there has been no systematic studies, which show whether these structures are effective in interceding for the community.

Therefore the overall objective of the study was to assess the effectiveness of health governance structures in enhancing equity of access and community participation in the delivery of health care services in Zambia. The specific objectives were to: (i) describe the status of health governance structures in Zambia; (ii) examine the linkages between the health governance structures and community; (iii) asses how the health governance structures represent and respond to community inters and needs; (iv) determine the extent to which the community is involved in the planning of health care services and resource allocation and (v) propose option for enhancing equity of access and community participation in the delivery of health care services.
A cross-sectional study design was used. Both qualitative and quantitative data were collected using various techniques; interviews, focus group discussion and review of records. Four districts (two rural and two urban) were covered in two provinces.

The major findings are: (i) health governance structures were established but the community is not aware of their existence and roles (ii) there is willingness by the community to participate in health issues but lack of knowledge limits there participation (iii) these structures are not effective in carrying there functions mainly due to a weak link between the community and the governance structures and (iv) gender issues are not adequately addressed in terms of composition membership to the structures and participation .

The paper concludes by making recommendations to make the structures more responsive to community needs and interest as well as revitalise community participation.

Historically, the state has played an important role as a social actor. Indeed, the social function of

the state was as critical to the constitution of the social contract as the quest for a secured territorial framework within which individuals and groups could exercise their livelihoods. The high point of the development of the social state came in the period after the Second World War with the growth and spread of different variants of social democracy and welfare states. Not surprisingly, African states at independence were invested with broad-ranging social responsibilities which they pursued with varying degrees of success. However; the onset of the African economic crises in the period from the early 1980s onwards and the rise on a global scale of the forces of neo-liberalism encapsulated the confluence of factors that culminated in the retrenchment of the social state - including from an institutional and expenditure point of view - and the enthronement of a narrow, market-based logic in the provision of social services - including, among other things, the pursuit of cost recovery, the imposing of user fees, the promotion of privatisation, and the employment of new public sector management strategies in the social sectors. At the same time, the social sectors, including especially the health system, were to suffer a serious erosion of capacity that was connected to the drain of talents, the degradation of the infrastructure of service, and the collapse of professionalism. Perhaps much more serious is the decoupling of social policy from macro-economic policy-making and its treatment as a residual category to which targeting strategies such as safety nets, various programmes for the alleviation of the social effects of economic structural adjustment and a plethora of poverty reduction strategies would be applied. It is suggested that this decoupling of social and macro-economic policy making is at the root of the expansion of the boundaries of exclusion that defines the structural roots of injustice in the social sectors generally and the health sector in particular. The prospects for the restoration of a socially-conscious state will depend on the capacity of governments to adopt an approach in which social policy is treated as an integral part of macro-economic strategies for growth and development.

1.2 Decentralisation and district health boards in Kenya
Amos Odacha KEMRI Kenya

Decentralization is one of the objectives emphasized in Kenya's Health policy framework paper and its subsequent implementation plans. It refers to the dispersal of power and transfer of responsibility for planning, management, resource allocation and decision making from central level to sub national levels or the periphery. There have been shifts towards decentralization as part of a broad policy framework in the recent past. Evidence to this effect includes the restructuring and strengthening of the Ministry of health District Level Management capacity under the District Focus for rural Development since 1983.

In 1992, District Health Management Boards were initiated to represent community interest in health planning and to coordinate and monitor the implementation of projects at the district level. These Boards *appointed by the minister* of health are in general empowered to superintend the Management of Hospitals, Health centers and Dispensary services and support Public Health care programs. District Health Management Boards have been mandated to superintend the

Management of the cost sharing and Exchequer funds and the overall delivery of district health services. Members of the Board represent the Ministry of Health, District Administration, Local government, Non Government organizations, Religious Groups and the local community. The representatives are selected by the Medical officer of Health from among the religious leaders s/he knows in the district, NGO leaders and community leaders using the recently updated guidelines. The names of nominees are forwarded through administrative ranks until ratified through the official government Gazette.

The term community participation is used loosely especially in international discourse. Often participation refers merely to " contributions" of community members to health service activities- be it in kind, cash or labor. This discussion will focus on community participation in the sense of decision - making (both private and public dimension). This extends the idea of increased involvement and responsibility from the personal sphere to the way people can influence the institutions and structures that operate in the health sector. Such influence remains very weak in Kenya. Rarely do health facilities take account of the views of the people they serve. This discussion will advance some reasons why this status exists from both historical and political perspectives. The way forward and possible solutions is to sensitize and empower communities to elect (not select) their representatives to boards and create community structures for debates and or feedback while at the same time working with Parliamentary committees on issues of equity in health and health care.

1.3 The voice of the community: Development of a procedural framework to facilitate the incorporation of the preference and priorities of the people in district health planning, Tanzania.

S Mbuyita S, AM Makemba and C Mayombana, Ifakara Tanzania

A fundamental move within the ongoing health sector reform has been the decentralization of planning and delivery of essential public services to the district. This requires the Council Health Management Teams (CHMT) to use an evidence based approach and cost effectiveness analysis as a measure to set priorities and allocate resources. However, these needs may not be adequate to capture and include the preferences and pressing demands of civil society in a given district, and in particular of the poor and marginalized members of the community. A procedural framework to echo the large voice of the community and their preferences into the planning process is lacking. We have developed a tool for the CMHTs that will facilitate the incorporation of the voice and preferences of the community through communicative actions in the district health planning processes.

Methods: We used participatory action research (PAR) approach to facilitate local planning process in two rural districts in southeast Tanzania. Two villages in each district were purposely selected. Using PAR, researchers and co-opted members of CHMT facilitated development of village action plans in which health priorities, preferences and development were systematically

identified by selected members representing all socio-economic groups in the community. Actions, roles and resources required were identified and included in the village action plans. Plans were then submitted and discussed at the district council planning meetings and dialogue initiated for inclusion in the district plan for implementation. We documented all stages of the process including, justifications used, actions and requirements at each level for the purpose of developing the tool.

Output: A draft tool to facilitate the incorporation of the voice and preferences of the civil society as well as their engagement in health matters and development activities has been developed. There is an on-going dialogue with Ministry of Health on its potential and perhaps wider use beyond the health sector. Also the potential of the approach in addressing issues of governance and equity in health will be presented and discussed.

1.4 The Work of the Permanent Committee on Patient Care and Infrastructure Management (PCPCIM)' as a voice of the community in patient care

CH Mwandingi, Namibia

The Permanent Committee on Patient Care and Infrastructure Management (PCPCIM)' was established by the Minister of Health and Social Services in Namibia in 2000 to counter a public outcry about the poor quality of health services. One of its main objectives was to ensure community involvement in the management of the health system in Namibia The Committee that was chaired by the Deputy Minister Of Health was given firing and hiring powers. It traveled the whole country visiting regions and health facilities to assess the quantity and quality of services that were offered. Their visits culminated in meetings between regional or hospital health authorities and regional councilors, including governors. The purpose of these meetings were to hear from community representatives how they see the quality of health services offered in their regions. One of the major lessons learned included the confirmation that communities and their representatives had good ideas that can aid in the improvement of health service quality. These ideas are usually not known to health managers at regional and health facility levels because of lack of regular communication between the two parties.

P2: **Community roles and primary health care**

2.1 Assessing the Effectiveness of Health Centre Committees in Zimbabwe

Rene Loewenson, Itai Rusike, Memory Zulu, TARSC and CWGH, Zimbabwe

This work sought to analyse and better understand the relationship between health centre committees in Zimbabwe as a mechanism for participation in health and specific health system outcomes, including representation of community interests in health planning and management at health centre level; provision of and access to primary health care services and community health knowledge and health seeking behaviour. A Case-Control study design was used, with four case sites with health centre committees and control sites selected in the same districts where there are no health center committees with sufficient distance between catchment areas to avoid spillover of results. This paper reports on the findings from the cross sectional community surveys OF 1006 respondents carried out in February 2003 and the health information system analyses. The study shows that public sector clinics are the primary source of health care for communities in Zimbabwe, but are not well resourced in terms of basic supplies and staffing. Health Centre Committees appear from the study findings to be associated with improved health resources at clinic level and improved performance of the primary health care services.. Communities in areas with HCCs had a better knowledge of the organization of their health services from the indicators assessed, making services more transparent to them. There was also evidence of improved links between communities and health workers in these areas. The study suggests an association between HCCs and improved health outcomes, even in the highly under-resourced situation of poor communities and poorly resourced clinics. This positive contribution of HCCs to health outcomes calls for greater attention to strengthening these structures as an important component of primary health care and of the health system generally.

2.2 Assessing the Effectiveness of Health Centre Committees in Zambia

TJ Ngulube, L Mdhluli, K Gondwe, C Njobvu, CHESSORE, Zambia

Introduction: This study undertaken by CHESSORE, as part of a collaborative multi-country study through EQUINET was designed to assess whether these perceptible positive gains were sustained; and if so, what factors contributed to this outcome. In addition, the study compared the performance of these four 'successful' HCCs with four poorly performing HCCs in districts with matching socioeconomic characteristics. The study also sought to identify the ideal desired features to successful community participation in the Zambian health system.

Methods: Using a semi-structured questionnaire, along with key in-depth interviews, PRA tools, stakeholder workshops, outcome mapping techniques and the collection of available data at

health facilities. A sample of 574 community interviews were undertaken, with 47 in-depth interviews, 35 key informant interviews, a stakeholder workshop, and 10 PRA sessions. To assess the impact of HCCs on the poor and vulnerable groups in the community up to four special group discussion sessions were held with representatives from marginalised groups (widows, orphans, the disabled and the elderly).

Findings: The HCCs were still in existence at all sampled health facilities. Those that performed well during the earlier survey had continued to perform well despite challenges faced, often with hostile reaction from the health system. The innovations introduced were still in place and functioning. However, on average HCCs were known to no more than 20% of community residents. HCCs were better known among the less poor socioeconomic groups than among the poorest groups in society. The better performing HCCs were also performed well with respect to participation in decision making, priority setting, monitoring expenditure and quality of services. Some HCCs had acquired authority to make own decisions on certain things. The better performing HCCs kept their user fees lower and provided for other alternatives to cash payments than the poor performing HCCs. All key stakeholders at district level, whether from HCCs, frontline health workers and from the DHMT were unanimous to say that HCCs have made an impact and their value to the health system was acknowledged. However, this impact was limited in terms of the desired equity goals and coverage. There was consensus too that HCCs had little or no impact among vulnerable groups and in important decision making roles at the health centre, especially in relation to clinical care services. Channels of communication have been developed between the health system and HCC in health promotion and provision of preventive services. Even then, there were still problems in the flow of information, which was usually one way from the health system to communities, with feedback being rare infrequent and ineffective.

P3: **Community roles in primary health care - communicable diseases**

3.1 Facilitating Local Participation In HIV and AIDS Management: A Case Study Of Volunteer Health Workers In A Rural Area In South Africa

Zweni Sibiya, University of Kwazulu Natal, South Africa

The study examined the role played by volunteer health workers in home-based care in a deep rural area in South Africa, in the interests of deepening our understanding of (i) the role that local community participation is playing in HIV/AIDS management in remote areas where people have limited access to formal health and welfare support; and (ii) ways in which community members can be supported in performing their vital role in this challenge.

BACKGROUND: Thousands of people in rural communities in South Africa are sick and they don't have access to health facilities. Many of them suffer from TB and are on DOT treatment. Home-based carers and community health workers (HBC/CHWs) who are currently observing these patients, suspect that most of them also suffer from HIV/AIDS though such suspicions have not been proved by medical staff, as these patients are reluctant to go for blood tests. Community members don't talk openly about HIV/AIDS, which they regard as a shameful disease. Traditional culture norms have lot of contribution in stigmatizing HIV/AIDS. HBC/CHWs that are doing voluntary work walk long distance helping sick people in their homes. However community members often don't give them much support in their difficult work.

METHOD: This paper draws on a study on home based care in a rural community, involving interviews and focus groups 100 people affected by or involved in responding to AIDS, as well as fieldwork diaries recording the context of the interviews, and observation of community meetings.

FINDINGS: Our findings shows that HBC/CHWs (95% women) are doing hard work with no pay trying to help sick people. Lack of support from the Health Department, government and other constituencies undermines their goals, as well as lack of support by community members. We are currently holding workshops with different organizations/groups in the community, and are planning to facilitate a community intervention. Our main objectives are to mobilize the community (i) to acknowledge the problem of HIV/AIDS; and (ii) to support the work of the HBC/CHWs. We also aim to facilitate partnerships between the local community and potential collaborators in local businesses, health and welfare departments and NGOs who have the potential to assist them in meeting their goals. The paper outlines the principles that are guiding these objectives. Providing information about HIV-prevention and AIDS-care; creating social spaces for dialogue about this information; promoting critical thinking about

the social roots of stigma; working with people to frame local responses to HIV/AIDS in a strengths-based approach; creating a sense of ownership of the problem; promoting an understanding of the role of social environments in helping or hindering effective responses; and building bridges with more powerful groups beyond the local community.

CONCLUSION: There is an urgent need for empowering local people with skills and training as well as alliances with outsiders who can help them. Projects only hope to succeed if local people are involved in programmes and planning. People feel proud and value the project if they have sense of ownership. This will also help them to be able to deal with other problems in their communities.

3.2 The HIV Gauge: Community Monitoring of HIV/ART services

Alfred Mafuleka, HST, South Africa

One of the major concerns is that the provision of antiretroviral treatment (ART) in the public sector is likely to exacerbate existing inequities in terms of access to and distribution of health services. (Ntuli A et al; 2003) The Equity Gauge and Treatment Monitor projects of the Health Systems Trust is in the process of developing a community based response to monitoring equity in access to ARVs by involving clinic committees / communities in documenting and monitoring access and impediments to HIV/ART services.

ACCESS TO INFORMATION There was clearly a need for information regarding HIV/AIDS in general as well as on the Operational Plan. Questions asked by the community and the request for a follow-up meeting on details of the Operational Plan reveal that there is a gap between governmental policy and knowledge of these polices on the ground. This is despite the active presence of certain CBOs dealing with HIV related issues in the community. There also appears to be communication gap between Dept. of Health staff at regional and district level as the sister in charge of the local clinic was not aware of certain issues around the implementation of the Operational Plan in her district. District level staff could also benefit from training around the biomedical issues relating to HIV and AIDS.

THE GENERATION GAP An abiding impression created at the meeting was that of a seemingly insurmountable communication problem between the youth and their parents/grandparents. Participants spoke of the impotence they felt in being able to exercise any cautionary or mandatory influence over the behaviour of the youth and of the effect of poverty in eroding traditional family hierarchies and powers. A suggestion from one community member that a support group be formed to assist parents and guardians to deal with these issues was enthusiastically met and developments in this regard will be obtained on our next visit.

STIGMA Discrimination and stigma still play a significant role in keeping the epidemic veiled – many participants spoke about the negative reactions of family and friends to finding out about their HIV positive status. However, at the same time, it was encouraging to note the desire of people to challenge and break stereotypes and misconceptions regarding people

living with AIDS – many people identified themselves as HIV positive at the meeting and there appeared to be a culture of openness around disclosure of status that we had not anticipated.

3.3 Identification Of Malaria In Children Under The Age Of Five Years And Correct Use Of Chloroquine At Household Level: The Role Of Community Participation In Health, Norhtern Province Of Zambia.

Fred Kaona, Mwengu Social and Health Research Center, Zambia

Nakonde district is in holoendemic malaria province, which is predominantly P. *falciparum*. While Zambia National Malaria Control Programme (ZNMCP) had specifically recommended chloroquine as first line anti-malarial drug, however, inappropriate use of this drug was prevalent in the district. Inappropriate use of anti-malarial drugs included taking drugs other than those recommended by National Malaria Treatment Guidelines on use or taking them for less than the recommended duration.

Objectives: To promote correct use of chloroquine in the community and evaluate the effectiveness of a health education and managerial intervention in changing the practices towards appropriate use of chloroquine and formulate a policy on the use of chloroquine at household level.

Design: Cross-sectional study in the intervention and control wards. A sample of 575 caretakers in the age range 15 years and above, whose children had suffered from fever 14 days prior to the commencement of the survey who consented to participate in the study, were interviewed. The sample was distributed as follows: 345 caretakers from intervention and 230 from control wards. Intervention and control wards were compared. Village Health Motivators and anti-malarial drug Vendors were identified and trained in 3 intervention wards, as a channel through which information on correct CQ dose malaria identification would be transmitted. Two control wards received no intervention during the study period

Mothers who considered fever alone as a sign of malaria, mothers consider it as malaria if a child had fever plus other symptoms. Type of anti-malarial drugs used, mothers reporting giving correct amount of CQ by National Drug

Results: There were 55% of the caretakers in the intervention wards who gave correct chloroquine dosage in the different age groups. A strong statistical difference was found regarding knowledge on correct CQ dosage between the intervention and control wards (PV= 0.000). Results revealed that there were 65.2% of the caretakers in the intervention wards who correctly mentioned malaria symptoms, as compared to 34.8% in the control wards. A strong association was found regarding action taken when malaria was suspected in the household between the intervention and control wards (PV = 0.000). Compliance with standard therapeutic doses and correct identification of malaria was poorest in control wards where no motivators and vendors were trained. Community participation was recommended as important in malaria treatment and control.

3.4 The Africa Partnership and Exchange Initiative on Local Responses to HIV/AIDS: Towards lesson-learning for HIV/AIDS prevention and control

Fackson Banda and Walter Tapfumaneyi, Panos, Zambia

The Africa Partnership and Exchange Initiative on Local Responses to HIV/AIDS project came into existence after a meeting held in Sun City, South Africa in May 2002. The meeting was attended by selected grantees in northern, western, eastern and southern Africa, with the aim of identifying common activities being undertaken by Ford-supported HIV/AIDS organisations in these sub-regions as well as mapping out a common agenda that facilitates the sharing of ideas and experiences in fighting the HIV/AIDS pandemic across the continent. The three specific objectives of this initiative are as follows:

- To provide a forum at which different Ford grantee organisations can share with one another their experiences from different geo-cultural contexts about how they are responding to the HIV/AIDS pandemic working at different levels (PLWAs, ordinary community members, local policymakers etc.);
- To undertake collation and analysis of such shared lessons as a way of helping the grantee organisations to develop more effective networking mechanisms among themselves as well as between themselves and other actors in the field of HIV/AIDS control; and
- To document any examples of good practices emanating from such shared experiences and lessons and disseminate them in easily accessible formats both for the benefit of the grantee organisations and others working around HIV/AIDS prevention.

This paper seeks to highlight the key lessons learnt by different Ford grantee organisations as a consequence of the face-to-face sharing of information and experiences, staff exchange programmes among the different organisations, and such other networking activities as were planned to achieve the three objectives above. Clearly, different organisations wrestle with difference problems. It is clear, however, that there is a certain commonality of response to the epidemic, not least reflected in the common themes pursued by the organisations - stigma, access to treatment, sexual health, poverty, gender relations, human rights, and economic empowerment – but also in the approaches deployed to tackle these issues - working with volunteers, the brain-drain from HIV/AIDS service organisations, working with the media, donor dependence vis-à-vis the sustainability of projects and the acquisition of property for organisations, access to ARVs and poverty. The grantee organisations studied were Catholic AIDS Action (Namibia); Health Systems Development Unit (South Africa); Women Fighting AIDS in Kenya (Kenya); Kibera Community Self-Help Programme (Kenya); Faraja Trust Fund (Tanzania); Centre for the Right to Health (Nigeria); and Community Life Project (Nigeria).

P4: **Community roles in primary health care - family and social environments**

4.1 Privatisation, prepaid water meters and its health implications on poor communities: A case Study of Phiri Soweto

Hameda Dedat, Municipal Services Project, South Africa

In February 2003 Johannesburg water which is a management company partly (part of whom is SUEZ)introduced a program called Operation Gczinamanzi (Operation Conservation)in a n area in Soweto, Johannesburg called PHIRI. The result of this installation reduced the estimated deemed consumption of 20kl to 6kl.The program was promoted as part of the Free basic water policy which the South African government and DWAF has endorsed. However, the form of implementation, both in terms of the prepaid meter and the water allocated to up to 22 people living on one area foretold disastrous social political and health implications. For example- in terms of households and indeed from a gendered perspective urban women were tasked with the responsibility of providing water in a dam, river, stream free environment. As such women were walking up to an hour to and from home and at times longer and more than once, to fetch water from friends and family in neighbouring areas. Many women were also having to walk with bundles of clothing since they are not able to wash their clothes at home. On returning these heavy bundles of wet clothes are placed upon their heads as they walk back kilometers to their homes. One of the women interviewed during the research had sustained a neck injury as a result. The inter-household dynamics are also important as women have to manage scare resource, determine which hygiene practices such as hand washing, bathing, toilet flushing, rinsing or washing of utensils etc can be compromised as a water "saving mechanism." in many instances some of the practices that families have had to embark on have taken the work "conservation to new heights" . Apart from this there are the intra- household dynamics amongst the community and between neighbours, with people either stealing peoples water from outside taps, people begging for water or being charged exhorbitant rates for water from neighbours. For example a glass of water cost R2 and a 5litre bucket costs R10.

Politically this raises serious issues both about governments commitment to improving the lives of the poor, especially when the implementation of a supposedly progressive policy has detrimental effects. It flies in the face of a constitution that upholds these rights. Worse still, given the HIV and AIDS epidemic, people with HIV are unable to bath or flush a toilet after use as a result of water limitations. If there is no money to buy water, PLWA have to survive or endure the risks of getting sick due to unhygienic and unsanitary condition as a result. Although the aim of the research was to look at the FBW policy it undoubtedly could not

overlook the deterioration in people's hygiene and health standards as a result of being subjected to 6kl or an entire cut off from any water and sanitation.

4.2 The development of and capacity building of a Water and Sanitation Forum in Khayelitsha

Nomvuyo Dayile Ruth Stern, Universoty of Western Cape, South Africa

Khayelitsha near Cape Town is an area with many socio-economic, environmental and health problems. Included are high rates of worm infestation and diarrhoea amongst the children in the informal settlements. In a recent study conducted by the Medical Research Council, it was found that diarrhoea was the third highest cause of death amongst children aged 0-4 in Khayelitsha in 2001. A multisectoral initiative, the Khayelitsha Water and Sanitation Programme (WSP) (formerly Khayelitsha Task Team, (KTT)) was established as a response to this problem. The WSP has two main components: a schools programme, that includes deworming of children, the development of educational materials, and improvement of water and sanitation in the schools; and a community based sanitation pilot programme to test different types of dry sanitation in two informal settlements in Khayelitsha. The importance of working closely with communities has been an important part of the programme from the start, although the nature of this involvement has changed as the programme has evolved.

The establishment of the Khayelitsha Water and Sanitation Forum has been an outcome of the community based sanitation programme. The importance of broadening the initiative to beyond the dry sanitation pilot was stressed by the community, as was the importance of extending the membership to represent all wards in Khayelitsha. The Forum therefore comprises representatives from each ward in Khayelitsha, plus an Executive Committee. The importance of linking community participation to the wider community structures in Khayelitsha, in particular the over-arching Khayelitsha Development Forum, was an additional factor in the development of the Forum. Building the Water and Sanitation Forum has been a lengthy process involving consistent input and support from the School of Public Health, supported by the Water and Sanitation Programme Coordinator and City of Cape Town officials. The Forum has two levels. The first, is an Executive Committee that steers the Forum. Members, who have been elected, meet weekly for business discussions, combined with capacity building. Included in the capacity building sessions is organisational issues, such as minute taking, and report writing, as well as discussions on the broader issues of health and sanitation. The Forum meets monthly and it is attended by officials from the Water and Sanitation Programme, which include representatives from Environmental Health and The Water Services Departments of the City of Cape Town. The agenda of the Forum is determined by the Executive Committee and/or previous Forum meetings, supported by the officials. Examples include the presentation of a report on the research into the acceptability

of dry sanitation, part of the former KTT programme. The proposed presentation will trace the progress of the Water and Sanitation Forum. It will present the history of the programme and providing the socio-economic and health context, and the capacity building process**.**

P5: **Which community? - voice and agency of youth**

5.1 Auntie Stella: Teenagers talk about sex, life and relationships – strengthening youth voice in adolescent health

Barbara Kaim, Training and Research Support Centre, Zimbabwe

'Auntie Stella' is an interactive reproductive health pack targeted at young people 13- 17 years in the southern African region. It arose out of participatory action research with school-going youth in Zimbabwe in 1997, drawing on and reflecting their experiences, stories and concerns in relation to their reproductive health. The pack and website use a series of 40 letters, written in the style of a missive to a newspaper agony aunt. Letters are accompanied by a reply from Auntie Stella, questions for small-group discussion and a facilitation and adaptation guide. Both the pack and website have been widely used in Zimbabwe and the southern African region, as well as in countries as far afield as India, Nepal, Ethiopia, Sierra Leone and elsewhere (see www.auntiestella.org). In 2004, TARSC undertook to update 'Auntie Stella', taking into account lessons learnt in the use of both the pack and website over the last few years, recent developments in the field of HIV and AIDS, and our growing understanding of the importance of moving youth beyond the concept of individual behaviour change to understanding their role in forging alliances with community and health services to effect social change.

The presentation to the EQUINET regional meeting will focus on lessons learnt in the design and use of 'Auntie Stella'. In particular, we will look at the central role played by young people in defining the content and methodology of the pack and how we use their collective voice to guide other youth through a process of critical reflection and change . We will draw on examples from the revised version to show how we are facilitating young people – through fun, creative activities - to explore their relationship with community and health services, and the important role they can play through advocacy and collective action to ensure their reproductive health needs are being met. This presentation will:

- Provide evidence of the link between youth involvement in participatory research and the uptake of these research findings in the design and implementation of youth/community action programmes
- Demonstrate effective ways of utilizing participatory methodologies to raise young people's voice and strengthen more collective forms of analysis and organization to pursue their interests in health

Auntie Stella: Teenagers talk about sex, life and relationships – strengthening youth voice in adolescent health

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'Auntie Stella' is an interactive reproductive health pack targeted at young people 13- 17

5.2 Peer Education as a Strategy for Community Behavioural Change in youth and vulnerable groups

Pedzisani Motlhabane, Matshelo Community Development Association

The Community based AIDS Education project, now Matshelo Community Development Association has been in operation since 1993, housed by the University of Botswana in Francistown Centre for Continuing Education. The project started with only twenty (20) peer educators. To date it is an autonomous NGO, with 16 projects and 350 peer educators in the country. It is an anchor partner to a Regional Project Support Group (PSG) in Southern Africa which has its offices in South Africa, Zimbabwe and Zambia. The project target unemployed out of school youth, commercial sex workers and single mothers. Its objective is to reduce STI/HIV transmission through safer sexual practices and to increase HIV/AIDS coping capacities in 16 prevention project communities.

Community Peer Education derives its strategy from the assertion that people evaluate changes not by scientific evidence or authoritative testimony, but by subjective judgements of close, trusted peers who have adopted changes and provide persuasive role models for change. Numerous reviews of health promotion campaigns affirm the importance of normative influence in promoting behaviour change. Community peer education program in Francistown Botswana has effectively harnessed social normative influence to successfully promote behavioural change at community level.

Through Peer Education, marginalised communities have been involved in HIV/AIDS prevention, care, support and treatment and orphan care. The project has managed to transform marginalised people with untapped invaluable skills into community's most valued complementary skills in health related field. They have dramatically increased manpower in HIV education and mitigation, reaching communities which are socially and geographically distanced from the conventional methods of health service delivery. Instead of solely relying on health facilities or health services for care and support, peer educators have been trained on Self Care and Wellness which is mostly psychosocial support and spiritual support.
Most of peer educators are now self employed, have formal employment or other sources of survival. Above all they has received outstanding community respect through community

involvement.

Matshelo Community Development Association is a member of Botswana Network of AIDS Service Organisation in the country. This is a national civil society organisation which represent all NGOs and CBOs dealing with HIV/AIDS issues in the country. The body seats in the highest policy making body, the National AIDS Council. At district level, it is a member of the local NGOs with a representation at the District Multisectoral AIDS Committees where NGOs and CBOs has special representation in pushing the agenda for the civil society and where interests of communities are articulated. MCDA has been instrumental in spear heading the opening of the counselling centre for HIV/AIDS people in Francistown. This has become the main national educational reference centre for other organisations starting similar centres elsewhere.

Challenges: All 16 projects are donor funded. It may be difficult to sustain these projects when donors pull of. There may be need to conduct research to find out why some community projects work and others do not work, what are motivators and de motivators. When are communities recognised by government as essential?

P6: **Bringing community voice to national level**

6.1 Bringing Community voice to monitoring access to essential drugs

Betty Amailuk, Health Action International, Kenya

In Africa, one in three people lack regular access to essential medicines. There are many well-known barriers contributing to poor access. Governments often struggle to manage, fund and regulate medicines supply, and consumers (“civil society”) often lack capacity to demand improved access to the medicines they need. As a result, essential medicines are too often unaffordable, of poor quality, or simply not available. This problem is exacerbated by the high burden of communicable diseases in Africa. The provision of essential medicines is, therefore, a key consideration in public health policy in every country.

Access to and appropriate use of essential medicines is a complex process, involving diverse stakeholders. Health Action International (HAI Africa) and the World Health Organization (WHO) have entered a partnership to address these challenges, drawing on each organization’s unique strengths and ability to bring several groups together in dialogue and cooperation. The purpose of the collaboration is to increase availability and affordability of medicines through improved interaction among ministries of health, WHO, and the civil society organizations of the HAI Africa network. Some of the major activities under this

collaboration include:

- Surveys were undertaken of the national pharmaceutical situation in Kenya, Uganda and Ghana. The surveys gathered data on availability, affordability, rational use and quality of medicines in health facilities, central/district warehouses and private medicines outlets. Data were also collected from households on access and use of medicines and from the national government on structures and processes related to medicines. The surveys will give a baseline on which to measure the impact of future interventions.
- Medicine price surveys are under various stages of completion in the three collaboration countries. The first survey was undertaken in April 2004 by the Ugandan Ministry of Health in collaboration with the WHO Uganda country office and Ugandan civil society partners of HAI Africa. Data are being compiled for the Kenya and Ghana surveys. By gathering comprehensive data about the prices people pay for medicines, it is anticipated that a strategy to improve affordability may be developed in order to improve access to medicines, even for the most poor.

HAI Africa would like to share some of the lessons that have come out of this collaboration project. Although a comprehensive and structured monitoring and evaluation plan for the collaboration is under development by HAI and WHO, HAI is currently in the process of seeking the perspective of the civil society partners specifically. This evaluation is being done by written questionnaire, and explores the civil society partners' view on perceived strengths and weaknesses of the collaboration, challenges experienced, and methods for improvement and further development.

6.2 Towards equitable access to anti-retroviral treatment? Experiences from Zambia

Peris Jones, Norwegian Centre for Human Rights, Norway

Universal access 'for everyone who requires it according to medical criteria' is the clarion call of the WHO/UNAIDS '3 by 5' initiative to extend life-preserving anti-retroviral treatment (ARV) to 3 million people by 2005. It follows in the wake of sustained pressure by treatment activists and their allies who layed bare the 'deafening silence' of the more affluent in their indifference towards People Living With AIDS (PLWA). When viewed against WHO's own estimates that, of the total number of adults in the developing world in need of ARV, only 8 per cent have access, the 'universal' ideal is still very much a distant goal. Attentiveness to the principle of 'universality' may even obscure anticipation of the problems of rationed phasing in and shortfalls. Such partial access sharpens the issue of 'who' exactly is receiving ARV. It is critical to ask how the increase in resources and new determination of governments and donors to extend access to ARV will impact upon these unequal relations. If we accept that the HIV/AIDS epidemic can be characterised as an expression of the crisis of governance,

then one avenue is explore how fairer decision-making might be instilled into governance processes. A fundamental starting point, and the concern of the article, is to scrutinize the criteria for patient selection for ARV and to explore the means and extent to which issues of equity and fairness in access can be located to the fore in policy.

The article will, first, critique the cornerstone '3 by 5' documents for their apparent neglect of equity in access. Second, in drawing on a desk study and short period of fieldwork in Zambia, alternative social criteria will be considered as necessary to avert social exclusion of particular groups. Different ethical principles underpinning selection criteria will be briefly discussed in this section. Third, some observers therefore attach great significance to procedural justice, and a fair process capable of adjudicating between competing principles, and, critically, in order to legitimize policy interventions. As important as a fair process is, it will be asked, nonetheless, whether this approach places too much faith in communicative reasoning and, as such, tends also to down play the vital role for alternative political readings of (community) 'participation'. Whilst it is claimed in ethical discussions that human rights do not offer much in adjudicating between and then prioritizing the claims of all those *eligible* for treatment, rights, following Uvin, should be considered as 'tools that crystallize the moral imagination and provide power in the political struggle, but do not substitute for either'. Scaling-up ARV, in conclusion, must consider and engage rights-based political efforts to recalibrate donor, state and civil society relations

6.3 Participation in Community Health Fund Schemes in Tanzania. Peter Kamuzora, University of Dar es Salaam, Tanzania

Within the health sector reform context, the Tanzanian government introduced district level prepayment schemes, known as the Community Health Fund (CHF) schemes as a mechanism for providing additional funds for financing health services in the rural areas. The government introduced the CHF schemes with one of the objectives being to improve health services management in communities by empowering the communities in making decisions affecting their health.

To achieve this objective, the government enacted a law (the CHF Act, 2001) that required the districts introducing CHF schemes to create, under the local government administration, a CHF management structure with organs incorporating community representatives. The management of CHF activities has to take place through two participatory organs: the District Health Service Board (DHSB) and Ward Health Committee (WHC) linked to the District Council and Ward Development Committee respectively. Although participatory mechanisms exist at district and ward levels, studies have indicated that there has been minimal community involvement in the management of the CHF schemes. One of the recent studies on CHF implementation in Tanzania identified two factors responsible for limited

community involvement in the schemes. First, covert resistance by the CHF officials reflected in a number of ways including failure to regularly hold meetings of the DHSB and WHC limits community involvement in decision making over CHF activities. Second, CHF implementation in the districts has been top-down in nature reflected in monopolization of decision making by the district officials and implementation of decisions taken at national level by the districts without consulting the communities.

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

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

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

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

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