# "Strengthening Community Voice and agency for health equity"

# Report



**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) Zambia and Training and Research Support Centre

(TARSC) Zimbabwe



CHESSO RE

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

# STRENGTHENING COMMUNITY VOICE AND AGENCY IN HEALTH

#### Report of the Regional Meeting January 26<sup>th</sup> to 28<sup>th</sup> 2005 Kafue Gorge, Zambia

#### 1. Background

The Regional Network on Equity and Health in Southern Africa (EQUINET) (<a href="www.equinetafrica.org">www.equinetafrica.org</a>) has noted that equity related work needs to define and build a more active role for important stakeholders in health. This means incorporating the power and ability that people (and social groups) have to make choices over health inputs and their capacity to use these choices to improve health. To do this requires a clearer analysis of the social dimensions of health and their role in health equity, i.e. the role of social networking and exclusion, of the forms and levels of participation and of how governance systems distribute power and authority over the resources needed for health. To understand these factors, EQUINET has been carrying out research work to evaluate the current and desired forms of participation within health systems in Zambia, Zimbabwe and Tanzania amongst other Southern African countries.

An EQUINET multi-country programme co-ordinated by CHESSORE and TARSC explored the functioning of district and clinic level structures (neighbourhood and health centre committees and district health boards) for community participation in terms of whether they

- i. represent the interests of communities
- ii. have any role in health system performance and resource allocation
- iii. include community preferences in health planning and resource allocation
- iv. improve equity in resource allocation
- v. improve health system performance, especially in relation to equity

The field studies and literature review in this programme explored outcomes in these areas, and how these outcomes were influenced by the functioning of these joint community- health service structures and the deeper underlying determinants affecting these outcomes, including their legal status, authority and mandate.

As a conclusion to this programme the EQUINET/ CHESSORE/ TARSC regional meeting on 'Community Voice and Agency in health' was held in Kafue Gorge, Zambia 26-28 January 2005. The meeting reviewed the results of the multi-country programme and of other experiences in the region of community participation in health, particularly in terms of representation of community interests, and of how participation improves the equity, relevance and quality of health systems. The meeting shared experience from individuals

and organisations working in east and southern Africa, and used this to identify a follow-up programme in the region. EQUINET proposes to produce a book on participation, governance, equity and health in 2005 using the papers from the multi-country programme and selected presentations from the regional meeting.

The meeting included presentation and discussion of presentations, participatory reflection sessions to build collective and shared analysis and working groups to discuss issues in more depth. Demonstrations were also provided of training tools. The meeting drew together a spectrum of different experiences from different countries and backgrounds in east and southern Africa. The delegates list is shown in Appendix 1 and the programme in Appendix 2. This report has been compiled by TARSC.

#### 2. Opening and orientation

TJ Ngulube, director of CHESSORE Zambia welcomed the delegates to Zambia. He introduced the objectives of the meeting as to:

- ⇒ 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

Rene Loewenson, TARSC director and programme manager of EQUINET gave an outline on EQUINET, its background and areas of work and on the background to its theme work on participation and health. It is six years since EQUINET was formed to support the Southern African Development community (SADC) in its commitment to secure equity in health. EQUINET offers a vision of health systems that serve equity. It presents a rallying call for those striving to work for justice hand in hand with the poor and marginalised.

She noted the guiding concept of equity in health developed by EQUINET in 1999:

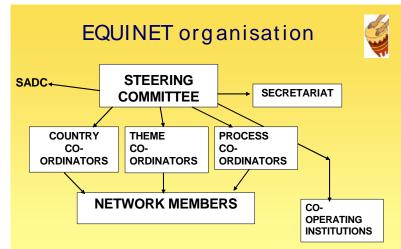
'Equity in health implies addressing differences in health status that are unnecessary, avoidable and unfair. In southern Africa, these typically relate to disparities across racial groups, rural/urban status, socio-economic status, gender, age and geographical region. EQUINET is primarily concerned 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 Steering committee, Policy Series #2, 1998

To advance people's health equitably / fairly / within the broader context of social justice, EQUINET called in 2004 for rising investments through the state and public sector in health, to build an effective state and public health sector able to exert leverage over the system as a whole, to value and entitle citizens in health and strengthen organized action of social groups. She noted that the space to implement these policies is being increasingly eroded by trade and economic policies in the current neoliberal globalisation.

EQUINET, as a network that has been explicitly formed to promote and realize shared values of equity and social justice in health, has produced research. evidence, stimulated debate and supported analysis on these elements of equity health oriented

systems, and has



supported networking regionally to support national and regional institutions in global engagement around these policies. As a result the conference has brought together a breadth of disciplines, institutional backgrounds, countries and experiences as a collective strategic resource to each other and to SADC on equity in health.

EQUINET works through existing institutions in southern and east Africa and supports the building of a perspective and knowledge on equity in through the provision of research grants and studies, including multi-country studies, of training, skills development and mentoring, of publications, through meetings and forums for dialogue, and through its newsletter and website. EQUINET supports equity actors and equity oriented social action, and their networking through information tools, issue forums, exchange visits, country level equity networks and alliances with parliaments and civil society. The evidence produced is used for policy engagement, to support SADC policies, to promote good practice and build skills.

She outlined the background of work on participation and health, and the key questions asked in the TARSC/ CHESSORE Multicountry research in Zambia, Zimbabwe, and Tanzania:

- Do participatory structures represent the interests of communities (and of which sections)?
- How are community preferences / evidence being included in health planning and resource allocation?
- Do participatory structures improve equity in resource allocation?
- Do participatory structures improve quality of health services?

This programme involved three field teams from Zambia (Chessore, Inesor) and Zimbabwe (TARSC/CWGH), a review of literature by NIMRI in Tanzania. This regional

• Strengthening peoples role in health systems

· A people oriented health system

meeting brings together the findings from the work with other research and community activities in the region. She noted that the discussions in the coming days would highlight many aspects of participation but that the work done in the last two years pointed clearly to the virtuous cycle that

needed to be build between strengthening people's role in health systems and building a people oriented health system.

Ngwengwe, R Loewenson, I Rusike on the effectiveness of participatory mechanisms in representing community views and enhancing health equity. The structures investigated included the Health Centre Committees (HCCs) in Zimbabwe, and the District Health Boards and Health Centre Committees in Zambia. Field studies aimed to understand how these structures performed, what impact they had on resource allocation and health service outreach and quality, and that influenced these outcomes.

The studies found that while social groups at either end of the extreme of the spectrum of wealth and poverty did not participate in these mechanisms, they were otherwise broadly representative of the community. Areas with functional participatory mechanisms generally had better Primary Health Care (PHC) statistics (EHT visits, ORS use) and better community health indicators (health knowledge, health practices, knowledge and use of health services) than in those without. The HCCs were taking part in many health activities and being increasingly relied on by health workers, particularly given staff shortages.

HCCs had however had a limited impact on management issues at the health centres, in meeting the needs of vulnerable groups, as well as in clinical care issues. Constraining factors included lack of information and asymmetry in knowledge. The studies suggested an association between HCCs and improved health outcomes, even in the highly under-resourced situation of poor communities and poorly resourced clinics.

Despite this HCCs were vulnerable to a number of factors limiting their effectiveness, including weak formal recognition by health authorities, lack of own area of authority, unclear reporting structures and role definition. The performance of governance structures was influenced by the attitude and responsiveness of the health authorities and the participation of strong community leaders, both highly variable across districts. The HCCs noted their lack of knowledge and/or training on the health system and the lack of resource investment in their functioning.

Even with a somewhat ambivalent attitude from health authorities, a strong will to sustain and maintain their participation in health service delivery exists. This needs to be built on and enabled. There are clear signals in these studies of the virtuous cycles of positive health outcome between HCCs and performing clinics. What is missing perhaps is to translate this into wider national policy and practice.

In the discussion delegates noted that skills in policy analysis were extremely important in engaging around health equity issues, but that they needed to reach community level if they were to assist communities to be more powerful in health. The extent of participation depends on how power is distributed across different actors and social groups, how health systems are structured to reflect this from community to national level. As noted in the EQUINET introduction understanding public participation is thus deeply connected with understanding how health systems are organized to reflect the central role of people.

We carried out a participatory exercise facilitated by Barbara Kaim and Rene Loewenson (TARSC) to reflect our understanding of our current health systems and our vision of what a people centred health system would be like.

A story was told of a girl aged 16 in her third trimester of pregnancy coming to the clinic in a poor rural area. She arrives on a day when the clinic is busy with mother and child health services and its usual line of patients for treatment.....

Delegates identified the different actors that would be found in this situation:

In the family: Young girl, Mother, Father of girl, Father of the child, Friend of the

girl, Aunt

In the community: Traditional birth attendant, community based health worker,

School, Chief/ traditional leader, Community health committee,

NGOs, Local councilor

In the health services: Nurse; Clinic receptionist, other patients In the state: Ministries of finance, health, labour, transport At other levels: Member of parliament, Cabinet, IMF/World Bank

We assigned ourselves in these different roles and placed the actors in a 'sculpture' at different heights, distance from the girl, linkages with her and positions to reflect their current roles in relation to the girl in responding to her health needs.

In the sculpture of the current health system

- The girl was the weakest person
- The father had greatest authority in the family and the mother took a role of pleading for her daughter and the father of the child was absent from the family.
- Community leaders were distant, and relatively uninvolved in the girl's problem
- Community based health workers were close to the family but not influential in the health services
- People at the clinic posed barriers to the girl and the nurse, while more powerful, was difficult to reach
- The political leaders in the area were distanced from health services and from the family
- Cabinet and Ministry of Finance made decisions on economic grounds that affected social ministries and the health services
- IMF and World Bank influenced these national decisions with little or no understanding of the family's situation.

We rearranged the sculpture to reflect a people oriented health system. In this case

- The girl was supported and surrounded by her family and by the father of the child:
- The father and mother work hand in hand to resolve the concerns of the daughter
- Community leaders are supportive intermediaries between the family and the state or other services
- Community based health workers are an active link between communities and health services
- The health services are accessible and health workers work as a team in the interests of the girl
- Political leaders intervene in the interest of the family and the heath services
- Cabinet and Ministry of Finance make decisions that balance economic and social priorities
- IMF and World Bank, together with donors, support national health systems to support the needs of the girl

We discussed in 'buzz groups' what we need to move from the current to the desired situation. There were different clusters of inputs or action:

- 1. In a people oriented health system, *supportive health services* ensure that clinics that are accessible and close to communities, provide reasonable quality services and are community oriented. They use participatory forms of health governance that provide platforms for community participation.
- People oriented health systems build social mobilization and strong social movements through skills and knowledge for community empowerment, supported by state, health services and NGOs who advocate

for community interests and who support networking of social groups within communities.

- 3. In a people oriented health system *political action and co-operation* from family to national level organizes community and social support to household level, and power and authority over resources is decentralized to lower levels of health and political systems. Parliaments are informed of and responsive to local issues, accountable to local communities, able to exercise pressure for communities and make links to the executive to influence finance and global institutions on behalf of the community. This calls for political willingness and leadership to change situations that disempower communities and states that are responsive to community issues.
- 4. In a people oriented health system economic resources are channeled by an active welfare state in favour of the people, ensuring growth in economic resources at community level and the infrastructure, human resources, supplies, and equipment for health. Such systems provide equitable resource allocation by government, with fair budget allocations to social needs through strengthened sector wide funding approaches and with resources allocated to empower communities and civil society organizations.

We noticed that there were delegates at the meeting that work in these areas, meaning that we ourselves could make a difference in moving from our current health system to the people oriented health system we desire. Those at the meeting primarily worked with communities and within political authorities, but there were also delegates from state, health services, and from institutions providing or involved with economic resources for health.

#### 3. Community roles and district health systems

Four presentations were made on how well community voice is integrated within district health systems.

# 3.1 Assessing the effectiveness of health governance structures in interceding for the community in Zambia.

M Macwangi INESOR, A Ngwengwe 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 this context, the community is viewed as an important stakeholder and 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. The study reported assessed the effectiveness of the health governance structures established at district level, their linkages with the community; how well they represent and respond to community interests and needs and the extent to which the community is able to use them to participate in the planning of health care services and resource allocation decisions. 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 were presented: These showed that district health boards (DHBs) were established but the community was not aware of their existence and roles. Communities are willing to participate in health issues but lack of knowledge limits their participation and the structures are not effective due to weak links between them and the community. Both in terms of membership and participation women were particularly marginalised. There were ineffective mechanism for information flow between the

community and popular structures, undermining the role of DHBs as a voice for the people in health planning and decision making.

"We ordinary community members are not involved in planning of health programs and activities, we just learn about most health activities of the NHC and other committees when our headmen call us for meetings. During these meetings we are only informed of what we are expected to contribute during the implementation of the activities. Sometimes they ask us to do some work or contribute towards a building" – male, from Monze, Zambia.

# 3.2 Decentralisation and district health boards in Kenya A 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 since 1983. In 1992, District Health Management Boards (DHMBs) were initiated to represent community interests 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 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 often very loosely. In this analysis community participation was used to mean involvement in decision - making 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.

# 1.1 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.

Ifakara used a 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. 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. All stages of the process were documented including, justifications used, actions and requirements at each level for the purpose of developing the tool.

The programme developed 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 . There is an on-going dialogue with Ministry of Health on its potential and perhaps wider use beyond the health sector. There were numerous lessons learned from this process:

- PRA processes and communities contribute to health sector and local government reforms (examples were given of community intervention to plan for a school & dispensary, construct a mortuary and provide sufficient clean & safe water)
- Communities are concerned and capable (as witnessed by the successful development of village plans; the long working hours, positive participation and contribution)
- These processes can support local initiative for participation, transparency and good governance (for example a special committee was formed in one area to explore misuse/misappropriation of village properties by local leaders)
- They offer a platform for marginalised groups, such as youth

# 1.2 The Work of the Permanent Committee on Patient Care and Infrastructure Management (PCPCIM)' as a voice of the community in patient care C H 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 was 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.

In the **discussion** that followed the presentations delegates noted the need to strengthen the work by clearly showing how the evidence was gathered (methodology and source). In Namibia delegates queried how the process, led by string central intervention, transfer power to the community. It was noted that the investigations were initiated by spontaneous complaints to the media coming from communities, but that thereafter high levels of political power intervened leaving both health workers and communities relatively marginal. It was suggested that it may be better to have dialogue between health workers and communities in a more structured manner. It would be

useful also to know how the health workers viewed the process

The delegates also observed the importance of selection in ensuring accountability of members of mechanisms for participation like the DHBs. Selection from above appears to lead to accountability to above, and to lead to lack of clarity on how people got to boards.

It was also noted that in environments of scarcity, elites can distribute resources as rewards undermining redistribution by the state or more popular approaches to planning. In these situations work on participation can become politicized and some groups can be excluded from the process. Further influence from donor projects and use of donor funds can confuse community roles.

#### 4. Community roles and primary health care

Two presentations were made on community voice within primary health care systems.

### 4.1 Assessing the Effectiveness of Health Centre Committees in Zimbabwe

R Loewenson, I Rusike, M Zulu, TARSC and CWGH, Zimbabwe

Itai Rusike outlined the work of the Community Working Group on Health and the work done to strengthen joint community health service structures, health centre committees (HCCs) linked to the clinic and covering the catchment area of a clinic. HCC's have great potential in improving joint community health service dialogue, representing communities in decision making and in the implementation of health services at local level. HCCs were proposed by the Ministry of Health in the 1980s to assist communities identify their priority health problems, plan how to include community input and contribution, organise and manage local resources. HCCs have however faced problems of top-down decision making, centralized decision making within the health authorities, declining support from primary care and preventive services and new challenges from HIV and AIDS.

The CWGH gave support to HCC's by reviving dormant committees, supporting community identification and prioritisation of local health problems and solutions and raising health concerns with relevant authorities at district level. The CWGH has promoted primary health care through its civic education programme, training of local community health workers and through building capacity in committees to manage local resources and promote voluntarism in community work. The CWGH provides technical and financial support (small grants to facilitate committee planning and administration) to the HCC's, advocates for decentralisation in the control of resources and decision making to district level committees and lobbies government to formally recognise HCC's.

In 2003 TARSC and CWGH 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. Rene Loewenson (TARSC) presented that case -control study 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. She reported 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 showed 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. Despite this only about a third of people actively participated in the work of the HCCs. 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. She noted that 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.

# 4.2 Assessing the Effectiveness of Health Centre Committees in Zambia

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

This study undertaken by CHESSORE, as part of the collaborative multi-country study through EQUINET was designed to assess whether positive gains from health centre committees were sustained; and if so, what factors contributed to this outcome. In addition, the study compared the performance of 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.

The study used 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).

The researchers found that 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.

In the **discussion** delegates explored further the background and functioning of the Zimbabwe and Zambian mechanisms. The importance of formal recognition through law was further discussed as important but not substituting the importance of their representativeness and capabilities and that the role of formal recognition as ensuring that they get resources for training, are included in planning processes and that their roles and functioning are transparently budgeted in district budgets. It was also noted that the structures need to keep close links with the communities for their sustainability

The issue of trust was raised: is it possible to better understand and operationalise what builds synergy between communities and health services at the primary care level. What contributes to relationships of trust between communities and health services and how can this be strengthened and reinforced?

# 5. Training in participatory methods for community voice in health planning

Selemani Mbuyita facilitated a training session on the use of participatory methods for community voice in planning. Through discussion of a series of 5 drawings that tell a 'story' he drew issues and views from the delegates as 'community members'. The discussion highlighted that it is not always useful to have a helping hand! There can be greater sustainability if the community owns and control the actions.

Ownership of policies and programmes central community voice This point was debated amongst the delegates. It was suggested that control should not necessarily mean self reliance and that community contribution in health is linked to community control over productive wealth. Communities need to be able to lever inputs from a range of sectors that have resources relevant to health.



A second exercise was implemented that demonstrated relations between leaders and people. A number of delegates as villagers closed their eyes and were led by one who could see. Each reviewed their experience.

The leader felt that it was not easy; there was resistance from the people, the number of people made it hard, it was not moving at the desired speed.

The villagers felt insecure, used survival tactics, were fearful of the obstacles and concerned at not being consulted.

Observers noted that the community did not ask and leaders did not consult. Lack of transparency, of information flow, weak consultation undermined the trust between leaders and people, and the effectiveness of their action. While leadership implies trust this needs to be supported by mechanisms for building communication and transparency.

#### 6. Community roles and primary health carecommunicable disease

A number of presentations focused on people's roles in specific areas of disease control within the health system. Many related to HIV and AIDS.

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

Z 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 understanding of 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 of the ways in which community members can be supported in performing their vital role in this challenge. Thousands of people in rural communities in South Africa are sick and do not have access to health facilities. Many of them suffer from TB and are on DOT (directly observed therapy) treatment. Home-based carers and community health workers (HBC/CHWs) who are currently observing these patients, suspect that many are HIV positive, although neither medical staff nor patients are open about this. Community members don't talk openly about HIV and AIDS, which they regard as a shameful disease. Traditional culture norms have stigmatized HIV and 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.

A study of home based care in a rural community involved interviews and focus groups of 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. The study showed that HBC/CHWs (95% of whom were 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. The team is currently holding workshops with different organizations/groups in the community, and is planning to facilitate a community intervention. The main objective is to mobilize the community to acknowledge the problem of HIV and AIDS and to support the work of the HBC/CHWs. It also aims 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.

The work indicates that there is an urgent need to empower local people with skills and training as well as alliances with outsiders who can help them.

# 6.2 The HIV Gauge: Community Monitoring of HIV/ART services A 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. In November 2003 the South African Government launched its Comprehensive HIV and AIDS Management, Care & Treatment Plan for SA ("the Operational Plan"). The plan aims to provide free ARV drugs through the public health system and to enrol and treat 53,000 people nationwide by 31 March 2004. Two operational sites have been set up in Sterkspruit/Entsimekweni (EC) – rural & Umlazi (KZN, Dbn) urban to monitor the roll out of the plan at community level. To monitor will highlight inequities between urban & rural areas and provide solid information on a range of HIV related services from a community perspective. It will provide baseline data,

to track changes & help understand factors contributing to those changes. The Gauge aims to assist communities take initiative to monitor, evaluate & facilitate provision and delivery of HIV related services in local areas

In the sites monitored there are harsh climatic condition, poor infrastructure and unemployment. By January 2005 only 51 clients were on ARVs. Barriers to access included lack of information, fear of knowing ones CD4 count, uncertainty about transmission of HIV after treatment, low perception of risk of AIDS in some groups and stigma.

"We are black people, we hear that there are these pills that can help us, but sometimes we need proof of these things. Do you have these pills so that we can see what they look like?" - Elderly man

Community members expressed doubts about the ability of the Health system to deliver "roll-out" of ARVs –negatively impacting on decisions to seek treatment.

Concerns were about Human resources & continuity of supplies. Further concerns were about transport costs to collect ARVs and food security. The need for food continued to outweigh the need for ARVs.

The findings indicate a need for partnerships with affected communities, including PLW HIV/AIDS, to determine how people living with HIV/AIDS understand ART, their health-seeking behaviour and the acceptability of treatment. Community participation provides an opportunity to include those living with HIV/AIDS, their families and communities in helping to assist people with HIV/AIDS and will help to overcome some of the key obstacles to an effective response, including denial, stigma and discrimination (Grubb *et al.* 2003).

The experience in Sterkspruit has demonstrated the potential benefits and synergies that can arise out of a co-operative working relationship between community members and health personnel.

Information is also needed. Key audiences for information exist at all levels of the community and include health care workers of all grades. In this context, community level refers to the general public, as well as people directly involved with HIV-related treatment for themselves or their families. Project staff have devised a plain language version of the Operational Plan and have run workshops on the various aspects of HIV and AIDS and the Operational Plan. Both communities and clinic staff have attended these sessions and discussions have contributed to sharing valuable information and demystifying many of the myths around AIDS. The presence of both health personnel and community members contributed to strengthening relationships between the two groups.

Shame and secrecy works against adherence to ARV treatment because privacy is sought and medicines have to be kept hidden. There is no easy way to address stigma. In the programmes interactions with community members, however, many people were publicly declaring their HIV positive status.

6.3 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, Northern Province Of Zambia. F Kaona, Mwengu Social and Health Research Center, Zambia

Nakonde district is in holoendemic malaria province, which is predominantly P. *falciparum*. While the 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.

The programme aimed to promote the 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. A cross-sectional study was implemented 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.

The findings indicated that 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. 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. 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.

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

F Banda and W 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.

The presentation highlighted 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).

In the discussion that followed the papers delegates asked whether the AIDS monitoring tool takes account of other health and health service concerns in communities, and whether it provides information on the nature of the people accessing ARVs in terms of income and gender. At this stage it does not. It was noted that decades after their introduction we continue to have problems of sustainability and support of community health workers and to give poor recognition to the role of non health service personnel in health issues, such as vendors, community motivators. We need more effective ways of structuring these roles into health interventions.

#### Community roles and primary health care- family 7. and social environments

Two presentations from South Africa focused on different approaches to dealing with essential services for health.

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

H Dedat, Municipal Services Project, South Africa

Hameda described how 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 an area in Soweto, Johannesburg called PHIRI. The result of this installation reduced the estimated deemed consumption of water from 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, and 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 also had 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 people's 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 cost R10.

Politically this raises serious issues both about government's 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.

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

N Dayile and R Stern, University 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 Khavelitsha 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 are 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 presentation traced the progress of the Water and Sanitation Forum, the history of the programme and providing the socio-economic and health context, and the capacity building process used within it. The programme built steps of climate setting (introductions, listening, building trust); studying the community, as individuals and as a group and assessing what they can do – generally and their skills. It strengthened the executive committee by determining potential roles and building their confidence through training. The team noted continuing challenges in the group dynamics, volunteerism, in the attitudes of professional staff and assumptions of the superiority of professional 'expertise'. Further challenges were experienced in the community and staff changes and constraints of bureaucracy. They recommended that work with communities take time, and integrate features of openness, shared ownership and planning, clear role definitions and development of professional capacity. The project demonstrated the importance of community entry processes, of working with bureaucracies at the same time as working with communities and the value of a

comprehensive PHC approach. The challenge is one of sustainability.

In the **discussion** the tension was noted between struggles against neoliberal policies that undermine community health and work that aims to improve life within these policies. Are these parallel, complementary or conflicting struggles? Do efforts to 'manage' life under these policies send an implicit message of the acceptability of such policies, even when they undermine communities? There was caution expressed that the alternative and interim becomes the permanent state and that we should not accept second best. The role of different forms of social action was also explored. Use of current legal, bureaucratic and other mechanisms were identified as important as were social movements. It was noted that communities should be included upstream in the policy analysis and engagement so that they build wider perspective on the issues they confront, and that there is need to bridge local struggles with national policy through key stakeholders in civil society, local government, parliament and so on.

#### 8. Which community? - voice and agency of youth

Do community initiatives really involve all in the community? Are the most vulnerable groups reached and included? How is this achieved? Two presentations looked at different dimensions of vulnerability and how work can be designed to build the role of such groups in health.

# 8.1 Auntie Stella: Teenagers talk about sex, life and relationships – strengthening youth voice in adolescent health B Kaim, Training and Research Support Centre, Zimbabwe

The presentation started with a story that showed the risks of 'thinking for' young people. This raises issues of how and when adults 'hand over the stick' to young people in health to enable them to play a more meaningful role in health.

'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 <a href="www.auntiestella.org">www.auntiestella.org</a>). 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 focused on lessons learnt in the design and use of 'Auntie Stella'. Barbara examined the central role played by young people in defining the content and methodology of the pack and how they used their collective voice to guide other youth through a process of critical reflection and change. She drew on examples from the revised version to show how they 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. The presentation provided 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 and demonstrated 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.

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

P 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 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 represents 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 have 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.

Pedzisani raised the challenges that all 16 projects are donor funded. It may be difficult to sustain these projects when donors pull out. There may be need to conduct research to find out why some community projects work and others do not work, what are motivators and demotivators. When are communities recognised by government as essential?

In the **discussion** the delegates gave other examples of how young people and other groups are 'overlooked' in health policy and planning, even when they have something vital to contribute. One example was of the youth parliament in Zimbabwe that gave very important input to the parliamentary discussions on reproductive health from their perspective.

Encouraging such input needs to take into account differences that may exist between urban and rural youth, and use exchange visits to facilitate exchanges across different

youth groups. In any programme the participation of such groups cannot be assumed – it needs to be encouraged through deliberate design of methods to incorporate marginalized groups, to encourage them .to look collectively and critically at their situation and to raise their profile in wider community initiatives.

#### 9. Bringing community voice to national level

How do these initiatives at community level translate into national profile, policy input and lobbies? How do social processes at community level influence policies at national level that have a strong impact on them? What vehicles exist for national level support of people centred health systems? The final presentations in the meeting focused on these questions.

# 9.1 Bringing Community voice to monitoring access to essential drugs B 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.

Betty presented the work of Health Action International (HAI Africa) to address these challenges, bringing 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.

She shared some of the lessons that have come out of this collaboration project. Within civil society she noted barriers of lack of capacity, funding and in the attitudes of public officers. The collaboration with WHO has opened doors for these civil society organisations and also brought financial support. It has widened the perspective of both WHO and civil society organisations. This raises new organisational challenges of how to build the partnership given the different systems and methods of work. Finally she noted that to translate the experiences and inputs from community level to national and even global policy you need to gain the "ear" of policymakers, ensure that advocacy is knowledge-driven, provide and improve the interface between CSOs and policymakers and provide checks and balances in the processes so that it can overcome possible areas of conflict.

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

P 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 laid 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 to 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.

In his presentation Peris drew on a desk study and short period of fieldwork in Zambia, to explore social criteria for ARV access as a means to avert social exclusion of particular groups. He reviewed the role of procedural justice in this, in setting up a fair process capable of adjudicating between competing principles, and, critically, in order to legitimize policy interventions. As important as a fair process is, he questioned 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, he commented that rights should be considered as 'tools that crystallize the moral imagination and provide power in the political struggle, but do not substitute for either'. He raised some implications for ARV roll out in Zambia if communities are to have an effective role and be reached. In terms of procedures 'scaling-up' requires greater clarity concerning criteria setting and eligibility for treatment, backed by publicity and treatment literacy so people know these. If ofeered on a first come first serve basis then scaling up calls for a specific budget to target those that may be excluded. National HIV/AIDS Policies should be finalized and should explicitly define channels that enable genuine and effective participation through advocacy. These should make clear the human rights standards and state obligations to provide a moral force for accountability. These measures are however difficult to apply without the material conditions for their implementation, such as for example the human resources to deliver on ART and the donor debt cancellation to enable this.

# **9.3** Participation in Community Health Fund Schemes in Tanzania. P 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. Peter outlined how 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.

To overcome these constraints he proposed a number of measures:

- Rejuvenate existing participatory structures such as the DHSB & WHC while balancing powers of different groups within them. They should have more community representatives, including from marginalised groups, participation contracts that spell out the agreed distribution of responsibility and powers of the different stakeholders
- Monitor and gather evidence to back community roles and inputs: On the functioning of the mechanisms, their composition and selection, process of involvement in decision-making and on community problems and needs,
- Advocate and change attitudes: networking community organisations to advocate for improving participation, to build a culture of consultation and to ensure transparent information exchange between communities & district health systems.
- Resource community levels of health systems: develop joint fund raising strategies; allow retention of funds by communities for agreed spending plans; ensure community mechanisms have a say in district health priorities identification and in resource allocation decisions
- Build key skills for participation: for Community organization; advocacy, negotiation and mobilization; communication; information collection and analysis; planning and priority setting; and for financial management

In the **discussion** that followed the session it was noted that structural and functional weaknesses in the health system at district level impede both the upward communication of community issues and the downward distribution of resources and policies for these. Access to ARVs is one measure of the state of the system in this respect. Weaknesses in using resources for ART may be 'blamed' in states politically, rather than on the weaknesses in the systems that they use for responding to problems. The design of policies also raises issues. For example pre-payment for health care can marginalize access and set up commercial relationships between providers and communities and needs to be questioned.

This raised a number of issues. How do we create structures at district level that are effective advocates for access? What common values across CSOs and states allow for the engagement of authorities around resources? How do we ensure that it is not only the strongest voices that get heard in this?

# 10. Learning from experience to build a people centred health systems

In the opening session it was agreed that rapporteurs would listen across all the presentations and discussions and note the major issues and actions arising in relation to the driving forces identified on day one of social mobilization, political engagement, resource flows and health service intervention. These inputs were integrated within a a framework and discussed by the delegates to identify the positive features of a people oriented health system and to highlight the areas that needed further debate and review.

#### Social mobilization and community organization

Community mobilization is central: this calls for a range of organizing, resourcing, supporting, caring, engaging and training activities. These activities form the basis for people oriented health systems and need to be recognized, resourced and supported by other levels.

Community mobilization needs to be supported by clear perspective, which builds understanding of how local situations reflect national and even global policies. Community action should not be isolated from how it affects and is affected by such policies.

Hence for example calls for enhanced community contributions to health cannot be isolated from policies that enhance the productive capacities of communities to make those contributions, the way the contributions change the relationships between communities and state or how these contributions affect access to services where access should be universal.

This raises a number of issues: What mechanisms and processes reach and



engage all levels of communities that need to be core to a people oriented health system?

The vehicles raised in the meeting to reach communities for this included religious and traditional groups and community and non government organisations, and within health systems the clinics, health centre committees and community health workers. This raises issues of how well these organisations reach the extended family, households and particular social groups, what perspective they work with, their capacities and resources, and how well

they bridge the communities and those with resources and authority.

There has also been significant use of volunteers within communities in health – this needs to be recognized, and the issues around this more thoroughly examined in terms of the role they play, and their motivation, payment, employment, and the opportunity costs and gains from volunteer work.

#### Community interface with the primary health care system

The interface between communities and the primary health care system is the foundation of a people centred health system.

This interaction needs to be informed by critical analysis of the way different policies affect it, of the policy goals and values that inform it, and of the power relations that impact upon it.

To build synergy, trust and co-operation between communities and the various elements of services, community and political leadership needed we need to recognise and manage the power relations that give space to these interactions, that build or block accountability of those with authority to people, that enable or block effective representation – including of specific groups like women and youth-and that shape the responsiveness of services to input from communities. Some recognized blocks exist, such as the reluctance of technical health services to devolve power, and there have been some initiatives to channel power, such as special committees mandated from higher levels.

Building trust and co-operation calls for a range of enabling measures:

- Formal recognition of community roles and ownership in health systems
- Structured 'space' for participation, that factors in the time, planning, decision making mechanisms, accountability mechanisms and resources to build and sustain them. This implies structures and intermediaries that build bridges that involve community and health service personnel. The weaknesses in the current mechanisms (e.g. selection, functioning of HCCs, DHBs) for this need to be addressed.
- Signals of recognition and value of community resources and experiences
- People oriented towards and capable of advocating and supporting participation supported by tools and resources for this
- Mechanisms and tools that reinforce transparency and trust (openness, honesty, information sharing, communication)

We should not assume that this interface is functioning well- we should monitor and evaluate its performance. How well are health systems reflecting social needs and priorities? How are health systems processes enabling co-operation and trust? How sustainable are the mechanisms and processes? Where are they making a difference?

#### A health system that supports participation

At **primary health care** level this was noted to call for well performing community oriented health services, that integrate, support and reward community health workers and have various forms of outreach to communities. It was noted that this also needs a basis in health care services that have motivated oriented health workers working in improved conditions with accessible medication and other inputs for health. At present clinics have too low a profile in the health care system to achieve this and participation is difficult to strengthen in the absence of a higher profile for the clinics and PHC services within the health system, including a more structured tracking of the resources and capacities at this level.

At **district level** there is also a need for quality accessible health facilities, that orient services to decentralize support to community levels of health services and that are able to articulate the needs of community levels and influence national policies. District level services have a number of problems in this respect: Colonial health services adopted without major structural reform continue to service higher levels of health systems and levels of greater wealth. District health boards need to strengthen positive forms of participation – but do they have the power or resources to influence national policy? Do we fully understand given the current pressures from neoliberal global policies how the districts exert community influence at national level?

At **national level** a number of features were identified that support participation, such as clear health policy frameworks and strategic plans that can be debated to community level, removal of cost barriers to services such as user fees, and devolution of meaningful budgets to lower levels of the health system. Other features undermine participation, such as the brain drain from lower level of the system, top-down policy formulation or weak information flow and communication within the system. Donors were observed to affect participation positively and negatively depending no how they impacted on these other trends.

#### A global environment that supports participation

It was however noted that a major change has taken place in the **global environment** that has influenced national relationships with communities: Neoliberal policies of privatization and commercialization in health, driven largely from global level, and liberalisation of markets and prices, have influenced the way participation is expressed, and weakened the role of the state. Policies such as debt payment or cancellation, the prices for commodities in global markets or the organisatioon of global funds for health all have a strong influence on the factors identified at primary health care and community level that affect participation. Responding to social pressure from communities implies that the national level has or is able to negotiate the space, policies and resources for this response at the global level, is motivated and interested in doing so and has the capacities and information for this. This may not always be the case. It also implies that communities know and understand how these global policies impact on them. This is not always the case.

This mapping of the issues raised in the presentations led us to identify three major areas for follow up discussion and future work to take forward our goals for a people oriented health system:

- 1. What actions can we take generally and as a community of institutions in EQUINET to strengthen the community and primary health care levels of the health system?
- 2. What do we need to know, understand and do for the district level to more effectively support and articulate the community and primary health care levels and to have greater influence on national policies and programmes?
- 3. What do we need to know, understand and do to strengthen national influence for community interests in health in the global policy environment?

Within these we also asked delegates individually to state the support they would need to improve action at community level; the unanswered questions they had on how the district could better reinforce a people oriented health system and the links they would want from regional networking. These answers, (shown in appendix 3) and the feedback from group discussions on the questions above, provide the major directions for follow-up work on participation in health and a people oriented health system.

#### 11. Follow up work

# 11.1 Actions to strengthen the community and primary health care levels of the health system

Delegates proposed a number of areas of follow-up work and action to strengthen the role of people in the community and primary health care level of the health system. We proposed as organisations to

- i. Ensure that our work is informed by critical analysis of the global to national to local policy issues in the areas we are tackling and find ways of building this critical analysis and reflection into community based programmes. EQUINET has outlined perspectives on health in its policy papers and can support strengthening of perspective through dissemination of popular materials on critical debates and perspectives in health.
- Provide issue based training to fill the information gap in health systems, to ii. build skills for community representation; to articulate community issues and engage authorities, to communicate with

communities, to identify problems and to take action. EQUINET can be a vehicle for sharing information on such skills building approaches and tools and sharing good practice.

iii. Carry out skills building activities on key capacities to strengthen community based organisations and organisations working with communities, i.e. in proposal writing, organizing, and other areas of organizational skills, EQUINET can share information of such opportunities for training and support regional exchange of such training.



Strengthen skills for mobilizing and managing resources so that iv. communities can demonstrate action and innovation and show solidarity within social groups in the community. EQUINET can be a vehicle for sharing information on such skills building approaches and tools and sharing good practice.

These interventions can be used to support a programme of community action that

- Holds national, regional, local workshops involving community based groups, informed by perspectives on health equity in the wider context
- Organises opportunities for stakeholders to engage on issues –MPs, policy makers, district administrators
- Builds coalitions between smaller like minded organizations to strengthen their voice and access resources, and share knowledge, skills and experience
- Uses critical research and information in planning and activities, including needs analysis and mapping of the community, so that interventions match needs. Invite policy makers to participate in this innovative way of dealing with community needs, with evidence of success.
- Disseminates information through existing structures to promote their
- Engages the community in collective fund raising and collective efforts to access available funds and supports this with training sessions on managing funds
- Sets up processes to promotes structures through which districts and communities can discuss community needs, plans and ideas

As noted above EQUINET can inform perspective; facilitate forums for dialogue and exchange of experience across programmes and countries; support some areas of skills training and disseminate information across various sites of work. EQUINET can further support this community level work by building and sharing a database of profiles and skills of organisations that can contribute capacities which can be shared across and between organizations. EQUINET can also document and share information on good practice and can facilitate exchange visits across programmes and countries.

It was noted that as a starting point TARSC, Ifakara and CHESSORE are

developing under the EQUINET umbrella materials and a regional training programme on participatory methods for strengthening community voice in people oriented health systems in 2005.

# 11.2 Actions to understand and strengthen district level support and articulation of community and primary health care interests

A number of questions still remained unanswered in the meeting and needed further evidence and review:

- What community oriented motivations, orientation, analysis and perspectives exist at district level?
- What human resources and capacities exist at district level for this and how are they deployed?
- What skills building is needed for planning, management, team work, communication and advocacy?
- How do district level financing mechanisms resource participatory mechanisms and processes and devolve resource control to district and local levels?
- How is partnership, co-ordination and networking being built with other actors in the health system – private sector, communities, NGOs, CSOs, other government ministries?
- What are the powers at district level and how are they translated and used?
- What role do the DHBs play and how is this strengthened?

As follow up it was proposed that a review of literature and secondary evidence be commissioned to present and analyse evidence of the current situation with regard to

- community voice and roles at district level (how is this structured, through what mechanisms, integrated into planning how etc)
- how district planning, decision making, financing and budgeting, resource allocation, programme implementation enables or blocks such participation
- how districts articulate and represent community interests at national level.
- What positive case studies or examples exist of community representation and district influence at national level
- What gaps in knowledge or evidence exist that need further research? It was proposed that EQUINET commission this review, and include a mapping of who the key stakeholders are for follow up on the issues raised.

It was further proposed that regional work be done building on existing sites to establish positive sites of practice at district level, with support from research, training, exchange visits and evaluation, which can be used to demonstrate and promote positive trends and practices.

Regional work can also be implemented to strengthen skills for community participation at district level, such as in PRA approaches, communication and information, advocacy. These skills building activities can be implemented within sites and by bringing sites together in the region.

EQUINET can convene cross cutting links with other areas of theme work (like fair financing, trade, and human resources for health), support exchange of information and skills and engage on the broad policy findings from this work.

# 11.3 Actions to strengthen national influence for communities in the the global environment

To better understand and strengthen support for people oriented health systems at global level it was proposed that we need to

- Understand the aims, existence, role and weaknesses of global institutions (IMF, WB, WTO) and the specific ways they undermine equitable, people oriented health systems.
- ii. Pressure national governments to share, consult and inform communities through provinces and districts to bring debates to local level
- iii. Create watchdogs nationally and regionally on the operations of these organizations, and on national government commitments to these organisations.
- iv. Use creative consultation opportunities for community consultation and involvement on national issues (e.g. parliamentary committees with civil society)
- v. Build alliances and strategic engagement around global policies based on real issues at community and national level
- vi. Pressure that national governments exercise caution / avoid individual bilateral agreements and commitments
- vii. Pressure for collective regional strategies and consultation to build regional strategies while enabling national autonomy on agendas and plans
- viii. Exploit all the spaces available to build political interest and will for forms of democratic practice that strengthen national and community voice

#### 11.4 Other actions by institutions in EQUINET

It was noted that EQUINET (TARSC and CHESSORE) will in 2005 edit and produce a book on this work, integrating the papers from the multicountry study and other papers produced for the meeting, after feedback and revisions. Further information on this would be provided after the meeting.

It was also proposed that the findings and recommendations be documented in a brief for districts, a brief for parliament and a community leaflet to outline the major features of participatory health systems, and the mechanisms and barriers for achieving them.

These various proposals will be reviewed by CHESSORE and TARSC and follow up made to define a programme of work for the coming few years within EQUINET involving the institutions at the meeting.

#### 12. Closing

The meeting was closed with remarks from different social groups participating.

Hon Chebundo, MP and chair of the parliamentary on health in Zimbabwe noted that this meeting had been complementary with the meeting just held of MPs. People perceive MPs as expert and blame them for failure, but MPs are stringer when they work with professional, civil society and health service personnel to deliver on common goals. It is therefore important to involve them in all of these areas of work and mutual exchange. Parliament has a critical role to play in holding the executive to account. This does however need to be backed by facts and information. MPs can also mobilize communities and influence social attitudes and society to take action on issues. He gave several examples on health of where community views are critical and stressed that parliamentarians were keen to ensure that they were linked with communities and with academics to better fulfil their role. For this he expressed gratitude to EQUINET for convening such exchanges across disciplines and stakeholders.

Ismael Mtitu of the Rufiji district health team in Tanzania noted that policies formulated at high level need to be translated to the district in ways that involve and engage communities. He recounted the various tools they have developed in Rufij for this, including a planning tool, and a health budget matrix that tracks resource allocation in relation to district, health management system priorities. He

appreciated the widening of information from different countries and sectors and expressed concern that knowledge, management, financial, operational research capacities be strengthened at the district through interaction and exchange of expertise.

Hameda Dedat, a civil society health activist in the Municipal Service Project in South Africa stressed that exchange and networking was important and that more should be done to bring out the link between the local and global given that the neoliberal framework affects all of those levels. It is important to make the connection- what you are struggling for at the bottom has a link with these wider struggles – and that you have a choice. Individual choices are a way of making some kind of effort. The water we drink, the products we consume, all reflect that choice. We need also to question whether the system we are in is the health system that we want. If we are to move from the current situation to the ideal we need to move beyond coping and challenge what we don't want from local to global levels.

Clara Mbwili, from the Lusaka district Board of Health commented that she found it encouraging to share experience. Many bureaucracies and obstacles exist that can discourage what is equitable and fair. It is therefore important to take opportunities to see the doors and loopholes that allow us to implement our vision and policies of equity in health. At district there are health workers who will continue to advocate for health equity and communication skills will widen the pool. She expressed desire to work with communities and to look to the community interest as a basis for making equity in health a reality. The workshop was thus an encouragement for individuals that are working on the ground level. The advocacy skills would enable her to better communicate issues between communities and national levels.

Finally TJ Ngulube from CHESSORE and EQUINET thanked his colleagues in CHESSORE and EQUINET (TARSC) for their work and thanked the participants for their high levels of commitment to this kind of work, within their own settings and regionally. He thanked IDRC for its support of the work over the past years and IDRC and SIDA for support of the meeting. He urged delegates to visit the EQUINET website and read the newsletter and undertook to follow up on the issues raised to frame the ongoing programme of work, drawing in the directions and lessons from this meeting. He urged delegates to continue to recognize the importance of an agenda and perspective that defines the type of work that will deliver on goals of health equity.

# APPENDIX 1: Delegates List

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#### **APPENDIX 2:**

# EQUINET in co-operation with CHESSORE and TARSC STRENGTHENING COMMUNITY VOICE AND AGENCY IN HEALTH Regional Meeting January 26<sup>th</sup> to 28<sup>th</sup> 2005, Kafue Gorge, Zambia Programme

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

Thursday Ja	nuary 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)	Chair: G Musuka	
	<ul> <li></li></ul>		
	Involving communities in malaria management	F Kaona	
	Lessons for HIV and AIDS prevention and control	W Tapfumaneyi	
	Discussions (15-20min)		
	IIC Community roles and primary he environments	alth care – family and social	

11.45pm	Session Introduction (5 min)	Chair: B Chebundo
	Privatisation of water and community roles	H Dedat
	<ul> <li>Community forums for involvement in water and sanitation</li> <li>Discussions (15 -20min)</li> </ul>	N Dayile, R Stern
12.45pm	Lunch	
2.00pm	Rapporteurs on issues and actions	Rapporteurs
2.30pm	Working groups	
3.30pm	Tea	
3.45pm	Plenary report back and discussion	
5.15pm	Close of day	

Friday Janua	ary 28 2005		
	IID Which 'community'? - voice of marginalized groups		
8.00am	Introduction to the issues (5 min)	Chair: A Mtukula	
	<ul> <li></li></ul>	B Kaim P Mothlabane	
	III Brining community voice to National lev		
9.00am	Introduction to the issues (5 min)	Chair: F Goma	
	Community voice in monitoring access to essential drugs	B Amailuk	
	Equitable access to ART	P Jones	
		P Kamuzora	
10,.30am	Rapporteurs on issues and actions	Rapporteurs	
10.45am	Tea/Coffee		
11.15am	Working groups:		
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, TJ Ngulube CHESSORE	
3.15pm	Closing remarks and views MP	B Chebundo	
	District health worker	I Mtitu	
	Community activist	H Dedat	
	National state institution	C Mbwili	
4.45	CHESSORE and EQUINET	TJ Ngulube	
4.15pm	Tea and depart		

#### **APPENDIX 3:**

#### **DELEGATE ANSWERS TO QUESTIONS POSED:**

#### WHAT SUPPORT DO YOU WANT IN YOUR WORK ON PARTICIPATION AND HEALTH?

Recognition

Voice to raise the profile of participation

Information from the community

Trust with the community

Political understanding

Knowledge on community dynamics, power relations

How to resolve questions of power – national – district- community

Training, (3)

Advocacy skills (2)

Skills building on knowledge, proposal writing, participatory methods

Sharing of lessons with others (3)

Co-operation with other sectors

Health system partnerships

Team approach to HCC work to produce clear strategies

HCC engagement and representation of communities

Income generating ventures for communities (2)

Financial empowerment

More technical and human resources to support me in my work (2)

Funding for training and sustaining projects (3)

Transport resources

More time = a 48 hour clock?

### WHAT ISSUES/ QUESTIONS DO YOU STILL HAVE ABOUT THE DISTRICT LEVEL?

#### To national

- How does the district package information and issues that need attention at national level?
- How does the district link with and influence the national level, including in relation to powers (... in a system that is inherently top down) (4)?
- What are the power dynamics in the system and where and how do they need to be challenged?
- How could new health system structures help districts solve problems in fitting into the national level?
- How can the national level be more outcome oriented (less political/authoritative)?
- How should finances be allocated to support district mandates?

#### At the district

- What other things besides policies and skills cause system problems at the district level?
- What powers and resources do districts need to enable programme implementation/ deliver on their mandate (4)?
- Does decentralization empower districts?
- What motivates action at the district level?
- Are the problems structural or capacity? What capacity building is needed at district level?

- How can the district deliver effective services?
- How can district personnel better understand their role?
- Should the DHB be elected or nominated?

#### To local

- What should the links, distribution of power and influence be between the districts and the community (3)?
- Through what mechanisms and how do communities communicate their needs to district level?

#### WHAT LINKS WOULD YOU WANT TO MAKE AT REGIONAL LEVEL?

- With district health teams that have succeeded to incorporate equity indicators in health care delivery
- With Ifakara, SA, Namibia to learn how they are implementing their work
- With the African development bank to finance work
- With institutions in Zambia and Tanzania because of their political stability and wealth of knowledge
- With research institutions in Malawi and Tanzania for collaborative work
- With Ministries of health,
- With HIV and AIDS organisations to share experience (2)
- With organizations who can explain how Uganda destigmatised HIV and AIDS
- With Ministries of health to clarify CHW roles
- With institutions working on drug monitoring and regulation to share experience
- With a grassroots organization that has influenced government policy
- With SADC to regionally co-ordinate strategies (3
- With EQUINET for information exchange and skills building
- With parliaments, MPs for common voice and information exchange
- With advocacy institutions regionally to enhance unity of voice and influence (3)
- With institutions working with PRA in health equity to share ideas
- With regional research networks (including in GEH to find ways to translate research to action)
- With gender, water, trade health organizations that have anti-neoliberal perspectives to share experience and build regional strategies
- For the region to link with global networks like PHM, WSF in a global watchdog role

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 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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