



CEHURD

social justice in health

REGIONAL MEETING ON HEALTH SYSTEM GOVERNANCE AND COMMUNITY PARTICIPATION IN HEALTH



Report of Proceedings

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International Development
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LEARNING NETWORK

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Abbreviations and acronyms

ADC	Area Development Committees
AMREF	African Medical Research Foundation
CAO	Chief administrative officer
CDA	Community distribution agent
CEHURD	Center for Health, Human Rights and Development
CWGH	Community Working Group on Health
DHO	District health officer
HC	Health center
HMIS	Health management information system
HSD	Health sub-district
HST	Health surveillance teams
HUMC	Health unit management committee
LC	Local Council
NHC	Health Committee
NRH	National referral hospital
RRH	Referral Hospital
VHT	Village health team
VHW	Village Health Workers

1.0 Background

CEHURD, in partnership with the Learning Network for Health and Human Rights (South Africa), and with support from International Development Research Centre (IDRC), is implementing a project titled, *Health system governance: Community participation as a key strategy for realizing the right to health*. The project is a pilot study implemented in Kiboga and Kyankwanzi districts in central Uganda.

The project aims to develop models for community participation in health that advance health equity and strengthen governance systems for health by testing approaches and sharing experience gained in the project area using a rights-based approach to health and build the agency of community structures to articulate more strongly claims for health rights, with a view to proposing models for best practice.

The meeting objectives were:

- 1) To share experiences of different models of community participation in health in the region, identifying strengths and weaknesses;
- 2) To identify opportunities for networking and synergy under EQUINET;
- 3) To develop a dissemination strategy for this work in the region.

The meeting brought together community leaders, community members, service providers, and civil society from Uganda, Kenya, Malawi, Zambia, Zimbabwe and South Africa.

The meeting included a field visit on the first day, where meeting participants met stakeholders at the community, local government and service point levels. The field visit provided the participants an opportunity to learn how the research has changed practices and systems in the health services. The second day was a whole day meeting at Kiboga Hospital. It involved making presentations and various discussions on community participation.

The meeting was jointly convened by CEHURD and Learning Network, with support from IDRC.

2.0 Highlights from the field visits

The first day of the meeting, 28 February 2013, was devoted to field visits to duty bearers and service providers in Kiboga and Kyankwanzi districts. The group visited Kiboga district headquarters, Kiboga Hospital, Kyankwanzi district headquarters, and Ntwetwe Health Center IV.

However, due to time constraints, planned visits to the subcounties of Kibiga, Mulagi, Wattuba, Kapeke and Gayaza did not materialize.

2.1 Visit to Kiboga district headquarters

At Kiboga district headquarters, the group was addressed by the district chairperson, Mr Israel Yiga. He informed his visitors that Uganda operates a decentralized system of

government in which authority has been devolved to Local Council V's (districts) and Local Council III's (subcountries) under the Constitution and the Local Government Act.



Mr Israel Yiga L.C 5

Mr Yiga informed the meeting that the decentralized system of governance creates the local government structure that gives districts and subcounties autonomy to make decisions based on local needs and preferences. He reported that the planning process currently uses a bottom-up approach with the views of the intended beneficiaries of government programs taking the center stage.

Mr Yiga cited the budget cycle for the financial year 2013/14 which he said was already underway, gathering views on programming priorities from community stakeholders, the civil society, local leaders, and local

government stakeholders. He said this was one example of how communities are involved in setting priorities in government interventions.

Another opportunity for community participation in decision making comes during the planning cycle, when district councilors convene community consultative meetings in their respective constituent subcounties. The district chairperson informed the delegation that councilors then present the views gathered during these community meetings to the District Council to guide decision-making on how best social services should be delivered.

Questions from the delegation centered on funding for decentralization structures, what measures are in place to capture views from marginalized groups, how health services are linked to community, and how the system promotes health rights.

In response, the chairperson explained that while the Local Government Act gives districts authority to levy taxes, the Constitution requires that all taxes must be approved by the central government. He said this apparent contradiction makes it difficult for districts to mobilize resources through taxation. He also pointed out that districts are not equally endowed, which means that the avenues for resource mobilization, and therefore the funding potential, differs considerably across districts. In all, he said, funding remains a major challenge for districts, in spite of the decentralization policy being in principle, a good policy.

On how inclusive the community consultative processes are, the chairperson admitted that only a limited section of the community can participate in the meeting because of limited resources. He said the district councilors can only hold meetings with a sample of constituents because the huge of many of the subcounties they represent. He also said that taking on all views from the community was a challenge because of the need to prioritize, which means that some views are deferred to later years in the development plan or even just left in suspense due to inability to accommodate them within the resource envelop.

On how health sector are linked to the community Mr Yiga informed the meeting that the district has a fully-fledged department for community-based services, which leverages

interventions at the community level, with specific mechanisms to reach marginalized groups, including women, people with disabilities, and others.

2.2 Visit to Kiboga Hospital



Dr Michael Musiitwa

At Kiboga Hospital, the delegation held a meeting with the acting medical superintendent, Dr Michael Musiitwa Mugwanya and other hospital staff.

Dr Musiitwa explained the structure of the health system in Uganda, which he said consists of seven levels. The first level, health center I, is constituted by village health teams (VHTs), that support community outreach work, including patient follow-up at the

grassroots level.

The second level, health center II, which should in principle be at the parish level, is manned by an enrolled nurse and an enrolled midwife. However, he pointed out that not all parishes have a health center II at the moment. He said resource constraints have prompted a slow-down in the establishment of health center IIs and a shift in emphasis to ensuring functionality of existing health center IIs. Health center IIs provide basic treatment and preventive clinical care, and also supervise the lower health care level, the VHTs within their jurisdiction.

The third level of health care, health center IIIs, are at the level of the subcounty. This level of care is manned by a senior clinical officer and provides a range of specialized services.

The fourth level, health center IV, is at the country level and provides general clinical care, including emergency obstetric and newborn care, anesthesia, surgery and other services ideally available at the hospital level but at a relatively smaller scale. Health center IVs are headed by a senior medical officer. The health center IV is at the same time the health sub-district (HSD), with the administrative responsibility of overseeing the lower health centers, overseeing and mentoring them, as well as managing their budget and resource allocation. Kiboga has one health center IV.

The fifth level of health care, the general hospital, is at the district level and provides more specialized services and ideally serves a bigger catchment area. Dr Musiitwa reported for instance, Kiboga hospital serving clients within the host district of Kiboga, as well as from the neighboring districts of Kyankwanzi, Mubende, Mityana, Kibaale, Luweero, Hoima and others.

The sixth level of health care is the regional referral hospital (RRH), that serve districts within the geographical region of the country. Kiboga falls within the jurisdiction of Hoima RRH. This level of health care provides a relatively high level of specialized services, and

has specialist consultants, including orthopedic doctors, gynecologists, pediatricians, and other specialists.

At the top is the seventh health care level, the national referral hospitals (NRHs), which provide care for all cases that other health facilities cannot handle. Mulago and Butabika are the only NFHs in Uganda. RRHs and NRHs are under the Ministry of Health, while general hospitals (level V) are under the jurisdiction of the district.

On community involvement, Dr Musiitwa reported that VHTs and health unit management committees (HUMCs) were the key link mechanisms of the health system with the grassroots community.

The questions raised related to whether VHTs are part of the health system, membership to the HUMCs, the population of VHTs, the contribution of the private sector, whether there was a formal patients rights protection mechanism, and among other things, the government position on traditional health care providers.

In his response, Dr Musiitwa said the biggest challenge in engaging communities is lack of funding for VHTs yet they are recognized as being part and parcel of the health system and are doing a lot of work. They are volunteers, selected to serve roughly 25 households, are sometimes only supported by non-governmental players.

He reported however, that HUMCs are in the work plans of health centers and their quarterly meetings are catered for in the health budget. He said the members to the HUMC are selected by the respective local council, with representation from the villages within the locality, with the facility in-charge being the secretary.

On user fees, Dr Musiitwa said public health services in Uganda are in principle provided free of charge, save for a few diagnostic services in certain centers, such as CT scan, X-ray and others. Even for these, there is a mechanism for people who are unable to pay can access them, as long as the facility in-charge is convinced that the patient is unable to pay.

He reported that the national patients' charter has been adopted by Kiboga district and distributed to all health centers. The challenge, added, was that the community is yet to appreciate their rights and how the charter can help them realize them. Asked whether they were involved in drafting it, the Medical Superintendent said it is standard practice for the Ministry of Health – like other government departments – to consult widely before coming up with any policy.

On traditional practitioners, Dr Musiitwa said there had been an effort to train traditional birth attendants but that an evaluation found that their work was not contributing to reduction in maternal deaths. For that reason, a decision was taken to stop them, and instead try to integrate them into the VHT structure.

2.3 Visit to Kyankwanzi district headquarters



*Elizabeth Namanda CAO
Kyankwanzi*

At Kyankwanzi district headquarters, the delegation met a team consisting of the chief administrative officer (CAO), Ms Elizabeth Namanda; the acting district health officer (DHO), Dr John Serebe; the chairperson of the Local Council V (LC V) social services committee, Mr Bukenya; and the district secretary for health, Ms Proscovia Tumusiime.

During the meeting, the DHO explained the set up of the health system in the district and the mechanisms for engaging community stakeholders. He said the health system is divided into seven levels, with level one consisting of VHTs at the village level; level two being represented by HC II at the parish level; level three by HC III at the subcounty level; level four by HC IV at the county level; level five by the general hospital at the district level; level six by RRH at the regional level; and level seven by NRH at the national level.

Dr Serebe informed the delegation that VHTs are the “community structure of the public health care system” that is “invisible” in terms of physical structures but “by human resources”. He said the district has an estimated 524 VHTs, covering 230 villages in the district. African Medical Research Foundation (AMREF), a non-governmental organization, trained seven individuals per village, implying that more than 1,000 individuals that were trained are not deployed.

VHT roles range from health promotion, including immunization, sanitation and other preventive health interventions; point-source diagnosis and pre-referral treatment of malaria, pneumonia, and diarrhea; as well as client mobilization and follow-up for maternal and child health services, HIV, TB and other communicable diseases.

During question time, delegates wanted to know what options were available to clients in case a VHT erred; what tangible contribution was coming from the community; how different sectors were working together to contribute to health outcomes; how progress in community involvement was being tracked, if at all; and the status of traditional practitioners, among others.

In response, he said there were a range of modalities to minimize risk of mistakes by VHTs. He said VHTs follow strict guidelines and are not at liberty to handle “a whole range of diseases or administer a whole range of treatments”. He said that in terms of management, they are restricted to three conditions – malaria, diarrhea and pneumonia – and there are clear guidelines to handle only mild and pre-referral cases, and to ensure cases receive referral services within 24 hours.

On integration of planning, the CAO informed the delegation that the district has technical planning committees chaired by heads of the different departments that consult one another.

The DHO informed the visiting team that joint planning has enabled the health department to conduct some activities jointly with other sectors, such as education.

The visiting team also heard that the health management information system (HMIS) was being expanded to be able to capture the impact of community interventions.

On traditional practitioners, the DHO said there was still a gap in their regulation, even though they register with their association and have organization such as THETA that support them in terms of capacity building, alignment with recommended practicing guidelines, and other forms of support.

The secretary for health closed the meeting and thanked CEHURD for their work in the three subcounties of the district. She requested CEHURD to continue working with the existing structures and pledged support for future work, given that that they are pursuing a common goal of improving the life and welfare of communities.

2.4 Visit to Ntwetwe health center IV



Dr David Mayengo addressing members at Ntwetwe health center IV in Kyankwanzi

At Ntwetwe health center IV, the delegation met the health center officer-in-charge, Dr David Mayengo, who took the group around on a tour of the facility before holding a meeting with the delegates. During the meeting, he informed the visitors that the health center serves an overwhelming number of patients, as it serves a catchment area that is at least 30km on one side, and more than 100km on the other.

He reported though, that the facility is near fully staffed, having 46 out of the recommended 48 staff. He said he runs the facility through a “governing body” of seven that includes himself, the senior clinical officer, principal nursing officer, and other senior staff.

The questions from the visitors centered on whether the staff had ever trained in human rights; the opportunities for community participation in decision-making; and the apparent invisibility of older medical officers in the health system, among others.

In response, Dr Mayengo reported that he trained in Europe where it is a norm for human rights to be integrated into medical school curricular. However, the health center had never got an opportunity of its staff being trained in human rights. The in-charge added that they would welcome such an opportunity. The executive director of CEHURD promised him that a half-day session on how human rights links with health would be arranged for the staff.

On opportunities for the community to participate in decision making, Dr Mayengo reported that the health center has a 10-man HUMC which meets quarterly to review the performance of the facility and plan accordingly. He said the HUMC is constituted by members who are “in direct contact with the community” and that they are the “ears” of the facility in the community that the health center serves.

On where the older doctors were, Dr Mayengo explained that poor remuneration was forcing doctors to flee the country for greener pastures elsewhere in the region. He singled out South Africa, which he said takes up to 70 per cent of Ugandan doctors. He said that senior medical consultants that stick around prefer to work in urban areas where they are in private practice or supplement the government job with a part time work in the better paying private sector.

Delegates from South Africa pledged to launch a campaign in their country against the “poaching” of doctors from Uganda and other poor countries in the region.

3.0 Highlights From The Meeting

On the second day, 1st March 2013, the meeting was joined by more participants from the civil society from the national level as well as community representatives from Kiboga and Kyankwanzi districts, including community leaders and members, service providers and district leaders. Malawi was represented at the meeting by one delegate, Zimbabwe two, Kenya two, Zambia one, and South Africa seven.

The sessions consisted of presentations and discussions in groups and plenary

3.1 Welcome remarks from the Executive Director CHURD, Mr Moses Mulumba

The Executive Director, CEHURD, Mr Moses Mulumba welcomed the meeting participants, and said he was delighted for the opportunity to meet again with partners they had met on similar issues in 2008 under a joint initiative with HEPS-Uganda, another national health rights organization, and the Learning Network.

Mr Mulumba said the meeting was an opportunity to develop a regional alliance and strategy on community involvement as an approach to realizing the right to health.

3.2 Remarks by Prof. Leslie London, Learning Network



Mr Leslie London informed the meeting that Learning Network seeks to identify and share best practices to realize the right to health. He said health is a right and community participation is key to realizing it. He said the project aims to give communities a voice.

He said IDRC was providing funding to test and strengthen models of community participation . He reported that the Health Committees in Western Cape in South Africa, where the Learning Network is based, have a lot of weaknesses as community involvement structures. He said the meeting was convened to understand how community health involvement models work in different countries in the region, and explore avenues to give communities a stronger voice on determining the health care they receive.

Prof. Leslie making his opening remarks

He said the project will be developing networks to share information on what models work in the different situations. He said the meeting was part of this effort. He said that the process should lead to a report that can be presented to policymakers on how they can engage communities in health.

3.3 Official opening of the meeting

The meeting was officially opened by the acting Medical Superintendent of Kiboga Hospital, Dr Michael Musiitwa Mugwanya.

Dr Musiitwa welcomed the delegates to Kiboga Hospital. He hailed the theme of the meeting, saying community participation is important because they are the people that the health system serves.

The chief guest acknowledged the existence of challenges in engaging communities, and added that there was need to find solutions that will work. He said he was impressed by the mission statement of CEHURD, which has a banner pinned up in the meeting room, which refers to “working towards an effective people-centered public health system”.

4.0 Country presentations on community participation

Different participants from different countries made presentations on how community participation is perceived in their countries. That's to say,

4.1 Community participation in health in Malawi



Linga Munthali doing his presentation

The presentation on community participation in Malawi was made by Mr Linga Munthali, who outlined the structure of the country's health system and the structures for community involvement.

Malawi's health system consists of four national referral hospitals, a network of district referral hospitals and lower health centers. It also has faith-based hospitals.

The presenter informed the meeting that the community involvement system consists of health surveillance teams (HSTs), community

distribution agents (CDAs), and counselors. The presenter said HSTs are the equivalent of VHTs in Uganda; while CDA's are in charge of distributing commodities for family planning, malaria, and other conditions, including supporting child immunization. The counselors provide HIV testing and counseling in the community.

He further reported that Area Development Committees (ADCs) are involved in health interventions and constitutes a major way communities are involved in health in Malawi. Policy makers provide briefings to the ADCs and ADCs make the necessary by-laws to effect policy at the community level. For instance, ADCs in most parts of the Malawi have made by-laws to fine women who seek the services of traditional birth attendants (TBAs) a goat.

The other community involvement structure mentioned in the presentation are small disease-based committees, such as the committees on HIV, malaria, TB, safe motherhood, and other conditions. These meet on a monthly basis and submit reports to the nearest health facility.

Further, it is a requirement that health centers to provide outreach services, which has proven effective in involving communities effectively.

Among the challenges facing the community involvement systems, the presenter highlighted the lack of information on whether the community voice was actually being heard; shortage of resources for health, including medicines and other supplies; and resistance among village chiefs.

4.2 Community participation in health in Zimbabwe



Itai Rusike doing the

The presentation on community participation in health in Zimbabwe was made by Mr Itai Rusike from Community Working Group on Health (CWGH) of Zimbabwe.

The presenter outlined the structure of the health system in Zimbabwe, which he said consists of Village Health Workers (VHWs), at the lowest level. Using standard kits, these provide door-to-door basic services at the community level. However, their facilitation is minimal, limited at a monthly allowance of a misery US\$14, which even comes irregularly.

Above the VHT are the first level health centers at the level of ward. This is where you find Health Care Committees (HCCs), chaired by people from the community. The health center in-charge is the secretary, while the traditional chief is the patron. The HCCs have membership from community-based groups, youth, women, elected councilors, and school health masters, among others. The members are elected by the community

Above the level I health centers, are district hospitals. Each hospital has a District Health Advisory Board with representation from civil society as the community voice. Here, the members to the Board are appointed by the Minister of Health.

Above the district hospitals are the provincial hospitals, which provide more specialized services. The Provincial Hospital Advisory Boards are also appointed by the Minister. This is also the case with the Board of the National Teaching Hospital.

The meeting further heard that Zimbabwe has a Public Health Advisory Board to advise the Minister of Health, who appoints its members. It has representation from the civil society but it is a Ministry of Health structure.

The presenter also reported that the National AIDS Council has set up AIDS Committees at all levels, which are elected by the community.

The presenter outlined the challenges facing community participation in health in Zimbabwe. He reported that by 1990, Zimbabwe had one of the best primary health care system in Africa, but the coming of structural adjustment programs of World Bank and International

Monetary Fund and the economic crisis of the 2006-09 effectively killed the system. The civil society has since 2000, been advocating for the revival of HCCs.

The meeting learnt that most health centers are owned by local authorities, while the Ministry of Health owns district and provincial hospitals. There is no law that governs the operation of HCCs, save for guidelines and a training manual.

The presenter reported that the civil society developed the training manual, which was reviewed by the Ministry of Health, and was being used to revive the HCCs. He reported that World Bank has provided funding for maternal and child health and the funds are being disbursed directly to HCCs which are managing health center budgets.

He further reported that the Ministry of Health has asked the CWGH to lead the process of drafting a legal instrument for HCCs, and it is expected that this should be finalized by the end of 2013.

The meeting also heard that the right to health is provided for in the revised draft Constitution on which a national referendum was due to be held on March 16, 2013. The 1924 Public Health Act was also being reviewed and an amendment bill was awaiting parliamentary approval. He said that the challenge henceforth will be to make the right to health a reality in Zimbabwe.

4.5 Community participation in health in Zambia



The presentation on community participation in health in Zambia was made by Ms Adah Lishandu.

The presenter informed the meeting that the community participation system consists of Community Health Workers (CHWs) and Neighborhood Health Committees (NHCs). She said the NHCs are not established by law, but that a law to support their existence was being drafted.

The members to the NHCs are elected by community members for three-year terms. They are trained using with a written training manual. Part of the funds that the government disburses to health centers go to NHCs to facilitate their activities, and they are free to decide how to use the funds.

The presenter further reported that health literacy was being scaled up in Zambia to improve communication between health workers and patients.

Adah doing her

4.6 Community participation in health in Kenya

The presentation on community participation in health in Kenya was made by Mr Francis Rakewa from Kelin Kenya.

The presenter narrated the case of three brothers who were suffering from multi-drug resistant TB. The Kenya Public Health Act provides that a TB patient who defaults on treatment can be arrested and courts can order for their isolation. The three brothers were arrested on the basis of this law and hastily sentenced to imprisonment.

Kelin, a civil society organization, sued the government for violation of the patients' rights. The court ordered for their release and order government to provide them with drugs. The accompanying community education by Kelin helped improve community awareness of the right to health, which has reduced TB rates in Kapsabet area where the campaign was focused.

4.7 Community participation in health in Uganda



Paul Akankwasa Doing his

The presentation on community participation in health in Uganda was made by Mr Paul Akankwatsa, who explained the public health structure as consisting of seven levels, right from the VHT level that handle basic health problems in the community, through health center levels II-IV, general hospitals, RRHs and NRHs.

Uganda's community involvement system hinges on Health Unit Management Committees (HUMCs), which are part of health centers at levels II-IV. These are chaired by a community person, with the in-

charge of the health unit being the secretary. The membership to the HUMCs are selected by the respective health unit.

The hospitals have Hospital Management Committees, which are selected by the district local councils from among the community where the health hospital is located.

Another way communities are involved in health is more indirect, through elected political leaders, with local governments having secretaries for health and the national parliament having a sectoral committee on social services.

4.8 Community participation in health in South Africa

The presentation on community participation in health in South Africa was made by Ms Hanne Jensen from the Learning Network. The presenter noted that the community are partners in health care and their involvement mean that they should participate in decision making, identifying needs and solutions, as well as in oversight of health care delivery within their communities.

In South Africa, unlike in many other countries in the region, the National Health Act requires public health facilities to be linked to a Health Committee constituted by community members. However, the law does not clarify the functions of the Health Committees, and leaves the responsibility of making policies for the committees to the provincial governments. Only two out of the nine provinces in South Africa have developed guidelines for the operations of Health Committees.



The presenter informed the meeting that Health Committees in Western Cape, where there are no policy guidelines yet on Health Committees, came out to demand to be heard, and the civil society came to their support, arguing that community participation should be an opportunity to listen to community representative rather than to lecture to them.

The presenter reported that 44% of the facility managers were not participating in the meetings of Health Committees, which means that the link with the community has been lost.

Hanne Jensen making her

5.0 General discussion

During the general discussion, the participants made comments and raised comments on the country presentations.

On the Malawi presentation, the audience were interested in knowing more about the ADCs. In response, the presenter said the ADCs are based on administrative units, and they cut across sectors, with each development issue being forwarded to the respective government department. They advise government ministries and departments on policy options for community interventions.

On Zimbabwe presentation, there was a question on how the monthly allowance, however modest, impacted on the performance of Village Health Workers, compared to Uganda's VHTs who are not paid anything. The second main concern was about accountability issues were catered for in entrusting HCCs with public funds.

In response, Team Zimbabwe stated that the allowance was given as a way of trying to tame the high attrition rates of Village Health Workers, but that it had not served its purpose well because it is too little and it does not come regularly. The presenter informed the meeting that the Village Health Workers are supposed to provide basic health care and to work for a maximum of three hours, but in reality they provide a lot more and work for long hours. The

country is supposed to have 17,000 of them, but the latest estimates put the number at a mere 6,000.

On accountability, the Zimbabwe team informed the meeting that the HCCs built their reputation during the economic crisis when government could not fulfill its obligations of providing basic health care. During that time, some HCCs were able to mobilize resources from the community to maintain basic health care at health centers. The meeting further heard that the health literacy manual that is used to train the HCCs contains a manual on financial management and HCCs in at least 16 of 64 districts in Zimbabwe have structured financial management systems.

On the Zambia presentation, meeting participants were interested in the composition of the Community Development Committees (CDCs), and how big the budgets they handle were. In response, the presenter said the CDCs are based on administrative zones, and it consists of about 10 representatives from the community who during sessions identify the needs of the people in the area and come up with action plans.

The NHCs receive funding from the government through the health centers they serve. The person who is appointed as Treasurer usually has to have some accounting or financial training, and is in charge of managing the budget and accounting for the funds.

On the Kenya presentation, one participant said a similar situation happened in Mubende in Uganda where a TB response official, frustrated by lack of drugs for MDR TB, was quoted as saying that the option for such patients was to pray they die soon before they spread it to other people. However, there was concern that the presentation had not touched the community involvement structures.

In response, Prof Okeyo informed the meeting that Kenya is implementing the so-called “community health strategy” that proposes a package of essential services he referred to as “six-by-six” – six priorities at six levels of care. He told the meeting that the Kenya health system has “all the strapping of community participation”, adding that the concern was to the substance of such participation and how it could be objectively measured.

He said that at the bottom of a six-layer health care system are Community Health Workers, who provide unstructured services and are less formal in their operations. Then there are Community Health Extension Workers, who are more formal. The system also encourages peer health education among mothers, as well as child-parent health education.

On the South Africa presentation, one participant asked if there had been a practice of shifting blame and responsibility as it is prevalent in Uganda. In response, the South Africa team said the civil society does not allow duty bearers to shift responsibility when it comes to provision of health care. They cited a case last when there was a stock out of medicines, and the provincial tried to blame the central government. But it was later discovered that the provincial government was responsible when they could not put out a public statement to explain the cause of the problem.

6.0 Community voice on participation

The community voice on community participation in health was given by Mr Leonard Kasirye, the coordinator of VHTs in Kiboga district, and Ms Damaris Fritz-Kiewiets from the Learning Network and Cape Metro Health Forum.

6.1 Presentation by Mr Leonard Kasirye



Mr. Kasirye

Mr Kasirye presented the community experience with the project, which was implemented in five subcounties – two in Kiboga and three in Kyankwanzi. He informed the meeting that community stakeholders convened for sessions in January and February 2013 to discuss opportunities and challenges for community participation in health and to come up with a community work plan to enhance their participation. The sessions were attended by community leaders, health workers, VHTs, and ordinary community members.

During the sessions, participants identified the following programs as providing the opportunity for community participation: Child Days; HIV counselling and testing; prevention of mother-to-child transmission of HIV (PMTCT); immunization; direct observation of drug adherence (DOT) in TB management; sexual reproductive health; circumcision; World AIDS Day; and district budget conferences.

The major barriers to community participation in health were identified, with community leaders being concerned about the reluctance of community members to participate in health programs; differences in political affiliation; poor quality of services; low and delayed funding; and lack of facilitation of VHTs.

The health workers and VHTs were concerned that community members are not informed about meetings; police, local leaders are not concerned about the issues that affect VHTs; community members are not given chance to contribute during the budget conferences; some community leaders are not supportive of VHT work; and VHT's are not facilitated.

From the point of view of community members, the major barriers are: scheduling meetings on days of worship; limited consultation by leaders; limited knowledge and awareness on health rights; lack of immediate results; insufficient mobilization; and lack of inclusiveness in interventions.

After a process of prioritization, the participants narrowed down to four key challenges that they were to act upon: 1) Lack of facilitation for VHTs; 2) Community members do not attend meetings; 3) Community members are not informed about health programs; and limited knowledge and awareness on health rights.

The sessions came up with following recommendations:

- Community members should be trained and taught about the need for participation in health programmes. This should be done from house to house.
- Forming smaller groups
- Community members that know about health programmes should tactfully inform their fellow community members and interest them in the same
- Encourage community members to be involved in trainings on health issues and health programs
- Radio programmes should be put in place as well as local announcers
- People should be taught the importance of involvement in community meetings relating to health programmes
- CEHURD should make a report on its findings and forward to the relevant stake holders
- Community meetings should be put during times that are convenient for most community members
- Local leaders should be facilitated e.g. CBOs
- VHTs should be facilitated with transport, bags, boots, umbrellas among others
- There should be bye-laws and punishments for people that do not participated in government health programmes
- Different areas and places should be used for these community meetings for example schools, parishes among others

6.2 Presentation by Ms Damaris Fritz-Kiewiets



Ms Damaris Fritz-Kiewiets from the Learning Network and Cape Metro Health Forum presented the community perspective on community participation in health in the case of South Africa. Ms Fritz-Kiewiets said community stakeholders in South Africa are actively involved in decision-making and holding government to account.

She reported that government withdrew funding after the health committees became a constant thorn their flesh, exposing them in the media and demanding quality services. She said that if what they had seen during the field visits to health facilities the previous day was in South Africa, activists would have “turned everything upside down”.

Damaris making her presentation

She said the role of community stakeholders, including civil society activists, is to ensure that government lives up to its commitments on health. He said they are not service providers, but are advocates who follow-up government promises, even if it means going to parliament to pursue them.

7.0 Key issues for follow-up

The concluding session was facilitated by Prof Stephen Okeyo from Kenya, who facilitated group work to identify the key issues that had emerged during the presentations and discussions under the themes: capacity building/ training; networking; system strengthening; resource mobilization; best practices; and lessons learnt. The following were the outcomes of the group work.



Prof Stephen Okeyo and Juliana Nantaba during the group work session

- 1) Capacity building/ training
 - Capacity building is not strong
 - Communities understanding their role
 - Strengthen community ability to support each other
 - Capacity building for specific interventions identified by community
 - Feedback
 - Accountability
 - Roles and rights
 - Motivation for community involvement
 - Support services – ambulance, infrastructure, law and order
- 2) Networking
 - Strengthening partnership in the region
 - Information sharing
 - Lessons learnt
- 3) Systems strengthening
 - Lobby for VHT mobilization
 - Continuous community mobilization and sensitization on health rights and health responsibilities
 - Monitoring and evaluation to ensure effectiveness in provision of health care services
 - Capacity building of VHTs on their roles and responsibilities, through refresher training
 - Government coming up with a legal framework for VHTs

- Establishing a forum for VHTs to meet and share experiences and network
 - Documentation/ taking recording of whatever is done and its outcomes, and sharing reports
- 4) Resource mobilization
- There is no political will
 - The ability to create opportunity for resource mobilization not allowed
- 5) Best practices
- Using the right o health as a benchmark
 - Social determinants of health
 - Adequate funding for health (Abuja Declaration)
 - Strengthening monitoring, supervision and support of community spaces, VHTs
 - Formal recognition of policy guidelines, dissemination, implementation
 - Community involvement in needs identification and planning at all levels
 - To learn to hold government accountable through litigation
 - Strengthening parliamentary committee networking: regional and national level
 - Documenting and tracking political debate, dialogue around health issues (monitoring the media)
 - Institutionalizing and sustainability – programs/ projects
- 6) Lessons learnt
- Community participation is a process
 - Community members' responsibility to identify government programs
 - It is a responsibility of the community to monitor VHTs
 - There is need to hold government accountable at the highest level
 - Community participation is defined a bottom-up approach in communication; it should participation, not consultation
 - Capacity building to the government
 - Empowering communities to take up their responsibilities
 - All countries in the region have similar challenges, which calls for establishment of a network to share experiences and bridge the gap
 - Government and community to work together
 - Community not involved in the planning process
 - Other countries in the region motivate community health workers
 - Government has good programs but implementation fails at lower level.

8.0 Closure

The meeting was concluded by Prof. Okeyo Stephen and Prof. Leslie London. Prof. Okeyo thanked the participants and presenters for the discussions while Prof. Leslie thanked CEHURD for having organized the meeting during which a lot had been achieved.

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