

REGIONAL MEETING ON HEALTH AND HUMAN RIGHTS



Report of Proceedings

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1. EXECUTIVE SUMMARY

The Learning Network for Health & Human Rights (South Africa) and HEPS-Uganda co-convened this regional meeting in Kampala on 8th October 2010. The primary intention of this meeting was to enable the regional sharing of best practice around the right to health and community participation, as well as to explore the development of a toolkit / training manual on the Right to Health for Civil Society groups in the region.

The meeting kicked-off with opening remarks from the director of HEPS-Uganda and a presentation of the issues emerging from the EQUINET conference plenary on the Right to Health. Session one encompassed presentations aimed at sharing regional lessons on best practice in the area health and human rights. The presentations in this session related to Community Health Committees as vehicles for advancing the right to health in Zimbabwe and South Africa, and to the experiences of HEPS-Uganda in establishing a complaints process to enhance rights claims. The second session included presentations from two civil society members of the Learning Network on health and human rights, namely Epilepsy South Africa and The Women's Circle, who presented the Learning Network as a case study and some of the lessons learned over its three years of operation. The background and overview of the toolkit and training manual on the right to health was also presented in the second session. Meeting participants discussed a range of issues following presentations in sessions one and two, including:

- Literacy as a barrier to community participation and the importance of community governance structures for advancing health rights in light of this barrier;
- The role and capacity for influence of the Community Working Group on Health (CWGH) and Health Centre Committees (HCC) on government policy in Zimbabwe;
- The difficulties with which persons with mental illness are able to assert their rights and counter rights violations through the legal system in Uganda;
- The failure of health systems and of punitive action against individual health workers to redress systemic rights violations, as well as the importance of popular education and information for the appropriate redress of these violations;
- Challenges and opportunities arising through the Learning Network for health and human rights in South Africa;
- Methods employed by the Learning Network, including auto-photography as a Freirian approach having the potential to engage communities, irrespective of literacy levels, in the identification of rights issue and to act as an impetus for action;
- The influence of external pressures (i.e. structural adjustment programmes) in diminishing health budgets and the importance of civil society action to enforce greater allocation of resources for health;
- The use of the progressive realisation clause by governments to evade their obligation to fulfil the right to health and the role of an active and informed civil society to hold government to account;

Later in the day, meeting delegates were involved in a practical demonstration of the toolkit in order to view the toolkit as would be experienced by members of the community. Following the demonstration, a general discussion was held when suggestions were made for the toolkit. Ideas were provided for additional chapters and sections as well as notes on logistical considerations for when the toolkit is to be applied more broadly. Discussions for the way forward included plans for future action on the toolkit, a human rights curriculum for

health workers, and for community governance structures for health. In summary, plans for the way forward included:

1) Toolkit

- Meeting delegates will use the South Africa version and adapt to their own context
- We will plan a for 2011, at which time we will share experiences of using the toolkit, introduce CGWH manual and share the UCHR toolkit on human rights.
- The Learning Network will lead this process to develop a more generic toolkit for regional application.
- We will need to seek additional funding or piggy back this work onto other activities taking place in the region (i.e. gathering for EQUINET).

2) Human Rights curriculum for health workers

- IFHHRO to serve as a clearinghouse to assist the sharing of research
- Multi-country human rights study to describe curricula and gaps
- Aim to identify evidence for effectiveness of training (produce policy brief to support lobby, advocacy work)
- Potential for this work to be guided by EQUINET

3) Health Committees

- Share research and information on different models for these community governance structures for health in the region (policies, structures, guidelines)
- Possible multi-country situation analysis of health committees
- Need to develop indicators of community participation for monitoring and evaluation
- Multi-country situation analysis of health committees
- Potential for this work to be guided by EQUINET

2. BACKGROUND

2.1 Introduction

Despite formal democracy, regional human rights instruments and national Constitutions embracing elements of human rights law, the practical realisation of the right to health remains elusive for many in East and Southern Africa. This is evidenced by profound inequalities in health status and in the distribution of resources needed for health. Underlying these inequities are varying degrees of powerlessness that render communities and individuals vulnerable to factors leading to ill-health.

While the researchers and academics play a critical role in gathering evidence on the right to health, civil society has an important role to play in mobilising communities around rights, by creating an awareness of rights and by ensuring greater state accountability for service delivery.

In this context, HEPS-Uganda and the Learning Network for Health and Human Rights under the School of Public Health and Family Medicine of the University of Cape Town jointly convened a one-day regional meeting of civil society actors from organisations working on

issues of the right to health in Uganda, South Africa, Kenya, Zimbabwe and Malawi. The meeting was held at Imperial Royale Hotel in Kampala, Uganda, on 8th October 2010.

It was a follow-up on the resolutions of past conferences of the Regional Network for Equity in Health in East and Southern Africa (EQUINET), also fed into work by EQUINET's social empowerment and country networking clusters. It was part of the long-term initiative to raise awareness around the right to health; empower communities to redress health rights violations; strengthen the capacity of communities and CSOs to take-up health rights issues; and increase value and participation in community governance structures for health.

The meeting discussed experiences and lessons from the different countries around the right to health. These discussions were to inform the development of a training manual on health and human rights for regional implementation. The manual being developed will be form a toolkit for civil society actors for mobilising and empowering communities to realise their right to health.

The key resource persons were Leslie London, Gabriela Glattstein-Young, Nicolé Fick, Wendy Nefdt and Vanessa Reynolds from Learning Network for Health and Human Rights, University of Cape Town, South Africa; Edgar Tatenda Mutasa, Community Working Group on Health (CWGH), Zimbabwe; and Moses Mulumba, HEPS-Uganda.

2.2 Meeting objectives

The overall objective of the meeting was to bring together various actors on the right to health in the East and South African region to discuss a toolkit on health and human rights.

The Specific objectives were to:

- 1) Enhance the agency of civil society organisations and communities in East and Southern Africa to realize their rights;
- 2) Develop the skills and knowledge needed to increase meaningful citizen participation in health governance structures; and
- 3) Strengthen regional sharing and exchanges of knowledge on best practices for health and human rights.

3. OPENING SESSION

Session chair: Moses Mulumba, HEPS Uganda

The meeting opened at about 9:45am with the session chair, Mr Moses Mulumba, welcoming the participants and giving an overview of the meeting and its purpose. He then took the participants through a round of self-introductions, before inviting HEPS-Uganda Executive Director Ms Rosette Mutambi to give the opening remarks.

3.1 Opening remarks

Ms Rosette Mutambi, Executive Director, HEPS-Uganda

In her remarks, Ms Mutambi welcomed the participants to the meeting and (first-time visitors) to Uganda. She said HEPS-Uganda was glad to have partnered with Learning Network to organise the workshop. She emphasized the importance of associating with other actors doing similar work for purposes of learning from one another and also coordinating activities that should facilitate the realisation of the right to health at community level.

Ms Mutambi briefed the meeting about HEPS-Uganda and its work around the right to health. HEPS-Uganda is a national health rights organisation, operating in 10 districts in Uganda. It runs three programmes:

- The Community Outreach Programme (whose manager coordinated the organisation of the regional meeting). Through this programme, HEPS-Uganda has established a network of more than 1,000 community volunteers who sensitise communities in the target districts about their health rights and health responsibilities. Through this programme, HEPS-Uganda also coordinates two coalitions of community-based groups involved in health: (1) the Northern Uganda Coalition for Health Advocacy (NUCHA), and the Eastern Uganda Coalition for Health Advocacy (EUCHA). Both coalitions were represented at the meeting.
- The Health Complaints and Counselling Programme (C&C Desk), which facilitates dialogue around, and resolution of complaints of health rights violations at the health centre level. In implementing this programme, Ms Mutambi reported that HEPS-Uganda has faced challenges related to the lack of an enabling law to get redress for victims of violations. To address this constraint, the organisation has been working around a model health complaints redress law and engaging the Uganda Human Rights Commission.
- Health Policy Advocacy Programme, which analyses of policies and engages policy makers to create consumer friendly laws and policies. The programme targets the Ministry of Health, Ministry of Tourism, Trade and Industry, other government ministries, parliament and other relevant stakeholders.

The HEPS-Uganda Director also noted that HEPS-Uganda, within EQUINET, coordinates the Uganda Health Equity Network (UHEN), some of whose member organisations were represented at the meeting. Under UHEN, with support from the International Development Fund (IDF), HEPS-Uganda has been trying to develop a model law to help the organisation address health consumer complaints. The process is still at the initial stages, and Ms Mutambi invited participants with experience in developing and advocating for such a law to share it with her organisation.

Ms Mutambi said HEPS-Uganda was looking forward to the toolkit around which the meeting had been organised. She said her organisation was open to learning and welcomed the toolkit as well as other opportunities that the Learning Network presents in order to learn from people doing similar work.

3.2 Issues emerging from EQUINET conference plenary on the Right to Health

Presenter: Prof. Leslie London, Learning Network

The presenter reviewed the discussions and relevant resolutions of the EQUINET conference on equity in health which took place at Munyonyo Resort in Kampala, Uganda, in September 2009. The conference was held under the theme, “Reclaiming the Resources for Health”, with

a special session on “Claiming the right to health” during which presentations were made by the Learning Network and HEPS-Uganda. The presenter said that the Commonwealth Foundation had provided a grant, which was supplemented by additional funding from Oxfam and the University of Cape Town to organise the meeting as a follow-up from resolutions made at the EQUINET conference.

The conference presentations noted that globalisation could limit, but also open rights opportunities; that ratification of the relevant conventions is itself not sufficient; that states have substantial policy latitude; and shared experiences of community structures for complaints of health rights violations. The Learning Network shared experience of access to training, information, materials and research (Community Agency).

Session participants discussed building a community of best practice; recognising rights of both health workers and community members; claiming rights at all levels, from local to global; how to measure empowerment; building synergy between stakeholders; and catering for vulnerable groups.

The participants made resolutions on ways to hold non-state actors to account; protect rights of health workers and labour rights; claim rights at all levels; build synergies around all stakeholders; protection for vulnerable groups; state transparency and CSO participation in treaty accession; develop community of best practice; and give a voice to communities.

4. SESSION ONE: LESSONS ON BEST PRACTICE

Session chair: Wendy Nefdt

4.1 Health Committees as a vehicle for advancing the right to health, lessons from South Africa

Presenter: Gabriela Glattstein-Young

The presenter shared findings from a thesis research she undertook around community health committees as part of her Master of Public Health programme at the University of Cape Town. She started by giving a brief background on the framework for community participation, citing the Alma Ata Declaration and international human rights instruments at the international level and within South Africa. At the local level, the National Health Act (2003) established health committees as formal structures for community participation in health while the Reconstruction and Development Programme of 1994 set the groundwork for development in the post-Apartheid South Africa and made extensive mention of the community participation as central to development processes.

She noted however, that studies have indicated a serious shortcoming in the implementation of *meaningful* participation of communities in health.

She explored the relationship between community participation and the right to health on the basis of the four criteria that have been used to evaluate the right to health: availability, accessibility, acceptability and affordability.

She argued that on the basis of experience from Western Cape, health committees could indeed advance the right to health. For example, through the work of one health committee a day hospital was transformed into a 24-hour facility (increasing availability and accessibility); one health committee assisted patients to find their way to a new pharmacy (increasing accessibility); several committees would talk to the facility manager when clinic staff were very rude to patients (increasing acceptability); one of the committees fund-raised for new equipment in the facility (increasing quality); while another lobbied for more staff (having the potential to increase availability).

Nevertheless, levels of community participation through the health committees were restricted by the amount of power they held. Vulnerable and marginalised groups, such as refugees, were most often under-represented. Health committees still lack a formal mandate in South Africa such that they exist in a vacuum, without guidelines for operation. For this reason, they tend to be at the mercy of facility managers, who are the gatekeepers to the level of participation in health that is able to occur. Thus, their ability to influence changes at the health facility level is dependent on the manager while influence at the health systems remained limited.

The lessons for best practice from these findings included intersectoral involvement, where people from different sectors related to health, such as local politicians and environmental officers, are members to the committee; apprenticeships between more and less experienced committee members; and the availability of a mechanism to lodge and resolve community-

level complaints; the health committee's use of local media strengthened their visibility and their ability to operate as a liaison between the facility and the community.

Ms Glattstein-Young also cited two other studies: (1) an ongoing study that she said had so far audited 70% of the health committees in the Cape Metropolitan Area; and (2) an investigation into the draft policy framework.

The key recommendations included the need to reassess the draft policy framework; monitor and evaluate using mutually accepted indicators of community participation; train members and build their capacity to make their participation more meaningful; and to use human rights norms and standards to promote the participation of vulnerable groups in the committees.

4.2 Community Health Committees as a vehicle for advancing the right to health: Lessons from Zimbabwe

Presenter: Edgar Tatenda Mutasa, CWGH, Zimbabwe

The presenter started by giving a brief background to the Community Working Group on Health (CWGH). Formed in 1998, CWGH is a network of 35 civic/community based organisations that have come together to take up health issues of common concern in Zimbabwe. The organisation, which is operational in 27 districts of Zimbabwe, aims to be a leader in the achievement of equity and accessibility in health by empowering communities and promoting the principles of community participation in health.

In Zimbabwe, health centre committees (HCCs) are a joint community-health service structure linked to the clinic and covering the catchment area of a clinic (usually a ward/larger area). They are composed of the nurse in charge of the health centre, the EHT, the kraal head, a councillor, a headmaster or health teacher, a church representative, a village health worker (VHW), a youth representative, a representative of other health providers in the area (e.g. traditional healers, private service providers, non-governmental organisations or NGOs).

Mr Mutasa emphasized the importance of involving all stakeholders as this promotes ownership over resources and facilities. The nurse in charge is the secretary of the committee, so that all the information is at the health centre. The councillor represents the local authority and government and helps to allay fears and suspicion. The Environmental Health Technician (EHT) promotes preventive medication through primary health care education. The teacher and clergy help in information dissemination. The village health worker brings information from the community and gives feedback. The youth represents the next generation (very active in networking and provision of manpower).

He then outlined the functions of HCCs: they use information from the health information system and from communities in planning and evaluating their work; assist communities plan how to raise their own resources; help people in the area identify their priority health problems; assess whether the health interventions in the area are making a difference to people's health; and provide a channel for information flow to and from the community and the Rural District Council (RDC).

HCCs were introduced by the Government of Zimbabwe in the early 1980s, to enhance community participation and ownership of the social equity (in health) agenda. Zimbabwe's

second decade saw a decline in the health delivery system attributed to Economic Structural Adjustment programme (ESAP), governance problems, droughts, political instability and polarization, economic sanctions, lack of firm policy positions and corruption, among others.

In 2001, CWGH initiated a process of setting up or revitalizing HCCs to strengthen the capacities to demand resources. In the spirit of enhancing public participation, CWGH in partnership with TARSC, established and built the capacity of HCCs using the Health Literacy manual specifically developed for the purpose. Currently TARSC is developing an HCC training manual yet to be tested by intellectuals and experts before it can be published.

The presenter listed the key issues that HCCs were called to promote using the manual. They were tasked by the community to advocate for the “bottom up” approach regarding policy issues; represent community preferences in the distribution of the national AIDS levy; facilitate community input into the parliamentary portfolio committee on health (e.g. scraping of user fees); and undertake health-related education and information to change mindsets (e.g. cultural and religious beliefs).

Mr Mutasa cited some of the key outcomes from the HCCs’ efforts. HCCs have acted on and improved primary health care services, increased health knowledge levels, and improved health-seeking behaviour and early use of services. They have participated in advancing gender issues, particularly women’s sexual and reproductive health rights (SRHR). They have also improved representation of community interests in health planning and management at health centre level.

Some of the practical examples cited in mobilising community resources for health included Nyava HCC in Bindura which constructed a nurses’ house; and Zhombe HCC which bought an electricity generator using funds sourced by the community.

The presenter recommended the need for HCCs to be recognised as legal entities to improve their effective; more resources at primary care level, including support for HCCs; and roll-out HCCs across the region. At the regional level, there is need to organise learning visits regional level so that other countries can learn from more functional HCCs; and improve documentation and sharing of the work being done by HCCs.

4.3 Complaints processes as enhancing claim for rights to health in Uganda

Presenter: Moses Mulumba, HEPS-Uganda

The presentation was based on the experience of HEPS-Uganda in establishing a health consumer complaints redress mechanism under its Health Counseling and Complaints Programme (C&C Desk). HEPS-Uganda reported serious challenges in its effort to gather and address health consumer complaints due to the absence of a clearly-defined and pre-existent remedial structure in the country. HEPS-Uganda noted that this is worsened by the absence of a feedback mechanism between health care consumers, health care providers, and policy makers.

HEPS-Uganda established the C&C Desk in an effort to create a channel for health consumers to complain about the violations and access proper redress. The ultimate objective was to ensure that providers and consumers can approach each other with mutual respect in a

consumer friendly setting and in which health rights are respected and individuals and institutions are accountable for their actions.

Through the C&C Desk, HEPS-Uganda has carried out three major studies on consumer complaints to establish the prevalence and nature of health consumers' complaints. The first was a pilot study conducted in 2006 at Mengo Hospital, which among others, found that complaints raised by consumers were related to violations of their human rights. The majority of both health care consumers and providers were not aware of their rights and responsibilities, and the existing local channels for forwarding their complaints at the hospital level.

The second study was conducted in Pallisa and Budaka Districts over the half year period July 2007-February 2008. This project was on Community Empowerment and Participation on Maternal Health in Pallisa and Budaka districts. This study also confirmed that there are multiple violations of health rights occurring in the context of access to health care.

The third study was conducted in 10 sub-counties of Lira district, which also confirmed complaints by health care consumers of the same nature. HEPS-Uganda noted that beyond initiating dialogue between a complainant and a health care institution, there was little that has been done to address complaints which require proper redress.

Another comprehensive baseline survey was done by the Uganda National Health Consumers' Organisation (UNHCO) on patients' rights. This study aimed at getting evidence on general awareness about patients' rights in Uganda and the extent to which such rights were being violated. This survey covered the capital Kampala and two other urban areas in Uganda. UNHCO identified the rights to information, dignity and access to medicines as the most violated without redress. The findings of this survey indicated that while there was some awareness about patients' rights, such awareness had an economic, social and gender dimension.

The presenter gave an overview of HEPS-Uganda's Model Healthcare Complaints Law Project, which investigated the shortcomings and proposed a legal and policy framework for addressing health rights violations, as well as structures and institutions to receive and address complaints from health consumers.

The study found that the existing policies and legal framework were largely discipline-oriented with a mechanism of professional self-regulation for their members, aiming to protect the public from harm. This has meant that regulatory authorities have referred health care consumer complaints, most of which concern individual conduct, to professional bodies. Thus, consumer complaints are merely a means of streamlining professional conduct and not providing redress for violations of health rights.

Uganda has three major health professional agencies established under statutes in Uganda: (1) the Medical and Dental Practitioners Council; (2) the Nurses and Midwives Council; and (3) the Allied Health Professionals Council.

Mr Mulumba pointed out that the professional codes of practice mention respect for human rights of patients, such as respect for patient human rights, non-discrimination, privacy, confidentiality, integrity, and entitlement to emergency treatment. He however, noted that placing these rights in professional codes of ethics effectively reduced them to moral

obligations. Thus, they do not entitle patients to claim violations of their rights. Breach of the code only renders a practitioner liable to disciplinary action, with the complaint only serving as evidence of the alleged breach.

And given that their mandate is health worker-centred, professional councils and their mandates are not widely known among health care consumers. As a result, only few cases reach them for consideration. In the year ending 2007, the Medical and Dental Practitioners Council received only 19 cases, out of which 11 were finalised. Only about one quarter of the cases received originated from health care consumers. Of the finalised cases, there were no documented reports from the Disciplinary Committee.

In selected and “deserving” cases, the councils make referrals to the Uganda Human Rights Commission (UHRC) for appropriate redress. There are also cases where the UHRC refers complaints to the MDPC. However, as observed by the Medical and Dental Practitioners Council Registrar, this collaboration does not seem to work effectively. UHRC’s work on health rights has so far been limited to civic education about patients’ rights through sensitisation campaigns targeting health workers and institutions.

According to the UHRC, violations of health rights are not dealt with in any specialised way for a number of reasons including: lack of a proper legal framework for handling such complaints and lack of proper and qualified staff.

Mr Mulumba suggested a few alternatives to the professional self-regulation framework. He reported that under the current system, there are means by which aggrieved health care consumers can access redress in the courts of judicature in Uganda. The aggrieved consumer can approach the civil courts seeking a remedy for wrong or harm done to them by a medical professional or even an institution. Once the consumer satisfies the court that they have suffered such harm, the court ordinarily would award damages as compensation against the wrong doer. There are however a number of procedures that the consumer must go through for this to happen.

The second alternative is lodging the complaint with the UHRC. Article 52 of the Constitution empowers the UHRC to “investigate, at its own initiative or on a complaint made by a person or group of persons against the violation of any human rights”. The UHRC has the powers of the High Court, and can summon witnesses and issue relevant orders against the State, its agencies and private persons in matters involving violations of human rights. The UHRC can utilise its wide mandate to protect socio-economic rights generally and the right to health in particular. Accordingly, UHRC has established a tribunal which handles human rights complaints against both the State and the individuals.

Although the UHRC provides an opportunity for handling health rights complaints, it still faces various problems, including the lack of a proper and precise legal basis for health rights and handling of patient rights violations. The other major challenge to date is the lack of information on the part of consumers on where to complain, how to complain, what to complain about and what remedies to seek. Information about the procedures addressing these questions is critical in ensuring that violations of rights are redressed.

Under the circumstances, the presenter then cited some opportunities for handling health consumer rights violations: public interest litigation; opportunities for *pro bono* (free legal) services; the Patient Charter; and the National Development Plan (Para 502-improving health

of the population, 614-health rights and responsibilities, 638-human dignity, 680-justice for all).

Mr Mulumba concluded his presentation by highlighting the following key messages:

- The existing legal and institutional framework focuses on quality delivery through regulation of health professionals by codes of conduct. The system is professional discipline oriented; there is no properly dedicated legal or policy framework for redressing health consumers' complaints. There is a need to establish an independent health care complaints commission (or ombudsman) to receive, investigate, consider, and determine complaints alleging the violation of health rights against both public and private health care institutions. Alternatively, the functions and powers of the UHRC can be buttressed by formalising the health rights desk for purposes identical to those of a health care complaints ombudsman.
- The current efforts epitomised by the incorporation of the Patients Charter within the national health policy is not enough because it is not law on which health care consumers can base their claim for appropriate remedies for violations of their health rights. Additionally that the Patients' Charter is silent on possible remedies for violations of rights it enumerates. The health rights recognised in the national health policy as social values need to be concretised into law.
- The alternative means of seeking redress such as civil suits is beyond the reach of the majority of Ugandans. As a result of the foregoing, the health care consumer who suffers violation of their rights in the context of accessing health care is left out without redress.

4.4 General discussion

The general discussion focused on the three presentations that were made during the session. On the presentations on health committees, one participant pointed out illiteracy and lack of awareness as major barriers. The participant gave the example of Kenya, where children under five years are entitled to free treatment, but people do not know about it and rarely claim it. One case was cited to illustrate how people are exploited due to lack of awareness, where parents paid Kshs500 in a government facility for a medication that should go for free or for Kshs 40 in the private sector!

In her response, Ms Glattstein-Young concurred that illiteracy was indeed a barrier to promoting health right as many people do not have the capacity to engage meaningfully with the facility managers. However, it is for this reason that health committees become important vehicles for advancing the voice of the community. She noted that in her study, stronger health committees tended to have members with higher levels of education.

On the experience from Zimbabwe, the audience raised a question on how the country ensured that the traditional healers were accountable. It was noted that traditional healers tend to claim to cure every problem. One contributor suggested that it is the role of government to protect people and should be held accountable for actions of the healers. It was noted that there was no monitoring and evaluation of the activities of traditional healers, citing the case of traditional birth attendants, who are sometimes implicated in infant and maternal mortality.

Responding to the issues raised, Mr Mutasa said that following the influence of HCCs and CWGH, the government of Zimbabwe put in place a body (ZINATHA) that is responsible for licensing and supervising traditional healers. The chair of the board of ZINATHA has been at forefront of fighting false claims from traditional practitioners.

On the experience of Uganda, with respect to handling violations of health rights, the participants raised a concern about the legal procedures that do not admit evidence from people with mental illness or who have a history of mental illness. The courts consider these individuals to be of “unsound mind” and therefore do not consider their testimonies, even when healed and normalised. It was further noted that the mental illness law was last revised in 1964 and is archaic in the age of promoting the rights of people with disabilities. Still, it was argued that even in the presence of an enabling law, the mentally ill would have great difficulty claiming human rights.

An issue raised was about professional self-regulation. It was argued that there is a weakness in focusing redress of violations on individuals when many violations are the result of the broader health system. One contributor suggested that civil society may need to think beyond punishment and compensation for the redress of rights violations, to consider the possibility of creative community-driven systems which have the potential to enhance respect for the right to health.

In his response, Mr Mulumba informed the meeting that the mental health law and policy had been in revision for the past five to ten years. He agreed that people with a history of mental illness face great difficulty in seeking redress through courts of law since current legislation continue to classify these individuals as being of “unsound mind”. However, Mr Mulumba noted that there are alternative, more creative ways of dealing with this challenge.

On professional self-regulation, Mr Mulumba agreed that professional codes are not sufficient or even relevant when dealing with systemic rights violations. He pointed out that negligence may also be difficult to prove in rural areas where knowledge of rights and codes of conduct is low. He cited a recent case in Buzibwera, a rural area of western Uganda, where politicians reportedly incited the community against health workers by making community members falsely believe that health workers were withholding drugs at the health centre. Mr Mulumba argued that these types of challenges need to be considered when considering ways to address health rights violations.

Mr. Mulumba went further to emphasize that it is not the government that gives rights, as one contributor had implied; it only protects and promote them. He said that there has been a challenge with the concept of “progressive realisation”, which connotes that the right to health will be “progressively realised” as the necessary resources become available. He suggested that the civil society should exploit and utilise human rights initiatives which are available to them at the global level, such as the United Nations Special Rapporteur on the Right to Health. He commended the efforts of CWGH to have the right to health enshrined in the national constitution of Zimbabwe, saying that this will strengthen advocacy for its realisation.

5. SESSION TWO: TOOLKIT ON THE RIGHT TO HEALTH

Session chair: Leslie London, Learning Network

5.1 Best practice on realizing the right to health: Experience of a South African Learning Network

Facilitators: Wendy Nefdt and Vanessa Reynolds

Ms Wendy Nefdt and Ms Vanessa Reynolds presented the Learning Network's experience as part of sharing best practice towards the realisation of the right to health.

Ms Nefdt gave an overview of the context of health and human rights. She said that despite the adoption of a range of international and national legislative instruments about Health and Human Rights over the past five decades, health status and access to health care has declined in many developing countries, including South Africa. Instruments relevant for health and human rights in South Africa include the International Covenant on Social, Economic and Cultural Rights; 1966 South African Constitution (1996); South African Bill of Rights; South African National Health Act (2003); Patients Charter (2007).

Quoting the South African Human Rights Commission Report and People's Budget Campaign, the presenter noted that people are not only uninformed of their rights but also struggle to access information about health services in their communities. Relevant education about health rights has increasingly become the responsibility of non-profit and civil society organisations. Therefore, a need clearly exists for CSO's to integrate health and human rights principles into their programmes for the attainment of these rights.

In order to intensify efforts towards the attainment of health and human rights, CSO's have been encouraged to work in partnership and through networks. Networks have been gaining attention in literature where their role has been emphasised in the development of agency amongst CSO's and communities.

The idea of the Learning Network originated from a research study in 2006 which explored how CSOs in the Western Cape use human rights approaches in their work. The organisations that were assessed in this study included: Women on Farms, a rural CSO focusing on women advocacy; Epilepsy South Africa, an urban CSO in disability; Ikamva Labantu, an urban CSO in development; and the Department of Health.

At the end of the research project, a workshop was organised to discuss feedback with members of the participating organisations and other stakeholders, to share findings of the study, and to develop recommendations on how these findings could be taken forward. Workshop participants recommended the creation of a Learning Network around the right to health which would work to build the capacity of CSOs around health and human rights and develop user-friendly materials.

Support from the South Africa-Netherlands Research Programme on Alternatives in Development (SANPAD) enabled the implementation of the Learning Network starting from January 2008. The implementation started with an introductory workshop with member organizations, which discussed the research aims and objectives and presented the process (spiral).

At present, the Learning Network consists of representatives of six member organisations and three academic partners. The organisations include Ikamva Labantu, Ikaya labantu, Women on Farms, The Women's Circle, Epilepsy South Africa, and Community Health forums. The academic partners are University of Cape Town, University of Western Cape, and the University of Maastricht. Its activities include monthly executive meetings, monthly research meetings and seminars, review and reflection meetings, ongoing research, training and learning, and presentations at relevant Forums.

The presenter explained an illustration of the Learning Network's methodology, which consists of a participative spiral of action and reflection. Reflection on the feedback of data collection and analysis is therefore used to inform the development of materials, to identify future training needs and new research questions. This process also facilitates the monitoring of impacts from both the training and reflection process.

The Learning Network has formulated its vision, mission, overall goal and governance structures. An executive committee consisting of representatives from each member organisation and academic partner has been established, and has been given the responsibility of making decisions about membership, overseeing the programme plan, and fundraising, among other things.

The Learning Network is currently involved in information dissemination, research and reflection on best practise, and training on the right to health. It supports advocacy and lobbying by member organisations, and networking with civil society partners in South Africa and Southern Africa. It has produced pamphlets for community members and leaders; toolkits and training manuals on the right to health; policy briefs; and case studies of rights violations to use for training and advocacy. It has also made presentations to public forums, papers for publication, undertaken a skills audit of health committees; and is documenting work of CSO's around the right to health.

In brief, the Learning Network has employed an iterative process to investigate the understanding and practice of human rights by civil society groups and health care providers. Through its activities, the Learning Network has contributed to the co-learning of researchers and CSOs on the implementation and realisation of the right to health. The Learning Network's first three years of existence has primarily been inwardly focused on the understanding and practice of civil society groups; however, the next three year period will incorporate the understanding of health care providers and examine whether bringing together members of civil society and health care providers to discuss and explore models for realisation of the right to health creates opportunities to build trust and overcome adversarial approaches to rights claims in the health sector.

Ms Vanessa Reynolds from The Women's Circle (TWC) shared the experience of her organisation with the Learning Network. She said that joining the Learning Network gave The Women's Circle greater capacity to roll-out its programme in the Western Cape. Participation in the Learning Network also enabled The Women's Circle to start working on its own programme to promote the right to health among its members, one third of whom are illiterate.

Ms Reynolds said that her organisation uses community photography and participatory reflection and action (PRA) tools to promote numeracy and literacy among its members. This enables TWC members to reflect on their own experiences and problems to develop their

own community-based solutions. Ms Reynolds said that The Women's Circle has used plays and drama to raise awareness and claim the right to health.

General discussion

- *What challenges have you faced in this network and how have you addressed them?*
Bringing civil society with academics together will bring up issues of trust, power-sharing and value-addition. From the lessons, we have found that engagement is better, especially when using feedback and the PRA framework. When issues arise, we bring them to the executive committee and discuss them. Power-sharing is partly resolved by sharing responsibility for chairing and hosting meetings, seminars, workshops and events. We have had two to three years of formative planning and organisational planning but we are still learning about the best approach to share power and governance. It takes time to build the trust needed in order to share resources and dialogue in ongoing. It is difficult to demand priority to network activities and to share responsibility equally within a network so we are still learning how best to do this.
- *Which stakeholders do you involve in these programmes? At what stage do you involve them? What have been the outcomes?*
Participation in the Learning Network has been largely limited to the six member CSOs and three higher education institutions for the first three years of its existence. It took three years to develop a level trust in the network where people were willing to share learning and resources therefore this required us to be quite inwardly focused. We did not expect the process to take this long but only now after three years are we at a place where we can engage with stakeholders and share the lessons learned. One of the ways of doing this is through dialogue and involving stakeholders in this dialogue, particularly the Department of Health. Therefore our plan is now to start looking outwardly to see how we can engage stakeholders in the action component, using what we have learned from research and reflection.
- *What do you take to be a community in South Africa, and what challenges does that bring working in same locality with different communities?*
Communities depend on context. In the case of the Learning Network, we do not define the community, rather the community defines itself. So long as a community see itself as such, then we have accepted to see the community in this way.
- *Is there a possibility that issues and concerns about the right to health from people will have a chance to be integrated into the national-level planning process for policy redress?*
The issues raised relate to advocacy and, depending on how successful our advocacy is, can lead to policy change. The network is relatively small, but we have been present at sessions of the human rights commission and have participated in submissions on the right to health. The South African Human Rights Commission held a hearing in 2009 on the right of access to health care and progress on socio-economic rights. The Learning Network participated in a broader submission by the South African NGO Coalition based on our experiences and our findings. There was an interesting interaction between the head of health for the Western Cape and the person from the Learning Network making the submission around community participation in health. The submission criticised the Department for failing to give a

voice to communities in the planning process. The Department responded to say that the community had a voice in the planning process, despite this being limited to involvement after plans had effectively been finalised. In 2010, the Cape Metro Health Forums have been involved at a much earlier stage, perhaps as a result of this engagement during the SAHRC hearings. Despite this progress, the Learning Network still feels that the health forums should be empowered to make more meaningful input in policy formulation.

- *Do you have samples of the photos you have used with audiences that are illiterate to help us clearly understand how you use them?*

Auto-photography is essentially a participatory method based on Freirian principles which enables members of the LN to act as co-researchers. This method, we have learned, can help us learn more about how people see health and human rights in their communities; however, it is also a method that leads to action by helping those involved to identify the key issues and start thinking about ways to resolve these issues. We asked some women to go out and photograph what they think is health or human rights and when the photos came back, there were a range of issues highlighted. In response, workshops were held where current practices within these communities were explored and the experiences of other people were drawn upon to discuss alternatives to addressing these issues. Therefore community members can teach on another about health and human rights issues, even when they are illiterate. We also discussed ways to share our lessons regarding ways to initiate change with people from other communities.

As an example, some photos by one participant identified open waste and drug use as health issues in the community. Discussion and reflection on these photos led to the development of a programme to get youth to start cleaning-up the community, learning how to recycle object and to prevent youth from getting involved with drugs.

- *I was brought up by a mother, who had epilepsy, and reflecting on my experience, I realise the rights of children in a similar situation have been ignored, yet their health is affected. How are you handling this problem in South Africa?*

This is not easy to answer the question. While the prevalence of Epilepsy is quite high, it remains one of the most discriminated disabilities by virtue of the fact that it is invisible. Research has shown that having an epileptic parent has psycho-social impacts on a child and the family. At Epilepsy South Africa, we try to implant interventions and programmes from birth. Therefore the focus is not only on the person with epilepsy but also on the family. We try to disseminate information on epilepsy so that children do not feel isolated with the disability or having a parent with the disability. The adults with epilepsy should therefore be encouraged to share their problem with their children. So yes, you are right, the children are affected.

5.2 A toolkit for advancing the right to health in the region

Facilitator: Nicolé Fick, Learning Network

The facilitator started the presentation with some background on the toolkit project. She indicated that the toolkit was designed in response to members of the Learning Network who identified the need for a tool to use to train communities on what the right to health means

and to identify violations of the right to health. An initial draft of the toolkit was piloted and based on feedback from the organisations changes were made. She said the toolkit as it stands has been drafted for use in the context of South Africa, and the purpose of sharing it at the regional meeting was to start a discussion on whether a regional toolkit is possible and what such a toolkit would look like.

The process of producing the toolkit has come through stages; through a cycle of action and reflection. The first draft of the toolkit was too academic and complicated. It was revised and adapted so that it could be used as a tool to run workshops on the right to health. The toolkit has been piloted with two member organisations of the Learning Network; The Women's Circle and Ikamva Labantu.

Ms Fick took the participants through the current structure of the toolkit. It has an introduction, which outlines the aim of the toolkit, who it is for and how it is structured. It has four main chapters: (1) What are human rights; (2) Health and human rights; (3) Dealing with violations of the right to health; and (4) Citizen participation in health.

The toolkit is a combination of theory, that has been illustrated with case studies of violations of health rights or other practical examples (which can be copied and given out as workshop handouts). The main focus of each chapter however is an outline of a workshop procedure based on the theory being discussed with practical exercises to be done in groups to give participants opportunities to apply the concepts that have been covered.

General discussion

The general discussion brought up several reactions to the presentation. There was a concern that the governments hide behind the concept of “**progressive realisation**”, and one contributor asked whether there were no rights that could be realised immediately. Later in the discussion, a different participant called for caution about pushing for constitutional guarantees on the right to health. He said governments have the tendency to give with one hand and take away with the other; while governments will put the right to health in the constitution, they may try to hide behind the concept of “progressive realisation”. He gave the example of Kenya, where the right to health has been included in the constitution but the government maintains that there are insufficient funds to realise the right. The participant wondered whether jurisprudence from South African cases around the right to housing could be used in litigation in other African countries to propel governments to fulfil their constitutional obligations.

Another concern raised was about the **lack of response to complaints raised by communities** at hospitals and health centres in South Africa. The contributor reported that there were people who had lodged their complaints but these are often not followed-up. She wondered how such complaints could be followed up to ensure that they are addressed.

Another contributor suggested that the toolkit look at violations of the right to health in totality at community, national, regional and global level. She noted that one of the greatest contributing factors impeding realisation of the right to health in Africa are structural adjustment programmes which promote privatisation of health which has the effect of privatising the right to health. The contributor pointed out that there are several **international conventions and agreements** that seem to create new **barriers to the realisation of the right to health**. For this reason, governments may fail to meet their obligations because of

encumbrances created by such agreements. The participant therefore appealed for closer networking around the international frameworks and how they relate to the right to health. Citing the situation of Uganda, where there is a high level of dependence on donor support, the participant suggests networking and sharing knowledge in order to raising resources for health from communities and thereby mobilise more resources for the health sector.

In relation to the toolkit, Mr Mulumba wonders how we can start developing tools that have simple policy messages on health rights. Mr Mulumba therefore wonders how innovative we can be to include labour policy and trade policy issues relating to human rights in a simple way into the toolkit. It was decided that this issue is one which would be explored in greater depth after lunch.

In response, Ms Fick agreed that progressive realisation can sometimes be used by governments to circumvent realisation of the right to health entirely; however, minimum obligations (from General Comment 14) related to the right to health must be realised immediately. Ms Fick highlights the role of civil society as a whole towards the realisation of the right to health and to promote the allocation of greater resources for health through lobbying and advocacy; governments need to be challenged and held to their commitments, national and international (for instance, the Abuja Declaration which commits governments to dedicate 15% of national budgets to health). With regards to the redress of complaints in complaints boxes in the health care system, Ms Fick notes that there are other strategies and these are addressed in the toolkit, such as the principle of escalation of complaints if no action is taken at the local level. There is also discussion in the toolkit of ways to employ collective action within civil society to move forward on a common issue.

Also in response to the issue of progressive realisation, Prof London agrees that this is indeed a double-edged sword; however, CSOs in South Africa have used this principle in creative ways. For instance, some CSOs, such as TAC, have challenged government by demanding proof that there is indeed a lack of funds preventing progressive realisation of its obligation to fulfil the right to health. Cases which have not challenged government on the basis of progressive realisation have not been as successful as they may have been if this challenge were made. Prof London also cites the Grootboom case in South Africa where the absence of civil society movement following a positive court ruling resulted in government failure to make good on its obligation to fulfil the right to housing. In light of these examples and the lessons which can be learned from them, the Learning Network is partly trying to involve and empower civil society to make human rights gains real. Although the constitutions of East and Southern African countries differ and the conditions in these settings differ, the same principle can apply, where we use human rights legislation in a progressive way to support civil society action.

6. SESSION THREE: WORKSHOP, FOLLOW-UP ACTIONS AND THE WAY FORWARD

Session chair: Leslie London, Learning Network

6.1 Workshop: toolkit on the right to health

Facilitator: Ms Nicolé Fick, Learning Network

Ms Fick took the meeting participants through a practical demonstration of how the toolkit would work, by running the workshop with them as if they were members of the community who wanted to learn about the right to health.

She started with an exercise to identify basic human needs, asking the audience to list what every person needs to survive. The exercise had the aim of illustrating that for every human need there is a corresponding human right (need for food, water, housing, education, access to health care). There was some discussion on a definition of human rights – as basic standards needed to live in dignity.

The workshop also covered some information on the right to health specifically as contained in The Universal Declaration of Human Rights (Article 25) which states that “Everyone has the right to a standard of living adequate for the health and well being of himself and his family, including food, clothing, housing and medical care and necessary social services...” As well as Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) which states that, “Everyone has the right to the enjoyment of the highest attainable standard of physical and mental health”.

During the section on right to health the point was made that the right to health is not the right to be healthy, but to access to healthcare and the determinants of health. There was an additional exercise by workshop participants where they worked to identify general human rights that are related to the right to health. For instance the right to life, dignity and equality; the right to a healthy environment; sufficient food and water and the right to housing were some of the rights that were identified, by the audience. There was a handout that listed all the human rights that specifically relate to the right to health or are essential for the achievement of the right to health.

The facilitator then presented information on how the right to health is measured through looking at the concepts of availability, accessibility, acceptability, and quality. Participants were given handouts that explained the definition of these concepts and taken through an example of a case study where health rights were violated to illustrate the application of the concepts.

Participants were divided into small groups to work on a case study in which they were tasked to identify which of the health consumer’s rights related to health were violated and whether they were dealing with a problem of access, availability, acceptability or quality in relation to the right to health. The four groups discussed the case and had to report back on their discussion to the plenary.

7. GENERAL DISCUSSION: SUGGESTIONS FOR THE TOOLKIT AND PLANNING THE WAY FORWARD

7.1 Suggestions for the toolkit

Prof Leslie London of Learning Network moderated the discussion in which the meeting participants made suggestions for the toolkit.

- 1) An additional chapter addressing **regional integration and international trade agreements**: Under the section on health policies and practices, include all policies and practices at community, national, regional and global levels that are impacting on the right to health (e.g. trade conventions); understanding international agreements in a simple way.
- 2) Link training to **health workers** HEPS (e.g. dialogue); address issues of health workers
- 3) **Intergovernmental organisations**: The table of state and non-state actors and what governments should do, should be expanded to include the inter-governmental organisations like the UN and how they are impacting on the right to health
- 4) Looking at problems that are due to **health systems problems**: Consider ways to make the toolkit helpful to communities to deal with weaknesses in the health system that impact on the right to health (i.e. drug stock-outs).
- 5) Tease out examples of **violations** i.r.t. General Comment 14: Can we have a separate section outlining violations of the right to health that communities can easily relate to so as to identify a violation when it happens?
- 6) Consider the **language** of the toolkit: translation of the toolkit into local languages, sign language for the deaf, Braille for the blind, etc
- 7) Find ways of making the toolkit “**culturally acceptable**”: What does it mean for people locally?
- 8) **Stakeholder identification and analysis**: The toolkit should identify all relevant stakeholders (including intersectional stakeholders) and their roles and obligations. How will the toolkit empower the community to take appropriate action i.r.t intersectional stakeholders? The communities need to be empowered to identify appropriate stakeholders in order to engage around issues and services that affect their health (i.e. water, sanitation, etc.).
- 9) Skills to use **government commitments** (e.g. Abuja, MDGs) and local and comparative service indicators. Skill people to use government commitments to advance their right to health. For example, in South Africa, people can use the Department of Health’s 10-point plan to their benefit but most do not know it exists and/or are not sure how to do this.

- 10) Collective responsibility and **community ownership**: Emphasise community capacity for action (what can the local community contribute – land? Bricks? Labour? – without necessarily taking away the government’s responsibility). Ownership of health system can be used for mobilisation but must also avoid government absolving its responsibilities (NB: strike a balance between community agency and government responsibility). For example, we could use two cases to illustrate this point: one where people work together and another where people are in conflict; Ask participants to discuss the cases and how to deal with the situation.
- 11) **Community monitoring and evaluation**: Use the General Comment (for indicators, government commitment, systems indicators)
- 12) **Further simplification** (e.g. more visuals, illustrations): Toolkit still may be difficult for communities in its present form, especially for countries with lower literacy levels (important for regional application); should use more visuals and simplify language further.

7.2 Planning the way forward

Prof Leslie London of the Learning Network moderated the discussion that identified three broad areas of follow-up work. It was agreed that the three thematic areas need to be elaborated and the required resources mobilised to facilitate action.

1) Toolkit

- South Africa version will be ready by the end of 2010
- Recommendations from this workshop will be written up
- Meeting delegates can use the South Africa version and adapt to their own context
- Get together at a meeting in 2011 to share experiences of using the toolkit, share adaptations made, also introduce CGWH manual, share UCHR toolkit on human rights. Learning Network to lead this process of continuing to work on a generic toolkit for regional application.
- Plan indicators for evaluation: Outcome mapping, Global AIDS Alliance tool.
- Will need to seek additional funding or piggy back this activity onto something else that is happen in the region (i.e. gathering for EQUINET).

2) Human Rights curriculum for health workers

- Multi-country human rights study to describe curricula and gaps
- Sharing research (circulate) - IFHHRO (Gerald) keen to serve in clearinghouse role
- Identifying evidence for effectiveness of training (produce policy brief to support lobby, advocacy work)
- This can be guided by EQUINET

2.1) Think about continuing education for health workers

3) Health Committees

- Share the different models in the region (different policies – legal basis, non-legal)
- Participants noted that there are different legal structures for community governance structures in different countries – we need to look at these; therefore suggest more time to discuss and understand these models,

- Monitor and evaluation indicators – develop evidence
- Similar suggestion as above: EQUINET to guide the multi-country situation analysis of health committees
 - a. legal framework
 - b. Policy basis?
 - c. Roles?
 - d. Opportunities for influence

8. CLOSING REMARKS

Uganda Human Rights Commission (UHRC) Ag. Director for Monitoring and Inspections Ms Freda Nalumansi-Mugambe gave the closing remarks. The highlights of her speech were:

- Health is a fundamental human right, indispensable for the enjoyment of other human rights and not just a privilege. The Universal Declaration of Human Rights 1948 (UDHR) and the International Covenant on Economic, Social and Cultural Rights 1966 (ICESCR) as well as the Constitution of the World Health Organisation (WHO) lay out the groundwork for the relationship between health and human rights. UHRC encourages all initiatives that are aimed at empowering ordinary people to have a say in matters that bear upon their enjoyment of the highest attainable standard of health which is conducive to living a life of dignity as well as determining the direction the country takes.
- Realisation of the right to health involves having an effective and integrated health system in place as well as the existence of underlying social conditions necessary for health, such as access to safe and potable water, adequate sanitation, an adequate supply of food, nutrition and housing, sound occupational and environmental conditions, and access to health related education and information, including on sexual and reproductive health.
- Key human rights principles, such as participation, accountability, transparency, non-discrimination, empowerment and local ownership should guide health interventions. The right to health may not be realised overnight, but governments have a responsibility to take targeted and effective steps towards the full realisation of this right, individually and through international assistance and cooperation, using maximum available resources.
- Human rights are particularly concerned about disadvantaged individuals and groups. In 1998, the World Health Assembly re-emphasized the urgent priority “to pay the greatest attention to those most in need, burdened by ill health, receiving inadequate services for health or affected by poverty”. A human rights based approach calls upon duty bearers to ensure that the necessary resources are given to those who have the greatest needs.
- The meeting has been timely since the issues discussed are relevant to Uganda’s preparations for the third Health Sector Strategic Plan (HSSP III). This discussion will contribute to strategies needed to improve the right to health.