Learning Network on the right to health
Final Report to OXFAM GB (for the period April 2010 – March 2011)
Development of a South African Health Rights Toolkit (RSAA44)

Leslie London (Project leader)
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Background

The Learning Network for Health and Human Rights (LN) is a project based at the University of Cape Town, but involving a network of Civil Society Organizations (CSO's) in the Western Cape and other higher education institutions to develop best practice around the realization of the Right to Health. Member organizations of the network include:

- The **Women's Circle** an organisation of grassroots groups of women in communities, working on empowerment and promoting respect for women's rights;
- The Western Cape branch of **Epilepsy South Africa**, an NGO providing services to people with epilepsy and other disabilities;
- **Ikamva Labantu**, an organisation that supports diverse community based development projects related to nutrition, early childhood development, activities for young people, seniors clubs and home based care;
- **Women on Farms Project (WFP)**, a rural feminist NGO working to strengthen the capacity of women on farms to claim their rights and fulfil their needs;
- **Ikhaya Labantu**, a shelter facilitating skills acquisition for refugees and members of the community that are homeless;
- **The Metro Health Care Forum** an umbrella body for health committees which are formal structures for community participation in health;
- The **University of Cape Town**, which has a health and human rights programme that does research exploring the role of civil society agency in realising health rights;
- **University of the Western Cape** department of nursing which trains nurses and midwives to work on sexual and reproductive health rights;
- **Maastricht University's** Centre for Human rights which is a world leader in research into human rights;
- **Warwick University's** Health and Human Rights Research Group, within the Institute of Health, which supports the development of multi-disciplinary research in the field of health and human rights.

The Learning Network is currently involved in training on the right to health, information dissemination, participatory action research and reflection on best practise regarding the right to health and how to use a rights-based approach to advance health.

The need for a toolkit on the right to health

Although South Africa is has one of the most progressive rights-oriented constitutions in the world, the practical realization of socio-economic rights remains slow and uneven. South Africa remains a country with profound inequalities in health status and in the distribution of resources needed for health. The Human Rights Commission (SAHRC) has identified ongoing violations of the right to access to

health care services as well as the fact that many patients are not aware of their rights or have difficulty asserting health rights. The research data collected by the Learning Network also includes community member's experiences of having their health rights violated. Themes related to rights violations emerging from case studies include: a) violations of access to care; b) violations of access to information; c) violations of confidentiality; d) poor quality of care, and e) lack of access to complaint and redress.

What also emerged from the case studies is that ordinary people realize that they are experiencing serious violation of their health rights but that there is a lack of knowledge on how to hold people accountable for health rights violations or even whom could be hold accountable for these violations.

Civil society has an important role to play in mobilising communities around the right to health and in involving communities in building equitable health systems. They do this by creating an awareness of health rights and by providing a voice to marginalised communities seeking health rights (Chapman, 2002; Thomas & London, 2006). In addition they can hold health services accountable and improve the involvement of communities in health promotion and tackling the social and economic determinants of health (Gilson, 2007; Vega-Romero, 2007).

A pilot study for conceptualising the role of human rights approaches in promoting health equity (Thomas & London, 2006) found that there is a need for practical support to civil society groupings to equip them to use human rights approaches to advance health objectives more effectively. In addition CSO's can provide important information about people's lived experiences with health services and how health policy is being implemented daily

Civil society members in the network identified the need for a practical tool to use to train communities on what the right to health means and to identify violations of the right to health. This led to the initial testing of a toolkit on the right to health.

Field Testing of the toolkit

The first version of the toolkit was designed by Professor Fons Coomans (Maastricht University) in collaboration with Maria Stuttaford of Warwick University (see Annexure 1). The result was a document that had some input on the right to health and some questions on health rights for CSO members to work through.

In April 2009 Professor Fons Coomans and Nicolé Fick piloted this first version with a group of coordinators organized by The Women's Circle (TWC). After the piloting members of TWC raised some important issues for the LN to consider, including:

- The need to think about the toolkit, as being structured to be part of a training programme (a manual supporting a Right to Health approach being taught in workshops)
- The need for additional practical information on how to complain about health rights violations.

After the initial pilot, a further 3 additional workshops were held to test out changes made to the toolkit (in workshop format) with TWC and Ikamva Labantu. The purpose of the workshops was to refine and modify the toolkit on the right to health to be more appropriate for use with community based groups.

The **highlights** of the pilot workshops were that participants gave mostly positive feedback about the workshops and that some of those who attended requested additional workshops for their members. A number of groups said they found the examples used in the workshops useful as they made difficult human rights concepts easier to understand. Participants enjoyed the space created for debate and interaction in the workshops. The use of people's real experiences of violations of the right to health in case studies proved to be helpful when people were asked to work on practical exercises to apply rights based concepts, as participants found it easy to relate to these stories. The piloting of workshops also gave people the opportunity to speak about occasions when their own health rights had been violated. The majority of participants recommended more of this kind of training on the right to health for communities.

Some of the **challenges** with piloting the toolkit were related to language difficulties. The workshops are only really effective when done in participant's first language. Initially we tried the toolkit workshops in English with a group in Khayelitsha, who indicated that they were comfortable in English even though Xhosa is their first language. The workshops require a lot of interaction from participants and I could see that this interaction was not happening. When I started doing the workshop with Xhosa interpretation, the participants interacted more and I really had a sense that they understood and were able to work with rights concepts.

Although participants indicated that the handouts given at the workshop were clear and understandable I noticed that some participants were either semiliterate or functionally illiterate. In order to try and deal with this problem, I tried to stick to exercises that were mostly verbal, asked for one person to read out the case study to the rest of the group or made the text in the handouts very large, to try and facilitate easy reading. It may be necessary to adapt the exercises and find a different way of facilitating toolkit workshops with groups that are functionally or completely illiterate.

There were 19 workshops to pilot the toolkit on the right to health. We tested the toolkit with 9 different organisations and with a total of 161 participants overall, however all the piloting only took place in the Western Cape (see table below for details). If the toolkit were to be implemented nationally then there may be a need to run more pilot workshops in other provinces.

The stated **objective** of this project was to develop a South African health rights toolkit that would provide clear guidelines on what is set out in law around accessing the right to health and how violations of the right to health can be dealt with. Although we met this objective, we did face a number of challenges. In addition to pilot workshops of the toolkit, there were a number of requests from other organizations for workshops on the right to health (based on the toolkit). This meant that the piloting went on for a longer period than we had anticipated. It also took a lot longer than we had anticipated doing the actual development and writing up of the toolkit.

Participant Group	Planned or requested	No of participants	Activity	No of Activities
The Women's Circle	Planned	15	Piloting the prototype toolkit on the right to health	1
Khayelitsha group (Ikamva Labantu)	Planned	15	Piloting all four the toolkit workshops on the right to health	4
Rawsonville health team	Planned	3	Piloting what are human rights/right to health (two sections of toolkit)	1
Family Support Services group (Ikamva Labantu)	Requested by Ikamva Labantu	7	Piloting what are human rights/right to health (two sections of toolkit)	1
Early Childhood Development groups (Ikamva Labantu)	Requested by Ikamva Labantu	7	Piloting what are human rights/right to health (two sections of toolkit)	1
The Women's Circle	Planned	10	Piloting all four the toolkit workshops on the right to health	4
Uganda	Planned	30	Piloting what are human rights/right to health (two sections of toolkit)	1
Review and Reflection	Planned	37	Piloting what are human rights/right to health (two sections of toolkit)	1
Epilepsy SA – Advocacy workshop	Requested by Epilepsy SA	30	Piloting what are human rights/right to health (two sections of toolkit)	1
Research Assistants South African Sign Language project	Requested by Sign Language Project	7	Piloting all four the toolkit workshops on the right to health	4
Totals		**161**		**19**

Development of the toolkit

The toolkit is structured as a guideline that enables the material to be linked to workshops and capacity building sessions on the right to health (utilizing participatory exercises, cases and role plays) as well having a stand-alone informational function. In addition the cases and examples used in the toolkit were drawn from people's actual experiences, based on the case studies of health rights violations collected in the broader Learning Network research project.

The principles of adult or popular education were used in the development of the toolkit. Activities and inputs draw on participants existing knowledge and experiences as a starting point. The case study questions and participants presentations of their answers are a good example of problem based learning and the aim was also for case studies or even examples to facilitate dialogue in the workshops (among participants and between facilitator and participants). This kind of dialogue acknowledges participant's different perceptions based on their experiences and sets up a situation where the facilitator learns from participants as well.

A number of sources of information were used to develop the content of both the toolkit and the examples or practical exercises in the workshops. Information was sourced or adapted from other toolkits on health rights/human rights:

- Haki Zetu (Our Rights). Amnesty International
- Socio-Economic Rights in South Africa: A resource book. Community Law Centre (UWC) and Foundation for Human Rights in South Africa.
- HIV/AIDS and Human Rights in Southern Africa. AIDS and Rights Alliance for Southern Africa.
- HIV/AIDS and the Law: A trainers manual. Joint OXFAM HIV/AIDS Programme.
- The Right to Health: A Resource Manual for NGO's. London: The Commonwealth Medical Trust.
- Health and Democracy: a guide to human rights, health law and policy in post-apartheid South Africa. Cape Town: Siber Ink.

Outputs

a) Nineteen workshops to pilot the toolkit (with a total of 161 participants)
b) A finalized toolkit for use by CSO leadership and community members

Long term benefits and potential impact of toolkit

The finalised toolkit could be a resource and training manual for CSO's and communities for creating awareness on right to health and on dealing with health rights violations. The toolkit may be used by civil society organisations and community members to advocate for the realisation of the right to health. This could be manifested in terms of improved accessibility, affordability, acceptability and quality of both health care and the conditions needed for health.

The consequence of such improvement would be reflected in improvements in the health status of communities most vulnerable in South Africa and the reduction of health inequalities.

Health committees are the formal bodies for community participation in health planning and policy making at clinic or health centre level. Effective community participation is essential for holding government accountable. Community members currently serving on health committees in the Western Cape (and other provinces) have indicated a need for additional training in order for them to be more effective in their roles in community participation in health. The toolkit could be used by health committee's as a resource for building capacity on the right to health and strengthening community participation in health. Health committee's may be better able to influence health policy through putting pressure on government to implement measures to realise the right to health.

In addition effective community participation in health has been shown to improve health outcomes and ensure more equitable access to health services. Research in Zimbabwe in 2004 by Loewenson et al. (as cited in Boulle et al., 2008) has shown improved health outcomes where health committee's are functioning well, even when these committee's were based in under resourced communities and clinics. She found that at clinics with functioning health committee's there were more staff members, higher budget allocations, better availability of drugs and improved primary health care services.

The toolkit may also be adapted by CSO's doing other socio-economic rights work. One of the organisations in the Learning Network, Epilepsy SA has started making plans for developing a toolkit on disability rights which would be aimed specifically at their members and could be used more broadly in the disability rights sector.

In addition a South African toolkit on the right to health would be useful as a basis from which to build a broader manual on the right to health for use regionally. Interest has been expressed by the Social Empowerment cluster of EQUINET in adapting such a manual for use in Southern and East Africa.

The way forward with the toolkit

The LN will roll out the toolkit and evaluate its impact over the next three years. There is a researcher who will start this process by interviewing participants who have attended toolkit workshops and doing an initial evaluation of people's experiences with the toolkit.

Members of the Learning Network have requested some train the trainer workshops on how to use the toolkit with their members and this is planned for the next three year cycle. The toolkit will also be disseminated more broadly amongst other civil society partners and health committees. In addition copies of the toolkit will also be disseminated to regional partners so that they could adapt it to their own context (which would be the starting point for a regional manual on the right to health).

Once CSO's start using the toolkit for training community members there will be opportunities to get feedback from them on how effective the toolkit is as a training tool and this feedback would be used to inform a revised second edition of the toolkit.

Members of the team working on the toolkit, including a partner from the Centre for Human Rights at Maastricht University will work collaboratively on an article titled "The development and use of a tool-kit for use by CSOs in South Africa for realising the right to health" for publication in an academic journal.

RSAA44 GEV Development of a South African Health Rights Toolkit

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Fund Accountability Statement for the period 01 April 2010 - 31 March 2011

	Budget	Actual R	Balance
INCOME RECEIVED			
2010/05/24		150,000	
TOTAL INCOME RECEIVED		**150,000**	
EXPENDITURES			
Personnel time	47,000	47,000	-
Pilot workshops	5,000	2,787	2,213
Translations	13,990	57,799	-43,809
Editing	4,000	7,800	-3,800
Desktop publishing and design	20,000	84,960	-64,960
Printing costs	30,000	69,523	- 99,523
Dissemination	5,000	-	5,000
Sub-total : Direct Costs	**124,990**	**269,869**	**-144,879**
UCT overhead costs	**25,010**	**25,010**	**-**
TOTAL EXPENDITURES	**150,000**	**294,879**	**-144,879**
Deficit		**-144,879**	

Narrative to the Income and Expenditure Report - 01 April 2010 - 31 March 2011

Pilot workshops

Expenditure on pilot workshops was less than expected, as a result of organisations that covered the costs for training they had requested.

Dissemination

We haven't started with dissemination of the toolkit, which why we have no expenditure on this line item.