SANPAD

South
Africa
Netherlands Research
Programme on
Alternatives in
Development

PHASE 2
2003 - 2007

FINAL PROJECT
REPORT FORM

FINAL PROJECT REPORT FORM

THIS FORM SHOULD BE COMPLETED AT THE END OF PROJECT AND RETURNED TO THE SANPAD PROJECTS MANAGER (shernice@sanpad.org.za)

1. PROJECT NUMBER	07/35	
2. TITLE OF PROJECT	Learning by doing and doing by learning: a civil society network to realise the right to health	
3. INDICATE YEAR OF PROJECT ACTIVITY	2010	
4. DETAILS OF PROJECT LEADER Name: Department: Institution: Address: Tel: Fax: E-mail address:	Leslie London School of Public Health and Family Medicine, Health Sciences Faculty, University of Cape Town Anzio Rd, Observatory, 7925 Tel: 021 406 6524 Fax: 021 406 6163 Email: leslie.london@uct.ac.za	
	Third and final (2010)	

5. RESULTS AND OUTPUTS	*Refer to the envisaged research results and outputs given in the proposal finally approved for funding by SANPAD and describe briefly the extent to which these were attained during the report period, as well as any other achievements and progress during this period. (MAX 1 PAGE)*

Outputs as originally proposed	Outputs at end 2010
Health and Human Rights materials were to be developed (number unspecified)	The project produced 26 case studies in total; Photovoice produced over 100 images for rights training and advocacy; training materials were developed and shared with PHM and Black Sash
A tool-kit / manual on the right to health to crystalise members' best practice health rights experience	4 draft chapters piloted; final draft being written up and due for finalization Dec 2010; discussions started to adapt toolkit for S and East African region.
Policy briefs were to be developed (number unspecified)	Following SANPAD policy brief training, 2 briefs were completed based on project's research: on "Community Participation in Health"; and "The Right to Health." Circulated to partners.
A set of pamphlets on health rights suited for community organisations' use (number unspecified)	Completed 8 pamphlets: A series of 7 Right to Health pamphlets; 1 pamphlet on LN: All open access copyrighted on URLhttp://www.hhr.uct.ac.za/about/about.php. A further pamphlet on the role of Health Committees (for community members and new Health Committee members) being used by the Metro Health Care Forum (MHCF) partners (not printed).
Conference presentation as outputs (number unspecified)	In total 17 presentations over three years: Including Warwick University, University of Illinois, PHASA, EQUINET, HEPS-Uganda, Colombia 2008: 2 conference presentations 2009: 8 conference presentations (6 oral, 2 poster) 2010: 7 presentations (5 oral, 2 poster) 1 abstract for 2011 submitted
At least one, but probably more publications were anticipated	By 2010, published: 2 journal articles, 1 book chapter, 2 peer-reviewed reports; Under preparation: 7 journal articles, 1 book chapter (at least 2 publications confirmed)
Two higher degrees' theses – one PhD, one Masters.	1 Masters in adult education graduated in December 2009; 1 Masters in Public Health graduated June 2010; 1 Masters in Public Health in process of data collection to graduate 2011; 1 PhD student registered and in process of data collection; 1 PhD student pre-registration.

Other achievements not specified in original proposal include:
- Joint submissions with other civil society organisations in health to SAHRC hearings on progress on socio-economic rights in 2009
- Hosting joint dialogue in 2010 with W Cape health department officials on Health Committee Policy;
- Partnership with HEPS Uganda to extend project to South and East Africa 2010+
- Secondary research projects on (a) Ubuntu and the right to health – reconceptualising human rights in an African philosophical frame (through UCT); (b) Language as a component of health care access (through NRF); (c) plural health seeking behavior in the rights framework (University of Warwick); (d) best practice on health rights for the Southern and East African region (Commonwealth Fund); (e) policy analysis of health committees (University of North Carolina)
- Partnership with SANGOCO on Health Summit (2008) and NGO week (2010); with PHM on health rights campaigns; with Black Sash and HEU on National Health Insurance advocacy
- Hosting interns from northern institutions for service learning: Mt Sinai School of Medicine and Yale University (US); York University (UK); collaboration with York (Canada) on postgraduate teaching
- Diversification of funding to include: Open Society Foundation, DVV, NRF, Commonwealth Fund, University of Cape Town
- Database of health committee contact details for community action; 20 capacity building workshops within the network; 6 Review and Reflect meeting

6. CONTRIBUTION TO SANPAD GOALS *(Max 5 Pages)* 6.1 The development of new knowledge	The LN generated new knowledge in 3 areas critical for health rights: 1) It has problematised issues of participation as part of the right to health and pointed to interventions needed in policy and implementation to achieve best practice. This is particularly evident in how health committee functioning can be strengthened. Lessons can be extended to sectors other than health; 2) Secondly, we have teased out how collective action is vital to realizing health rights, particularly for socio-economic rights claims. The contribution of traditions and practices based on African philosophies could help to shape how the right to health is conceived and defined in international human rights law. We are working with partners in the region and internationally to see if we can provide guidance to human rights scholars and advocates to reframe rights away from individual claims towards approaches based on social solidarity and to locate such an analysis firmly in international human rights debates; 3) The LN has shown the need for adult learning is to go beyond knowledge and awareness; rather, through practice and reflection, civil society groups are able to develop agency to change conditions of vulnerability– this is what constitute real capacity building; The LN also provided other insights into processes of knowledge generation: 4) We have placed the issue of power within the research process under a rights analysis, surfacing what is hidden and openly engaging with inequalities in power between partners, so as to develop strategies to manage power imbalances and reflect that equality in our Network's practices. This has provided new insights into the way in which knowledge is generated and owned, with implications for how universities engage with communities. The resulting debates provide direction for best practice regarding service learning and socially engaged research. By acknowledging that CSO's provide unique information about people's lived experiences and how policy is being implemented daily, and through universities providing knowledge and access to intellectual resources that would otherwise not be available, a mutual partnership is better able to influence policy; 5) Within the above paradigm, the LN has also developed some experience and success with the process of co-learning and collaborative data gathering. Novel methods of data collection (e.g. use of photovoice; different forms of reflective practice) allow for higher degrees of participation and more meaningful co-learning.
6.2 Alternative approaches to development	Key lessons from the LN concerning development approaches thus far include: 1) Confirming the key role of an active civil society in realizing health rights: Without strong and empowered civil society groups, the state is not held accountable, whether at national or local level; Moreover, focusing participation as a rights argument ensures that community voice is not displaced into political fora, but can act at the point at which public servants make decisions which affect people's rights. 2) Human rights as part of development discourse: Engagement at regional level pointed to the importance of CSOs at country level lobbying and holding state officials accountable for their existing treaty commitments; and can influence how future treaties are expressed. For example, attainment of the Millenium Development Goals require a human rights perspective. Because human rights are about giving communities the agency to change conditions of their vulnerability, rights are deeply intertwined with development.

	3) The value of networking and reflective learning for development: Through the LN, member organizations have not only gained knowledge and awareness, but have been able to share skills across organizations and integrate new strategic approaches in their work. This has led to benefits not only to individuals but to groups and to the organization as a whole, enabling vulnerable communities to move beyond awareness, to conceptualizing action to realize their rights. 4) However, what has been much more difficult to accomplish has been engaging with the services to bring them into the same space as the CSOs. Building trust within the LN CSO's has taken three years. Building trust between the health services and the CSO's is more complex and takes far longer.
6.3 Policy development	The current problem is not lack of policy, but obstacles to implementation. In many ways, the policy framework is well developed and, at face value, respectful of a rights orientation. For example, the National Health Act, the Constitution and Bill of Rights and a host of departmental policies should afford users and communities greater say over the decisions that affect conditions and services needed for health. However, in practice, there is a gap between what the policy says or intends, and what exists on the ground. This is most clearly borne out in relation to structures for community participation such as clinic health committees. A draft policy has been pending political sign-off in the Province for 5 years. In this policy vacuum, officials do not have to account to communities for substantive decisions, and health committees are disempowered by a lack of clarity on roles and responsibilities, often ending up serving as appendages of the facilities at the beck and call of the facility manager, rather than providing governance oversight or community voice in decision-making. Key factors in distinguishing effective from ineffective committees relate to the amount of power and support granted at different levels of decision-making, involvement of ward councilors in health committee structures, and the ability of stronger health committees to support weaker committees. One striking shift that occurred during the project was that the Department of Health appeared to move from a position where it only engaged with communities at the very last stage of its planning process (i.e. when it reached parliamentary consultation) to allowing health committee input much earlier in the planning stage. Whether this was due to LN advocacy is not clear, but it did represent a major shift in thinking within the Health Department. We anticipate being able to build on this by structuring safe spaces for dialogue about health rights where community structures and services providers come together with shared objectives – avoiding adversarial approaches to patient rights, but rather constructing opportunities for communities and providers to hear each others' perspectives of obstacles to access to quality care, and to create opportunities for joint action to achieve realization of rights. Going forward, this may take the form of a 'health systems ward round' where complaint cases are discussed to identify the systemic reasons for the problem, so as to identify systemic, rights-based solutions. A second lesson has been the importance of wider partnerships as instrumental to achieving policy shifts. For example, the SANGO Coalition (SANGOCO) has created spaces for public debate on policy issues. The LN's participation in these activities brought evidence to a

	structured dialogue with service managers about health committee roles and functions. This also strengthened the LN's grasp of strategic interventions needed to advance health rights. It has also enabled the LN to influence the agenda of SANGOCO to the extent that human rights have emerged as a unifying theme within the work of SANGOCO in the health sector. These lessons learned have enabled the LN to engage with other stakeholders and networks more substantively. This means that the LN can undertake lobbying and policy advocacy in a way that it was not able to previously.
6.4 Research capacity development	The LN has contributed to research capacity building in different ways 1. Individual postgraduate students The project has supported 8 postgraduate students, 3 at postgraduate diploma level (still ongoing), 3 at Masters level (2 completed – 1 a Masters in Adult Education in2009 and 1 a Masters in Public Health in2010) and 2 at PhD level (still ongoing). All are part-time students. The student theses have addressed different aspects of the LN's programme (Rights awareness; models for community participation; effectiveness of rights pamphlets; building organisational capacity; interventions with providers to support community participation). All but one of the students are female, 4 are black and the 2 PhD candidates are black women. One of the PhD candidates is also the director of a LN CSO member organisations; she was part of the SANPAD RCI programme in 2008-9 and will visit the Netherlands in 2011 for PhD write-up. During Prof Coomans' visits, students presented their research to him for feedback. Additionally, 6 students have been supported by the LN to present their research at 7 national and international conferences. One student (GGY) obtained a distinction for her Masters thesis. The 3 postgraduate diploma students in Adult Education are leaders in their CSOs and gained access to the programme at UCT through the LN. They will graduate in 2011, which opens the door to higher studies towards Masters qualifications. 2. Internal research team seminars The LN research team set up a series of internal seminars to build knowledge and capacity within the team. Over the 3 years of the project, 20 meetings or seminar were held. Speakers were mainly participants in the Research Team presenting in areas of their expertise or research. Topics included research methodology approaches (Participatory Research Methods; Case study methodology; Mixed methods; Photo-voice; the role of theory), conceptual issues in human rights (Community Participation and the right to health; Social Capital; Gender and Human Rights; human rights in globalization; Networks and Networking; Power and trust in health care; The Right to Health in the African cultural context) and presentations by researchers of their research or proposals (An audit of health committees; language and the right to health; Disability and Human rights; Communication for social change). One seminar examined Outcome Mapping as a tool for monitoring and evaluation. Visits by Prof Fons Coomans included seminars to the Research Team and to the Department. Dr Maria Stuttaford also visited the project 4 times and hosted seminars on qualitative data analysis, qualitative methods and mixed methods. Besides internal seminars, LN members attended short courses hosted at UCT (topics included Research Planning and time management; Optimising conference attendance; Writing a successful grant proposal; Research Budget management; Using NVIVO 8 for qualitative data analysis; Using RefWorks; Writing for Publication; Theory and methodology in cross disciplinary research) and audited

selected modules/seminars within the SOPHFM at UCT (on Public Health and Human Rights; Gender and Public Health Research). In total, 16 short course opportunities were taken up by LN members.

3. Capacity of member organisations
   Research capacity of CSO member organisations was strengthened as follows: In 4 of the 6 LN member organisations, organisational leaders were able to study at UCT (3 for PGD in Adult Education and 1 for a PhD). Additionally, the LN facilitated sharing with the members of research methods through its internal seminars (see above) and through training opportunities hosted as part of regular Review and Reflect meetings. This included training in community mapping; use of photovoice and application of research tools. Epilepsy South Africa adapted LN research instruments for their own research to identify training and advocacy needs of people with epilepsy. This research will be presented at the PHASA Conference in December 2010.

4. Visiting interns
   The LN hosted 7 visiting interns during the project, placed with member organisations to work on specific projects within the LN programme (e.g. health committee policy, language as part of the right to health, experiences and conditions of women farm workers, etc). Interns came from US and UK institutions through planned arrangements. For one of the US institutions, the grant supported minority students only, so their South African experience was part of affirmative action redress in the US context.

5. Engagement with other capacity building opportunities
   The LN, because of its base within 2 Universities, was able to access other opportunities for capacity building (some described above). The LN obtained a grant from a UCT Programme for Enhancing Research Capacity for a knowledge project component which sought to explore the contribution of African philosophy to re-conceptualising the right to health. Specifically, we are interested in how concepts of social solidarity (e.g. as encapsulated in the idea of 'ubuntu') can strengthen socio-economic rights claims. The grant enabled the LN to host two public seminars and involve legal academics from UCT (Professor Chuma Himonga) and from Uganda (Ms Moses Mulumba). Outputs planned from this project will expand the reach of the LN and have also provided the basis for an application to the NRF for 2011 to 2013 to extend the LN research into the process of knowledge production. A 2nd grant secured from the British Academy includes provision for supporting LN researchers in manuscript writing (2010/11).

6. Disability
   From a subsidiary NRF grant to support research into language as part of the right to health, we secured funding for 2 deaf researchers. This enabled their training in research methods and will give them skills that will make them more easily employable at the end of the project.

| 6.5 | Inter- and multi-disciplinary collaboration | The research team draws skills from a variety of academic disciplines – public health, health economics, health policy, nursing, social work, adult education, anthropology and law. Methods used have embraced the full range of qualitative and quantitative approaches. Additionally, we have engaged with academics in other related disciplines (linguistics, education) and fields (African studies, Customary law, disability) as the project unfolded. The LN programme integrates academic insights within the health sector with approaches derived from the development sector (e.g. participatory action research, outcome mapping) and the policy context.

Additionally, the LN has developed a major collaboration with the Law |

	Faculty at UCT to generate new knowledge around framing rights within African philosophy, more particularly, the concept of ubuntu. Two seminars, open to the academic community, were hosted to get feedback on this research in March and September 2010. These seminars explored the contribution of African theories and philosophies to concepts of individual and collective rights, including the place of ubuntu as a tool to advance theoretical discourses on human rights. The discussion examined issues relating to universalism vs. cultural relativism as well as highlighted opportunities to address an existing conundrum in the public health field – viz., the apparent trade-off between individual rights and collective good, by introducing greater emphasis on social solidarity in the conceptualising human rights. These insights would not have been possible without a rich inter- and trans-disciplinary engagement. Policy analysis of community participation in health has also led to collaboration with legal researchers
6.6 Inter-institutional collaboration	Within the project, the LN has enabled collaboration between UCT and UWC (Professors Mbombo and London co-convene the Rights Theme for EQUINET; both were members of a Review Committee for the School of Public Health at UWC in August 2010, and Professor Mbombo will spend part of her sabbatical at UCT in 2011; Ms Nako, a lecturer in Nursing at UWC, is registered for a PhD at UCT and was supported to attend an international human rights conference in 2009.) Professor Coomans (Maastricht University) visited in April 2009 and March 2010, during which time he gave seminars, met with postgraduate students and participated in some of the field research. Dr Stuttafford (University of Warwick) visited in January and November 2008, and June 2009 and September 2010. Her visits were used to build qualitative research capacity amongst project staff (including qualitative data analysis, writing workshops) and students, and provided open seminars at UCT and UWC and participation in project activities. Professors London and Mbombo were invited to participate in a successful Warwick University grant application to explore plural healing systems and the feasibility of incorporating 'non-Western' modes of health care into normative standards for the right to health.

A second component of inter-institutional collaboration includes external links (outside the project participants). These include researchers at Temple University (Professor Scott Burris who presented a seminar to the LN), University of North Carolina (Professor Ben Meier, who placed an intern with the LN), University of York, UK (Professor Paul Gready, who placed students with LN member organisations X 2 years), Professor Richard Sanders from York University, Canada (who is exploring a joint funding applications to the IDRC in Canada, Mt Sinai School of Medicine in New York (who place minority interns with the LN on an annual basis) and Yale University (who had a placement for study abroad programme students with the LN and will continue this in future).

The most important regional link has been through the Network on Equity in Health in East and Southern Africa (EQUINET), to develop regionally appropriate health rights materials and share best practice. The LN participated in the EQUINET Conference in Kampala in 2009 and secured a small grant to work with Ugandan partners (HEPS-Uganda) to set up regional collaboration on health rights. A regional meeting in Kampala in October 2010 was attended by 25 participants from 4 countries and other NGO partners (including Oxfam, Fair Play for Africa and IFHHRO) to establish a regional programme and network under EQUINET. Further fundraising will be undertaken to secure this work. |

7. DECLARATION BY THE PROJECT LEADER

I certify that the information in the Financial and Project reports are correct.

SIGNATURE: _____   **DATE:** _____

8. CONFIDENTIAL REPORT FROM INSTITUTIONAL REPRESENTATIVE ON PROJECT PROGRESS, MANAGEMENT AND FINANCES AND OUTCOMES.

NAME: _____

DESIGNATION: _____

SIGNATURE: _____

DATE: _____