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Author(s): Leslie London, Nicolé Fick, Khai Hoan Tram and Maria Stuttaford

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Leslie London is Professor of Public Health and Head of the Health and Human Rights Programme, School of Public Health and Family Medicine, University of Cape Town, South Africa.

Nicolé Fick is Research Coordinator in the Health and Human Rights Programme, School of Public Health and Family Medicine, University of Cape Town, South Africa.

Khai Hoan Tram is Research Assistant at the ONE Campaign, Washington, DC, USA and was a student on the Bing Overseas Studies Programme of Stanford University, Palo Alto, California, USA.

Maria Stuttaford is Senior Research Fellow at the Institute for Health, Warwick University, Warwick, UK.

Please address correspondence to Leslie London, School of Public Health and Family Medicine, University of Cape Town Health Sciences Faculty, Anzio Rd, Observatory, 7925, South Africa or to leslie.london@uct.ac.za.

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FILLING THE GAP: A LEARNING NETWORK FOR HEALTH AND HUMAN RIGHTS IN THE WESTERN CAPE, SOUTH AFRICA

Leslie London, Nicolé Fick, Khai Hoan Tram, and Maria Stuttaford

ABSTRACT

We draw on the experience of a Learning Network for Health and Human Rights (LN) involving collaboration between academic institutions and civil society organizations in the Western Cape, South Africa, aimed at identifying and disseminating best practice related to the right to health. The LN's work in materials development, participatory research, training and capacity-building for action, and advocacy for intervention illustrates important lessons for human rights practice. These include (i) the importance of active translation of knowledge and awareness into action for rights to be made real; (ii) the potential tension arising from civil society action, which might relieve the state of its obligations by delivering services that should be the state's responsibility—and hence the importance of emphasizing civil society's role in holding services accountable in terms of the right to health; (iii) the role of civil society organizations in filling a gap related to obligations to promote rights; (iv) the critical importance of networking and solidarity for building civil society capacity to act for health rights. Evidence from evaluation of the LN is presented to support the argument that civil society can play a key role in bridging a gap between formal state commitment to creating a human rights culture and realizing services and policies that enable the most vulnerable members of society to advance their health. Through access to information and the creation of spaces, both for participation and as a safe environment in which learning can be turned into practice, the agency of those most affected by rights violations can be redressed. We argue that civil society agency is critical to such action.

INTRODUCTION

Despite having adopted one of the most progressive human rights-oriented constitutions in the world and created additional mechanisms to support its implementation, South Africa has lagged behind in the practical realization of socioeconomic rights for its people.¹ Nowhere is this more obvious than in relation to health. Maternal mortality in South Africa doubled between 1990 and 2008, and, as a result, South Africa is unlikely to meet all of its MDG targets and will be hard pressed to reduce this upward trend.² Child mortality, seen as an indicator of health care quality, has also remained high, with child mortality in 2008 at similar levels to 1994, and mortality in under-fives, having risen since 1994, just beginning to tail off.³ Mortality rates vary greatly between provinces, with large disparities, of the order of threefold between provinces with the worst and best rates.⁴

In its 2007 public hearings on health, the South African Human Rights Commission identified ongoing violations of the right to access health care services.⁵ Human Rights Watch recently reported severe problems

with maternity care in the Eastern Cape province, including health workers abusing maternity patients and other examples of substandard care that increase the risk of morbidity and mortality amongst women and their newborns.⁶ Indeed, South Africa remains a country with 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 that lead to ill health.⁷ This situation reflects, by and large, growing global inequalities in power and resources needed for health, and such disparity is evident particularly in this region.⁸ Human rights-based approaches are key to addressing health inequalities but are dependent on two key factors.⁹ Firstly, case studies from South and southern Africa illustrate the importance of community agency in realizing the right to health.¹⁰ They illustrate that for human rights approaches to redress social inequalities effectively, such approaches must incorporate the full spectrum of civil, political, and socioeconomic human rights and empower those vulnerable to human rights violations. It is both at the individual and collective levels that civil society action is able to redress social inequalities. For example, the social movement behind the Treatment Action Campaign changed treatment access and prevention related to HIV in South Africa, and to a lesser extent, within southern Africa.¹¹ In contrast, a seminal court victory for residents of an informal settlement resisting eviction in an area near Cape Town, while hailed as a precedent for justiciability of social and economic rights under South Africa's constitution, was not accompanied by civil society action to pressure the state.¹² As a result, no steps were taken to provide the community with housing, and the primary plaintiff in the court case, Irene Grootboom, died in 2008 in the same state of poverty and homelessness that she was in at the time of her historic court victory eight years prior.¹³

Secondly, health workers can facilitate and promote the right to health or act as barriers to achieving health rights.¹⁴ Intervening with health professionals to identify and engage with human rights concerns in their practices, whether at the individual or population-based level, is therefore a critical component of enhanced civil engagement with human rights. Where a health system protects and promotes human rights, health professionals are often agents of change helping to advance objectives related to social justice and

equity in the health sector. On the other hand, where health workers act as gatekeepers control access to resources, as has happened with abortion services in South Africa, participatory mechanisms may result in conflict that limits the extent to which health rights can be realized.¹⁵

These cases provide lessons as to the importance of strong civil society agency as essential for realizing the right to health. Thus, a human rights approach is not only about state accountability, but also about active participation of those most affected by state policies and gaps in state delivery of services.¹⁶ For that reason, the key role of civil society in realizing health rights is essential to combating poverty.¹⁷ Further, the right to information is instrumental to this capacity to act. Access to information underlies the accountability and participation components that are essential to a rights-based approach to health. For that reason, human rights education can be key to turning awareness into action, but has also suffered from a lack of evaluation.¹⁸

A LEARNING NETWORK FOR HEALTH AND HUMAN RIGHTS

This context provides the background for the origins of a novel collaboration between four universities and six civil society organizations (CSOs) in the Western Cape seeking to identify better practice for the realization of the right to health. The Learning Network for Health and Human Rights (LN) was established in 2008, emerging from different pieces of previous research that realized the importance of civil society agency in achieving the right to health.¹⁹ One of the recommendations emerging from a study with three civil society organizations of their understanding and use of human rights approaches was the need to establish a space in which CSOs could share experiences, both positive and negative, in order to learn from each other what strategies work best to realize health rights.²⁰

The LN was therefore established with an explicit agenda to build member organizations' capacity to be agents for the realization of communities' rights to health. It also seeks to share the lessons generated from this process with organizations beyond the LN, and to strengthen civil society action more broadly for the right to health. It brings together six community-based organizations in the Western Cape (Table 1) that represent a diversity of different organiza-

Table 1. Research activities undertaken within the ambit of the Learning Network for Health and Human Rights (LN), 2008–2011

Year	Research Activity	Description
2008	Organizational profiles	Collection of basic demographic information on all the Learning Network (LN) member organizations
2008 and 2010	Knowledge and practices of participant organizations	Questionnaire administered on the knowledge, attitudes, and practice of human rights among LN member organizations at baseline and after three years
2008	In-depth interviews	CSO understanding of health rights and perceptions of LN activities
2009-2011	Organization learning for health and human rights (PhD thesis)	Mixed methods research to explore the impact of LN participation amongst member organizations; does the LN generate social capital in enabling members to integrate human rights into their health programs?
2009	Photovoice project	CSO members involved in taking photos about health and human rights, which are used as a basis for reflection through focus groups and in-depth interviews
2009	Case studies, including evidence of coerced HIV testing	In-depth interviews regarding health violations experienced by community members; use for training and advocacy
2009-2011	Toolkit on the right to health	Development and piloting of a toolkit on the right to health as a training and advocacy tool; monitoring and evaluation of roll-out; adapting for use in Southern and East Africa
2009	Evaluation: “Community Participation Through Health Committees” (Master’s thesis)	Mixed methods study of community health committees as vehicles for community participation in advancing the right to health
2009-2011	Audit of health committees	Study of the capacity-building needs of health committees and barriers to participation
2009	Documenting health team development	Tracking the development of a health team in a rural farming region
2009	Language as a component of the right to health	An exploration of how language acts as a barrier to realizing the right to health; based on data from experiences of deaf persons using Sign Language and Xhosa-speaking patients
2010	Evaluation of LN pamphlets (Master’s thesis)	Qualitative thesis assessing the coverage and effectiveness of the LN pamphlets
2010	Policy study	Documentary review and key informant interviews analyzing the provincial draft policy on community participation and health committees
2010	Disability and human rights	Qualitative study by LN member organization of the understanding of human rights among disabled people
2010	Co-learning and knowledge creation	Monitoring and reflection on the process of co-production of knowledge on health rights by University-based researchers and CSO partners within a Learning Network

Table 1 (cont'd.)

2010	Exploring the contribution of African philosophy to conceptualizing the right to health	Literature review generated an annotated bibliography; theoretical analysis of the traditional value of 'Ubuntu' as being expressed in the rights concept of dignity; rights explored as collective entitlements
2011	Women's development within the LN	Ethnographic study of the experience and development of women participants in the LN
2011	Power and trust in the context of University-CSO engagement	Mixed methods research to explore the process of knowledge generation through rights-based research processes
2011	Health care provider training	Development and evaluation of modules for in-service training on the right to health for health care providers

tional types, approaches, constituencies, mandates, and geographical locations. Most of the beneficiaries of the organizations' services and advocacy are women; women also constitute the majority of most LN member organizations' staff. The beneficiaries of LN member organizations are also mainly drawn from working class and socioeconomically depressed communities in both urban and rural settings, and while many had limited formal education, were mostly literate in their mother tongue. While the LN has operated as a closed network, it has partnered with other CSOs on similar campaign and activities, particularly in relation to work around the right to health.

The LN has four roles related to linked objectives: 1) An informational role to ensure communities are better informed about rights to health; 2) A research role to document and analyze best practices in realizing the right to health; 3) A capacity-building role to promote access to learning opportunities for member organizations; 4) An action role to use the learning gained by member organizations to support services and advocacy around health. Underlying these objectives are three principles that inform the LN's practice: that empowerment implies knowledge, assertiveness, critical engagement, and collective action; that health is a state of wellbeing, determined by access to health care and healthy social conditions; and that networking for rights must be based on a partnership of mutual respect, benefit, and equality.

This paper explores the extent to which these objectives and principles have been put into practice and examines the lessons that emerge from the LN's experience for wider application in health and human rights practice. By bringing together evidence from the LN's experiences over the past four years, teas-

ing out how an action research program centered on learning and sharing has changed organizational and individuals' views and practices related to the right to health and its achievement, we hope to identify opportunities for increasing understanding in the field, with a view to moving from research to action.

LEARNING BY DOING AND DOING BY LEARNING

At its inception, the LN conceived of the process of building capacity as one in which the LN activities would be iteratively linked in a continuous process — research conducted with and by CSOs would be presented back to organizations to inform CSO action, training, advocacy and further co-research questions.²¹ A second construct was that the strengthening of community members' agency would proceed apart from activities aimed at health workers, the gatekeepers of health rights. The community members and health workers activities were to come together at a later stage. Both these notions, while attractive in concept, have proven less than robust in reality. We explore below how the LN has operated, drawing out from this analysis some of the key themes we believe helpful for consideration of health and human rights in practice.

Materials development and networking

Information is instrumental in affording the most vulnerable with opportunities to change the conditions of their vulnerability; indeed, recognizing the importance of information is central to the realization of human rights. Both participation and accountability, as key elements of the right to health are irrevocably dependent on information in order to be actualized.²² The LN therefore focused on developing materials for community and organizational users intended to

enable community members to realize their rights. The materials consisted of a series of pamphlets and a toolkit on health and human rights.²³ Whereas the pamphlets were part of a strategy to ensure that the information was understandable, the toolkit was specifically designed to turn knowledge into action, and both relied on easy-to-understand visual and written material suited for user groups with little formal education. For example, in one LN review meeting, a LN member framed the importance of materials as follows “We learned that there is a great need for the toolkit, providing information on how to identify health rights violations and how to respond to these violations. . . . Importance of using the pamphlets in conjunction with the workshop; the pamphlets alone are not enough for people to feel that they know their rights.”

Whereas typical state obligations of respecting, protecting, and fulfilling rights do not necessarily become reality without community action, measures linked to rights promotion—a specific South African constitutional provision which obliges the state to take positive action to promote rights—aims to create an enabling environment for people to exercise their rights.²⁴ However, notwithstanding the presence of a number of institutions intended to promote a human rights culture in South Africa (such as, for example, the South African Human Rights Commission, the Public Protector and the Gender Commission, all bodies set up in terms of Chapter 9 of the South African Constitution), the low level of awareness of and engagement with human rights identified in studies to date suggest a gap in realizing the constitutional imperative to promote rights.²⁵ In this sense, the LN materials have filled a gap, aiming to empower community members to take action for their rights to be realized.

The LN also uses other methods to disseminate knowledge about human rights. Use of electronic communication amongst member organizations (email and an internal project website) to share information about events, meetings, and new knowledge, along with periodic presentations of research findings, strengthened both the networking function of the LN as well as the role of information dissemination.

Research

Research activities within the LN aimed at identifying best practice were not classically aligned with the participatory research norm in that CSO members did not participate in the design of the original research proposals and the initial funding application. However, as the LN has developed, CSO members are increasingly identifying research questions for which they need answers and which the LN can and has undertaken to research. For example, faced with ambivalence on the part of health services in recognizing structures for community participation, the LN member with the mandate to coordinate Community Health Committees requested an audit of committees in the metropolitan area to identify areas for capacity-building and to strengthen its arguments for legal recognition of its mandate for community participation.²⁶ More importantly, the LN has moved from a situation where the academic partners were the researchers suggesting research to their CSO “clients” to a scenario where organizational meetings have served as spaces in which all LN members jointly determine important research needs.²⁷ The implementation of the research is also increasingly done jointly, rather than by academic institutions on behalf of CSO partners; CSO members act as peer researchers in data collection, analysis, and dissemination. For example, social service workers in an LN member organization went from being “participants” who were asked about their understanding of rights to being researchers who initiated and conducted their own inquiry into their client’s knowledge and understanding of disability rights.²⁸

Table 2 summarizes the research activities undertaken through the LN; these include case studies of CSOs addressing violations of the right to health (for inclusion in training materials); examination of language as a component of the right to health; audits of skills needs of Community Health Committees; research into disability and the right to health; and examinations of participation and the right to health. The collected data focused on both network research goals as well as the organizational goals of the member CSOs. Multiple methods were used, including questionnaires, focus groups, structured interviews,

Table 2. Skills training undertaken within the Learning Network for Health and Human Rights (LN), 2008–2011

Training area	Focus	Number of Events	Target Audience	Facilitator
The right to health	General information on what the right to health means and how to hold government accountable	14	Mainly LN members One session at public health summit Two sessions targeting LN member constituencies (e.g. home-based care workers; health committee AGM; health team on farms; deaf research assistants in sign language)	Internal to LN
	Piloting of toolkit on the right to health	8	LN member constituencies (e.g. home-based care workers); workshops for deaf research assistants in sign language; participants in regional meeting; two train-the-trainer workshops	Internal to LN
	Training of trainers on the right to health toolkit	2	LN members	Internal to LN
	Disability and the right to health	3	LN members	Internal to LN
	Rights advocacy	1	LN members	Internal to LN; external NGO
	Community participation as key to the right to health	2	LN members (health committees; public officials; NGO sector)	Internal to LN
Engaging state services	Accessing basic services – advocacy with provincial and municipal authorities		LN members	Two external NGOs
Community development tools	Participatory community mapping as an action research method	1	LN members	Internal to LN
	Alternative methods for community decision-making in social structures	1	LN members	External visitor
	Leadership training	1	LN members	Internal to LN
Re-theorizing the right to health based on our experience	What do African theories and philosophies say about human rights, individual and collective rights, and the right to health?	2	Academic seminar and LN members	Internal to LN and Ugandan collaborator
	Culture as obstacle and opportunity	1	Academic seminar and LN members	Internal to LN
Writing skills	Building capacity of LN members	2	LN members	Internal

in-depth interviews, photovoice, observation, and document analysis. The later sections of the paper focus on results from three specific studies undertaken within the LN to map the impact of the learning process on organizational practice.

Training and capacity building for action

Through periodic review during its first three years, the LN identified different areas for training. The areas included training in the “right to health” concept, and also skills training in areas organizations identified as important for mobilizing their constituencies or for advocacy (Table 3). Rather than a unidirectional process of academic partners sharing information with CSO partners, the training included cross-organizational events where CSO partners led instruction according to their areas of skills and experience.²⁹ For example, the experience of health committees in the metropolitan area served as a learning opportunity for a CSO that was organizing rural farming communities to engage with local services to lobby for a health committee to facilitate community participation. As a result, a health agent from the CSO, which is composed of women workers living on farms, was elected to the newly formed local health committee.

In another example, an LN member organization that uses the adult education method REFLECT (Regenerated Freirean Literacy Through Empowering Community Techniques) trained an LN Executive Committee in the method.³⁰ The REFLECT methodology is based on empowering groups typically deprived of power to change the conditions of their disempowerment; as such, it provided an ideal base on which to see CSOs turn human rights entitlements into active engagement in solving their most pressing problems. As previously noted, the LN materials were geared towards supporting members’ action around health rights.

Lastly, a key learning element has been the systematizing of opportunities for LN member organizations to review and reflect on progress and difficulties experienced in realizing the right to health. These times for reflection have taken place approximately four

times a year, and have been supplemented by periodic strategic planning processes and the establishment of an executive committee structure to take ownership of key decisions. All partners give presentations in which they report on activities, identify new research and advocacy activities (see Tables 2 and 3 for examples), and propose lessons for wider learning. These meetings, which have explicitly recognized power differentials between LN member organizations—particularly between academic and CSO partners—have come to reflect far greater equality in decision making, with shared agreement on agendas, rotation of chairing roles, and collective agreement on future strategic direction. All partners, both academic and civil society, now participate as equals on an executive committee to set organizational goals through periodic Review and Reflection Workshops and through an annual strategic planning process. While not negating the existence of power and power differentials within the LN, the explicit recognition of power enabled the LN to work with power in understanding how to strengthen CSO capacity for action. In this respect, the rights framework has proven invaluable in acknowledging the agency of those most affected as critical to changing the conditions of vulnerability which predispose to rights violations.³¹

Advocacy and interventions

Building capacity for rights is meaningless unless it leads to action. LN members have used knowledge from training and sharing of experiences to advance their advocacy, strengthen their programs, mobilize communities, and improve services. For example, one LN member organization went door to door delivering pamphlets to raise community members’ awareness of their rights. LN programs also led a member CSO to use photovoice as a local advocacy tool to prompt community action on waste dumping around an open pond.³² Through taking photos and reflecting on the problem together, local CSO members identified income-generation opportunities from waste recycling and mobilized youth in the communities to participate in clean-up activities.

In addition to highly local activities, the network also facilitated advocacy at a provincial level in 2010, hosting a structured dialogue with health service managers on the question of community participation. In

2009, the network facilitated action at the national level, contributing to a shared civil society submission on the right to health, presented at South African Human Rights Commission hearings on progress on realizing socioeconomic rights.³³ Engagement in other civil society campaigns, both as the LN and through member CSOs’ individual participation, has provided a vehicle for advocacy around various health issues. Co-hosting a provincial health summit in 2009, for example, provided the LN a platform to

engage with health policy makers about the right-to-health challenges facing communities.

THE EMPIRICAL BASE – LESSONS FOR HEALTH RIGHTS IN PRACTICE

From a range of research investigations the LN conducted (Table 2), we present findings from three specific research foci that illustrate important lessons related to putting health rights into practice.

Table 3. Knowledge, attitudes, and practices among Learning Network participants

Domains			Percentage Change
	Baseline	Follow-up	
Understanding (Six questions)	64%	77%	+22%
Agency (Seven questions)	50%	65%	+31%
HCW understanding (Three questions)	59%	29%	-50%
Collectivist understanding of rights (One question)	29%	41%	+40%
Social capital (Four questions)	81%	91%	+13%
General trust (Three questions)	57%	86%	+52%
Trust in government (Two questions)	53%	21%	-61%
Bonding social capital (Sixteen questions)	63%	72%	+14%

The first was a quantitative study in which a questionnaire including both structured questions (using a Likert-type rating scale) and open-ended questions were administered at baseline and repeated three years into the study to LN organizational member staff. Of 40 questionnaires administered at baseline, 18 participants were accessed again after three years. Comparison from baseline to follow-up reflects shifts in understanding and beliefs related to health rights amongst LN participants. The 40 questions were clustered into eight domains: understanding of rights (six questions); belief in agency to implement rights (seven questions); orientation to rights as having collective elements (one question); perspectives on providers' views and practices relating to rights (three questions); the capacity of rights to enhance social capital (four questions); trust in general (three questions); trust in government (two questions); and trust in, and identification (as in bonding social capital) with the LN (16 questions). Table 3 summarizes findings across the baseline to the follow-up, conducted approximately 30 months after baseline. Appendix 1 gives further details on the questionnaire and domains used.

The second is a qualitative study which evaluated the LN-produced series of Right to Health pamphlets.³⁴ The evaluation sought to describe how the pamphlets were used and disseminated, and resultant changes in understanding and practice of health.³⁵ Data were collected in 18 interviews and eight focus groups involving a total of 59 participants, drawn from eight CSOs including all six LN members and two associated CSOs working on the right to health. Slightly more than half of the respondents (n=34) were CSO staff or trained volunteers, while the others were beneficiaries or constituents served by the CSOs.

Finally, we analyzed data assembled for a paper examining the process of co-production of knowledge within the LN.³⁶ These data were based on email and face-to-face interviews conducted with 11 LN participants between October and December 2010, and documentary review, which included Learning Network Executive Meeting Minutes, Review and Reflection Workshop notes (2009 and 2010), Strategic Planning workshop notes (2008), and Learning Network workshop reports (2008). These data sources were managed using the qualitative data analysis software Nvivo.

Given the participative research framework employed, there was no control group against which to compare changes for the quantitative questionnaire. While this

design limits the extent to which changes may be solely attributable to the LN activities, the findings can be regarded as suggestive of the impacts of the LN, particularly when triangulating the data emerging from the three sub-studies.

In analyzing results from these three studies, we identified four related themes:

1. Rights awareness, capacity, and challenges

Previous research has shown that most South Africans are aware at a general level that they have rights under the new democracy, but they lack specific understanding of what that means in practical terms.³⁷

There was evidence suggestive that LN activities, including the development of materials and training, contributed to increased understanding and were linked to a stronger sense of enhanced skills for action. In Table 3, mean scores for understanding and agency increased by about one-fifth (22%) and one-third (31%) respectively, particularly related to increased recognition of the importance of accountability and strategies to enforce rights. When asked to define how health is a right, about a quarter of respondents were unable to provide any such definition at baseline, whereas at follow-up all LN respondents captured some element of the right to health.

As one LN CSO member explained,

In [our organization], the new knowledge has provided us with the skills to integrate the principles of health and human rights into our existing advocacy, awareness and training programmes. . . . The aim of the programme is to inform and promote the rights of people with disabilities and to prevent any violations thereof.

Some comments from in-depth interviews conducted with LN members support findings from the quantitative data that suggest a positive impact from engagement in the LN. A service provider in an LN member organization commented:

Prior to the LN pamphlets, our organization did not focus on the broader theme of health, but rather on the

problems facing people with disabilities. Since [joining the LN], staff are aware of issues surrounding health rights and are developing a program on disabilities and the right to health.

Another member explained how the LN's capacity-building had contributed to their sense of agency and that of their fellow members, creating a cascade of knowledge for action:

Our organization had a workshop on health rights through the LN and the pamphlets [helped the attendees a great deal]. It gave them ideas on what was the right to health [*sic*] and the PRC [Patients' Rights Charter]. It created a ripple effect among the women in the organization as they passed information to one another.

The work of the LN therefore showed how important it was to complement provision of information with active engagement for capacity-building. Passive distribution of information, often the typical way in which state services distribute patient rights information, is of limited value.³⁸

We first saw the pamphlets in a media training with the People's Health Movement. The training was informative because it triggered discussions and enabled us to see how all community issues are interlinked and have an impact on health. It created a platform to understand, because sometimes written information, like the pamphlets, is hard to understand.

Rather, it was the combination of information with other community action that was most effective.

It is difficult to say that the pamphlets alone have empowered community action. Rather, it is a process of various steps, including community meetings, public hearings, workshops on issues raised by the community, pamphlets that eventually provide communities with enough strength to gather and assert their rights.

These findings confirm the literature highlighting the importance of participatory learning in an environ-

ment that models human rights as central to changing attitudes, behaviors, and practices.³⁹ For example, writing about the Sonagachi Project, an intervention to address HIV prevention among sex workers in Kolkata, Cornish illustrates the role of rights in reframing discrimination experienced by sex workers as something capable of being challenged rather than being inevitable. Through collective action to restore those rights, the sex workers involved in the project have used the mobilizing effect of human rights to challenge stigma and the conditions of their vulnerability.⁴⁰

However, what appeared to emerge in the LN's research was that when people became more aware of their rights and what those rights mean, they realized the difficulties in claiming rights from the state. As a result, those rights paradoxically appeared to become less accessible.

For example, quantitative comparisons of knowledge and understanding among LN members, despite showing improved insights into the nature of health rights, also demonstrated that LN members were more likely to report a lack of trust that the state would honor its rights obligations; the score for trust in government declined by more than 60% (Table 3). Nonetheless, even in the face of such challenges, LN members were still more likely to report greater confidence in being able to empower their constituency members to take action to realize the right to health (from 18% to 41%). This apparent anomaly may be explained by an increased realization among LN members that rights are best realized through action by ordinary people exerting pressure on the state, rather than reliance on state largesse.⁴¹ For example, when asked who is responsible for the realization of the right to health, one LN participant responded:

The Health Committees—as they are the forefront of channelling information and activism for civilians, CSO's like [name of organization]—to be a voice and practically propagate for health equity from hospitals to state institutions. Ordinary people are vital.

Thus, while increasing rights awareness might be associated with decreased trust in the state to deliver on its rights obligations, this was more than compensated for by a growing understanding that civil soci-

ety agency can be as powerful, if not more powerful, in the realization of health rights.

2. State accountability for the right to health and civil society participation

While civil society action is deemed essential for realizing the right to health, it nonetheless also presents the possibility of tension between holding the state accountable and taking over state responsibilities when it fails to deliver or is perceived as unwilling to deliver.

Evidence from the open-ended questions in the baseline questionnaire suggested that clients, member of CSO constituencies, and CSO staff came to expect that CSOs would play a role in providing services that are the responsibility of government. For example, a number of participants indicated that home-based carers, health committees, community leaders, NGOs, or CBOs were responsible for realizing the right to health. One respondent argued that NGO's should be "... helping with these home carers to take treatment for sick people." Another organization described how engagement in the LN allowed one of the member organizations "to relook at our human rights program more critically and as result ... incorporate the right to health and disability rights into our existing program." The organization was then able to enhance its own service delivery.

At the same time, one LN member commented, "People do not listen to us in the clinics. When we do assert our rights, we are told we are being 'too clever.'" LN members' scores for their view on how much health workers understood about rights dropped a bout 50% over this period, confirming the sense of a serious disjuncture between state services and rights-based CSOs. Indeed, as CSOs have become more knowledgeable about human rights and more empowered as to act on rights, they have come to realize that health workers do not have a clear understanding of rights.

The gap between state obligations and state delivery therefore looms large and many CSOs gravitate towards filling the gap in services because of their concerns for marginal groups in communities. However, rather than simply substituting for state

services, CSO action on the right to health can be more effective where it also holds services accountable. Thus, as explained by two LN participants:

One of our community members lost her child due to bad birthing medical support. This provided a timely opportunity to move people in her community on health rights and create some awareness and action.

I led a training on breast wellness and used the pamphlets to encourage young women to go for check-ups and get tested for breast cancer. Fortunately, they all came out clear, but this was possible as a result of these young women understanding their right to health.

Another LN member CSO explained how it increased its participation in budgeting decisions for the health department.

Community members and patients wanted to be a part of the discussion and planning of the health budget. The Rights and Resource Allocation (6) pamphlet created awareness as well as a sense of responsibility among people as to what their rights and responsibilities are. This has contributed to participation of health committees, for the last two years, in the provincial planning of the health budget.

Thus, while providing services which are otherwise not addressed by the state is an important step towards protecting health rights, it is by itself an insufficient measure to fill the gap required for realizing health rights.

3. Promotion of rights as filling a gap

The above quotes illustrate the critical accountability role CSOs can play in turning rights obligations into reality. Through information for action by rights holders, the state obligations to respect, protect and fulfill rights are transformed into a dialogue between rights-holders and duty-bearers, providing what the South African Constitution frames as an obligation to promote rights. One LN member organization illustrated the idea:

Through the work of my organization and the pamphlets, I no longer just complain about rights violations, I take action. A man in my community had chest pains because he was exposed to pesticides. I gave him the pamphlet on the right to health and explained the rights he had with his employer. He now receives medical treatment.

Moreover, because information is best understood in the context of collective actions (for example, workshops, community distribution of materials, public hearings, and other community meetings and activities), the dissemination of information through an organizational network is more likely to lead to the type of rights promotion envisioned in the South African constitution. By increasing CSOs' focus on collective action (Table 3), the LN's programme could be described as one intended to fill the gap related to promotion of the right to health.

4. Cross-pollination between organizations (CSO-to-CSO work) is part of filling the gap

The last theme illustrated from the data is the unique value of organizational sharing in contributing to this filling the gap between formal rights entitlements and on-the-ground rights realization. Establishing a space for shared learning increased individual CSO member's skills capacity, gave their organization credibility with other stakeholders, and created a sense of solidarity within the LN. This was attributed to the opportunities provided by LN meetings for stocktaking and reflection; guidance on how to solve human rights violations; learning between organizations; provision of opportunities for advocacy and lobbying; plans for cascading knowledge and skills; and moving from asking for help to thinking about how organizations can be their own agents for change. These views are reflected in the changes in scores shown in Table 3, where measures tapping both bridging and bonding social capital increased in the course of the project. For example, LN members reporting that they had "a

lot of trust in the organizations with which my organization collaborates" increased from 63% at baseline to 94% at follow-up. The role of trust as a key factor facilitating collective action enabling people to work together has been well-documented in the literature, as has the importance of forming networking paths that are both horizontal (across agencies and sectors) and vertical (agencies to communities to individuals).⁴²

Notwithstanding the potential for inter-organizational competition, this increased trust linked to increased capacity was illustrated in one LN member's account:

Organizations are beginning to share their information, skills, and experiences . . . The relationship between organizations has improved and we are able to utilize each other's skills, information, and knowledge in order to provide a more holistic service to our beneficiaries.

Notably, two of the main contributors to the increased score for bonding social capital were increased acknowledgement that different organizations' expertise and experience were recognised through the LN (from 67% to 94%) and an increase in members disagreeing that it was difficult to share "what has not worked so well in my organization" (from 40% to 63%). Keijzer and colleagues argue that human interaction around evidence always leads to some form of learning.⁴³ Networking is more than dialogue as it encompasses action-oriented elements such as policy influence, advocacy, negotiations and an overarching search for social change. By bringing together CSOs with different mandates, working in related but diverse sectors, and generating spaces that provide opportunities for participation and to access information, the LN presents an example of the notion of creating multiple sites for rights.⁴⁴

CONCLUSIONS

A 2009 report by the South African Human Rights Commission highlighted low awareness of rights among patients attending health services and that those patients who are aware of their rights have difficulty asserting these rights due to feelings of powerlessness.⁴⁵ The challenge of building a human rights culture, even in a country with a high degree of formal institutional commitment to rights, therefore looms large. It also speaks to the distinction made by capability theorists between functionings (what a person manages to do) and capabilities (what a person can or could have achieved, contingent on their freedom to be in a position to choose a particular set of functionings).⁴⁶ Realization of the right to health is not just a matter of knowing what one should be entitled to—it is also a function of having the freedom to exercise these entitlements.

Whereas past research has shown that increased awareness and knowledge of rights improves people's attitudes to and willingness to take action on rights, our experience is that training alone is insufficient to turn understanding into action.⁴⁷ As Stellmacher and Sommer conclude, promoting human rights skills and action requires more than improved knowledge and attitudes about human rights.⁴⁸ Rather, agency is built by providing an environment in which learning can be turned into practice. Moreover, it appears to be the sense of solidarity and trust amongst co-learners that is most effective in giving adult learners confidence to engage with rights in their work, as the responses in Table 3 illustrate.⁴⁹ In other words, through fulfilling the right to information, the LN at the same time ensures the conditions for community action. Moreover, the importance of complementing

human rights learning with opportunities to practice human rights through implemented activities is what is needed to build a culture of human rights, in which learners own understandings of justice, freedom and equity can flourish.⁵⁰ In this way, the transformative potential of human rights is most evident.⁵¹

Lastly, we believe that the gap between policy and implementation is one that leaves the most marginalized people in society particularly vulnerable. Translating the intent of policy into freedoms that enable vulnerable populations to change the conditions of their vulnerability – realizing their capabilities – is a key role for human rights work at all levels, local, national and global.⁵²

By facilitating dialogue at the community level, bringing injustice into the public sphere, exerting pressure for change, reinforcing the limits of state and business action, and monitoring to ensure government policy is consistent with human rights discourse, CSOs can create a new “norm cascade” to effect policy and programmatic changes needed to advance health.⁵³ Models on a local scale show the possibility of solutions to issues of justice on a larger scale.⁵⁴ There is a gap to fill—a gap in terms of access to information and the creation of spaces for participation—and CSOs are filling it.

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APPENDIX 1. QUESTIONNAIRE ON HUMAN RIGHTS UNDERSTANDINGS AND APPLICATION

Learning by Doing and Doing by Learning: A Civil Society Network to Realize the Right to Health

The Learning Network for Health and Human Rights questionnaire sought to tap knowledge, understanding, and practice related to health rights. The questionnaire was comprised of four sections, as detailed below. The construction of scores for different domains in Section 4 is detailed below.

Section 1

Seven questions collecting general demographic information

Section 2

Two questions related to socio-economic status

Section 3

Nine open-ended questions (including question 27 from Section 4)

Section 4

Forty-three forced choice questions (strongly agree, agree, disagree, strongly disagree, can't say, don't know)

Each respondent was asked how strongly he or she agreed or disagreed with the statements below. The responses were post-coded as positive for the said

domain, and each question was weighted equally for a positive response.

1. Everyone is equally entitled to have their human rights respected.
2. Human rights are nice to have, but you can't enforce them.
3. Having a right to health means that someone must be accountable.
4. Most staff in the health services understand that health is a right.
5. The best way to access your rights is by having a clever lawyer to go to court for you.
6. Because one person's right might clash with another person's rights, we sometimes have to balance rights.
7. A human rights approach means that the needs of people who are most vulnerable must come first.
8. It is easier to use a human rights approach to fight a case for an individual claim than it is to secure rights for the whole community.
9. I think my rights are respected when I go to a health service.
10. In South Africa, rich people are able to look after their rights more easily than those who are not rich.

Domains	Questions
Understanding of rights	1, 3, 6, 7, 11, 13
Belief in agency to implement rights	2, 5, 10, 21, 24, 25, 26
Orientation to rights as having collective elements	8
Perspectives on providers' views and practices relating to rights	4, 9, 12
Capacity of rights to enhance social capital	14, 15, 19, 22
Trust in general	16, 17, 20
Trust in government	18, 23
Trust in and identification with the LN (bonding social capital)	30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44

- 11. Having a right of access to health care means that I can expect the state to give me a liver transplant if I needed one.
- 12. Most staff working in the health services respect patients' rights.
- 13. All human rights are absolute and can never be limited or restricted.
- 14. I think it is important that people should participate in a civic or community organization to improve their social conditions.
- 15. If I had a sudden emergency, I will have a neighbor or friend who would be able to help me.
- 16. I have a lot of trust in the organizations with whom my organization collaborates.
- 17. I have a lot of trust in the people with whom I work.
- 18. I have a lot of trust in the government departments my organization works with.
- 19. I think it is important that people should rather participate in a civic or community organization to help others.
- 20. Collaborating with other organizations can often be to the detriment of the achievement of your own organization's objectives.
- 21. My organization can influence decisions by health care professionals in ways that benefit my organization's constituents.
- 22. I am confident that if my organization had an urgent issue to take up, we would get support from other Civil Society Organizations (CSOs).
- 23. I am confident that if my organization had an urgent issue to take up, we would get support from the government.
- 24. I can easily convey to clients of my organization what it means to have a right to health.
- 25. I find it difficult to empower the clients of my organization to take action to realize the right to health.
- 26. If I felt my own rights were being violated, I would be confident to speak out about it.
- 27. Who would you speak to if you felt your rights were being violated? (Open-ended question)
- 28. I know about the Learning Network and the work that the network does. (Y/N)
- 29. I have attended a Learning Network workshop. (Y/N)
- 30. I am confident that if I needed information on a specific right, I could get that from someone in the Learning Network.
- 31. I feel a strong sense of belonging to the Learning

- Network.
- 32. People in the Learning Network can be trusted.
- 33. Sharing information in the Learning Network about what has not worked well in my organization is a difficult thing to do.
- 34. Sharing information in the Learning Network about what has not worked well in my organization is very important for the objectives of the Learning Network.
- 35. I understand the objectives of the Learning Network.
- 36. I think the Learning Network will address the learning needs of my organization.
- 37. I think the Learning Network will add value to what my organization does.
- 38. The range of CSOs in the Learning Network is appropriate.
- 39. The CSOs in the Learning Network are stable organizations.
- 40. The Learning Network has common objectives.
- 41. There will be shared ownership of outputs from the Learning Network.
- 42. The Learning Network is facilitated in an open way.
- 43. The expertise and experiences of all member organizations is recognized.
- 44. The different reasons for organizations joining the Learning Network do not influence participation.