Beyond Scaling Up: Pathways to Universal Access

Citizen/Health System Relations

This briefing is part of a series from a workshop held at the Institute of Development Studies in May 2010. The workshop was co-sponsored by the STEPS Centre and the Future Health Systems Consortium. The objectives of the workshop were to:

- Explore approaches that have fostered innovation, rapid learning and large scale impact in the health sector that incorporate context and social arrangements as central to learning and change
- Identify practical approaches for collaboration between innovators, researchers, governments and funding agencies to strengthen the capacity of health systems to meet the needs of the poor

The briefings provide summaries of the presentations that were given and key issues and concepts that were raised by participants.

The collective response to HIV and AIDS in South Africa
Hayley McGregor and Elizabeth Mills, Institute of Development Studies (IDS)

McGregor and Mills discussed the shift in focus of South Africa’s Treatment Action Campaign from biomedical issues and improving access to ARVs to a broader set of vulnerabilities concerned with socioeconomic rights and helping people manage HIV as a chronic condition. South Africa in the 1990s offered unique opportunities for activism around HIV/AIDS: it was a new political space with a lively civil society; health had been enshrined as a human right in the new constitution; international activist networks provided influence and resources; and there were powerful local actors in the health and legal fields supporting campaigns. The strategies used by activists included street protests, civil disobedience campaigns, mobilisation for international condemnation, legal challenges to state legislation using the constitution and legal action against pharmaceutical companies. Notions of ‘therapeutic citizenship’ and expert-patients emerged through large-scale ‘treatment literacy’ programmes and strategies such as drawings of body maps depicting the impacts of the illness on the body enabled people to articulate their experiences to researchers and policy makers.

In September 2003 the government was compelled by cabinet to commence public sector provision of ARVs; this was finally initiated in March 2004, but the struggle to legislate dual therapy for the prevention of mother to child transmission of HIV and to scale up the ARV roll out more quickly continued to shape activist engagement. In 2010 South Africa has the largest ARV programme in the world, but it is also home to the largest number of people living with HIV, and the country is still lagging behind policy targets to reach 80% of all those in need of ARVs by 2011.

In recent years, as access to ARVs has increased and people are better able to manage the illness in medical terms, issues around housing, sanitation and education have become the most pressing difficulties faced by people living with HIV/AIDS. Activist strategies and coalitions have changed to reflect this and a new agenda has emerged to incorporate a broader focus on the right to health and ARVs in conjunction with social justice and socioeconomic rights.

Useful links
View Mills’ and McGregor’s presentation from the workshop http://www.slideshare.net/katecommsids/beyond-scaling-up-hiv-and-citizenship
Mills and MacGregor worked with Nondumiso Hwele to update a series of body maps; these are displayed in the ‘Assembling Bodies – Art, Science and Imagination’ Exhibition at the Museum of Archaeology and Anthropology (MAA) at the University of Cambridge http://maa.cam.ac.uk/assemblingbodies/exhibition/multiple/
The MAA Exhibition Catalogue article on the original and updated Bodymap narratives, written by Macgregor and Mills: http://www.cssr.uct.ac.za/sites/cssr.uct.ac.za/files/MacGregor_and_Mills.pdf

“There has been a shift in focus in South Africa’s Treatment Action Campaign from biomedical issues and access to ARVs, to a broader set of vulnerabilities and socio-economic rights...”
Organising people with diabetes to manage their disease in Cambodia
Maurits van Pelt, MoPoTsyo

Despite accounting for a huge proportion of the disease burden in many developing countries, non-communicable diseases are currently not a priority on the international health agenda and only a tiny proportion of donor funding goes to supporting people with chronic conditions such as diabetes. In Cambodia, chronic illness constitutes at least 50% of the morbidity burden. There are around 255,000 people living with diabetes, 90% of whom have no access to care. People with chronic diseases must bear the cost of treatment themselves and do not have access to good information about their condition.

Van Pelt suggested that there are opportunities and good reasons to act on chronic disease in low income countries. The costs of living with diabetes, for example, can be slashed dramatically if patients are able to self-manage and have the knowledge to make well-informed decisions about medical treatment. Training patients and lay persons to perform care duties also reduces health system stress.

MoPoTsyo is an NGO that has established a peer education network in which people with diabetes help others to manage the condition. Peer educators offer lessons and counselling in their homes on healthy eating, physical activity, and how this influences glucose levels. They show the other patients how they can practise self-measurement of their glucose levels, and explain the importance of treatment adherence. Peer educators also organise screenings and help facilitate access to medical services from appropriate providers. The relative performance of peer educators is assessed every six months in popular local events during which patients are called in to participate. Patient-experts or peer educators become intermediaries between the isolated sick person and professional health service providers. A further aim is to encourage stronger representation of chronic patients at policy level.

MoPoTsyo started in 2005 and is gradually being scaled up, with numbers attending doubling every year: there are currently more than 2000 people involved in the programme. About 10% of patients annually leave the programme, because they migrate to another region (5%), are no longer interested (3%) or because they die (2-3%). The peer educator model offers potential for scaling up support for chronic conditions and reducing the burden on the formal health system.

Useful links
View Van Pelt’s presentation from the workshop
http://www.slideshare.net/katecommsids/van-pelt-diabetesincambodia

The MoPoTsyo website
http://www.mopotsyo.org/

Building a coalition to make the right to health care real in Brazil
Alex Shankland, (IDS)

Shankland’s presentation, which drew on research carried out with Vera Schattan Coelho of the Brazilian Centre for Analysis and Planning (Cebrap), also highlighted a shift in focus from health care provision and access, to issues of social justice, equity and the experiences of marginalised groups. The right to health was recognised and a unified health system, the ‘Sistema Único de Saúde’ (SUS), was established in Brazil’s 1988 Constitution in response to the demands of broad based social movements. The SUS has successfully scaled up regional innovation and pilots and has now established near universal primary health care access across the country.

The idea of ‘universal health care’ and the right to health, however, is often interpreted as everyone getting the same, which can undermine the need to understand diversity and encourage flexible approaches. The presentation focused on the campaigns of indigenous people who are a small minority in Brazil (less than 1% of the population) but politically visible with powerful links with NGOs. These groups are physically hard to reach, speak different languages and often receive poor service from health care providers. They have the worst health status of any population group in Brazil, with infant mortality and many infectious disease prevalence rates 2-3 times higher than those for the population as a whole. While the health policy process has worked to be inclusive, it has not proved flexible enough to address the specific challenges of delivering effective services to indigenous people.

In 1999 a decentralized indigenous health sub-system was established by the Ministry of Health which outsourced a lot of service provision to NGOs, encouraging innovation at the local and regional level and permitting strong early progress in improving health indicators. Management problems led to a breakdown of trust, however, so the programme was dismantled and services were decentralised; much of the learning from this experience was lost and a lot of money invested into restarting a standardised universalist approach. Improvements in health outcomes among indigenous people, however, have stalled despite the massive increase in spending.

To address the issue, a World Bank loan was used to conduct a situation analysis and develop new models of health care. This was undertaken by a consortium that included the Institute of Development Studies (IDS), the Brazil Health Unlimited Association (SSL), a health rights NGO, and Cebrap; a diverse team was chosen to facilitate engagement with a wide range of stakeholders. The consortium proposed an innovative approach to reforming the health system by facilitating stakeholders themselves to experiment and model new ways of doing things.

In April 2010, a Presidential decree paved the way for a new Special Secretariat of Indigenous Health, whose head committed it to implementing the recommendations that had emerged from the consultancy process. The SUS had constructed a narrative that interpreted universal rights as
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‘one size fits all’, which was in the interests of the Ministry of Health who did not want the expense and challenges of differentiating services. While the creation of the Special Secretariat was forced on the Ministry by political pressure, senior managers have said that they see it as an opportunity to pilot new approaches to tackling the challenges that face the SUS, now that it is coming to the end of its successful initial phase of scaling up. These experiments with indigenous health can be used to learn more about equity and quality.

Useful links
View Shankland’s presentation from the workshop http://www.slideshare.net/katecommsids/shankland-rights-in-brazil
Brazilian Ministry of Health page with the outputs from the consultancy (in Portuguese) http://www.funasa.gov.br/internet/vigNovosModelosSsi.asp
For a non-academic account of experiences of indigenous health in Brazil, you can read the Survival International story ‘Indigenous children dying as health crisis deepens’ at http://www.survivalinternational.org/news/1504

Innovations for social organisation for village sanitation
Lyla Mehta (IDS)

Community Led Total Sanitation (CLTS) is a bottom up, participatory approach pioneered by Kamal Kar in Bangladesh that has emerged in response to the failure of top down development projects to successfully address the neglected problem of poor sanitation in rural areas of developing countries. In the past ten years CLTS has grown from a single intervention to a global movement practised in over 30 countries. The approach uses participatory methods such as mapping to enable people to understand where and why open defecation takes place and to make collective decisions around how to address it. This means that interventions such as construction of latrines are driven and owned by the community members themselves. Local community champions of CLTS are a very important part of the process.

Scaling up CLTS presents a number of challenges and dangers. In particular, when going to scale it is often difficult to avoid compromising on the crucial diverse and localised nature of the approach, as less time is invested in mobilising communities and developing local champions. If not well facilitated social and power relations can be glossed over and some people, often those already marginalised within the community, are left out. There are also question marks over the sustainability of the intervention and risks that, if not carefully planned, latrines can lead to groundwater contamination in some contexts. Once CLTS started being used on a large scale questions about its institutional home arose; in some settings NGOs have led scale up, and in others the public sector. The ministry in which the programme is housed can have significant impacts on the time and resources invested into it. Incentive and reward structures have also presented challenges; in India rewards for CLTS champions have been detrimental, as they have become more important than the participatory process itself.

During discussion participants asked if there had been an evaluation of the health impacts of CLTS and it was noted that sometimes open defecation is more sanitary, particularly if closed latrines are located close to drinking water sources or residences. Mehta agreed that this was a risk, and was one reason why the careful attention to context that underpins the CLTS is so important.

Useful links
View Mehta’s presentation from the workshop http://www.slideshare.net/katecommsids/mehta-community-led-total-sanitation
The CLTS website http://www.communityledtotalsanitation.org/

Below In the past ten years CLTS has grown from a single intervention to a global movement
Session discussion

One set of comments from participants were concerned with the exceptionality of the case studies presented. One participant asked how citizens might mobilise around more widespread issues such as infant and maternal mortality, which – unlike chronic diseases – cannot be planned for in the long term, and ‘happen instantly’? Other participants emphasised that indigenous programmes, and possibly chronic disease focused programmes may have the potential to create a path change in the system; change within the broader system may be led by changes in the sub systems associated with these movements. McGregor pointed out that in South Africa campaigns around HIV have catalysed other changes in the health service that have supported other health conditions. Shankland noted that in Brazil mobilisation happens around health service user category rather than around a particular health issue and that being different perhaps allows for experimentation. Mehta said that sanitation is not an exceptional issue and has important implications for problems such as child and maternal mortality which have become naturalised or accepted as inevitable. The power of imagination and the ability to see a different kind of future is a trigger to mobilise; it breaks the naturalisation of these deaths. The session Chair Melissa Leach noted that the presentations all started with a particular grievance or neglected health problem that was a ‘niche’ which then transitioned outwards and was scaled up in different ways.

Echoing these points, one participant asked whether the peer educators model and e-health programmes (discussed in a previous session on ICTs) might intersect. Diabetes is a good disease to start initiatives with but there is scope for addressing other conditions as well as instigating geographical expansion; an example in Cambodia are the Mum Clubs that have increased the number of deliveries taking place in healthcare facilities. Van Pelt noted, however, that this initiative did not work well in rural areas because of distance from health facilities.

Barun Kanjilal: Discussant

Kanjilal commented that the presentations were concerned with local community responses to the widening gaps in the existing health system. He warned that strengthening community movements can result in the increasing development of parallel systems. There is a risk that this can lead to groups refusing services from the formal health system, such as immunization, which has important public health implications. He also noted that in many contexts the right to health and the right to livelihood are closely linked. Does scaling up of one thing mean scaling down of another? What is the opportunity cost?

Hilary Standing: Discussant

Standing also raised a number of questions in her comments on the presentations. She noted that the examples show different people in very different contexts, using very different strategies with different long term trajectories. AIDS activism in South Africa has been a huge success story but it is still all about HIV – therapeutic citizenship was framed around a single condition - what does it imply for other people living with different issues? New forms of health citizenship could usefully be articulated – for example around responsibilities and resource allocations. Other questions emerging from the presentation include: do competing concepts of fairness clash with the rights discourse? Do we need to look beyond rights? Whose knowledge is privileged? She noted that shifting disease patterns require new approaches, which can be driven by patient-action linked to the rapidly changing information economy in health and facilitated by ICTs.