13. Social movement activism[1]

Social and political movements as vehicles for social change

In an earlier period political parties, including Leninist left parties and social democrat mass parties, were the preferred vehicles for activists seeking to effect social change.

With the widespread loss of faith in both of these pathways, activists in many countries have turned to social movement activism as the framing paradigm for their political engagement. In Chapter 12, discussing the social movement as a vehicle for social change, we defined the social movement as having a loose organisational structure with many autonomous organisations, networks and individuals; a shared analysis, sense of direction and broad strategy; a shared consciousness or sense of identity (being part of the movement) and a shared repertoire of action. We identified and discussed four main sources of power: inspiration, delegitimation, mass refusal and 'practising differently'. However, ultimately these boil down to numbers; they all depend on mass participation. Examples of social movements include the labour movement, the women's movement, the environment movement and various religious fundamentalisms.

An activist is someone who is ethically driven to go beyond the boundaries of their conventionally 'assigned' social role to work for social change. A social movement activist is one who orients their activist work within the broad purposes, analysis and norms of a particular social movement. A people's health movement activist is one whose actions, beyond their conventionally assigned social role, are oriented around health care and/or the social conditions which shape people's health and who works within the purposes, analyses and norms of the people's health movement. An activist is not necessarily good. Anton Brevik is an activist. A social movement is not necessarily good. Al Qaeda is a social movement.

Five case studies of health activism

Our focus from here on is on the people's health movement, defined as the loose aggregation of individuals and organisations whose work is broadly aligned with the People's Charter for Health.

We start our exploration of health activism with five case studies of health activism[2].

- Promotores de salud in Guatemala,
- Community monitoring in India,
- TAC in South Africa,
- Universities Allied for Essential Medicines,
- WHO Watch.

1. Work in progress. Feedback to dlegge(at)phmovement.org would be appreciated.
2. See also the story of the Green Area of Morro da Policia in Annex 1 of Chapter 10. Also at http://www.who.int/sdhconference/resources/draft_background_paper24_brazil.pdf

Promotores de salud in Guatemala

One of the case studies which was particularly influential in the preparation for the Alma-Ata Conference and Declaration concerned a project involving community health workers (promotores de salud) in Chimaltenango in Guatemala. The story of the Chimaltenango project was recorded in the influential Health by the People edited by Kenneth Newell and published by WHO in 1975 (Behrhorst 1975).

Behrhorst tells the story of the health promotores from the perspective of a US physician who arrived Chimaltenango in 1962 and had been there for 12 years when he wrote this account. He describes the deep poverty of the Mayan people living in the Guatemalan highlands with small parcels of not very fertile land. Malnutrition was rife. He describes working with the Mayan communities and learning from them. One of the main projects he worked on was the training of health promotores, village health workers who provided basic clinical services but also worried for the living conditions of their neighbours. A number of village enterprises were established including agricultural improvement projects. Behrhorst's story is worth reading in the original rather than trying to summarise it. See http://whqlibdoc.who.int/publications/1975/9241560428_eng.pdf.

Behrhorst's story needs to be contextualised in relation to the history of Guatemala and there is a very useful account provided in Wikipedia (http://en.wikipedia.org/wiki/Guatemala). The Wikipedia article describes the Guatemalan Civil War from 1960 to 1996 although the term 'civil war' does not capture the role of the CIA in its support of the death squads.

A further account of the Chimaltenango project written 10 years after Behrhorst is provided by Heggenhougen (1984), an evaluator from the London School of Hygiene and Tropical Medicine. He describes the work of the promotores de salud during the earlier period described by Behrhorst and the progress made in health care agriculture, land tenure, water supply, sanitation and other areas. Following a devastating earthquake in 1976 many of the promotores played leading roles in projects directed to social and economic recovery. However, this was also a period of increasing lawlessness with paramilitary gangs conducting increasing campaigns of violence and repression. The health promotores were particularly singled out for reprisals, disappearances and torture. Eleven of the 49 health promotores in the Chimaltenango project were 'eliminated' and members of their families killed. Their crime was that they were helping to organise the Mayan communities to gain some economic independence in the context of an hierarchical and exploitative regime. The CIA involvement was in part directed at supporting the United Fruit Company (later Chiquita Brands International Inc) and also as part of defending the US imperial interests generally in Central America.

Heggenhougen asks whether PHC is possible when in circumstances such as these it elicits such horrific violence and repression. He comments:

> "The violent repression of the VHWs in the Chimaltenango Programme was of course not a direct result of, nor proportional to, the threat their activities represented to local elites. But these activities were associated with those of others throughout the country which at this point in Guatemala's history could have succeeded, collectively, in restructuring the total society."

While the civil war ended in 1996 the inequalities and contradictions have continued. At an IPHU held in Chimaltenango in April 2010 the widow of Francisco Tepeu of San Juan de Sacatepéquez, who was assassinated in 2008 spoke. See http://www.iphu.org/en/node/457 from the video reports from the 2010 IPHU in Guatemala.

Community monitoring in India

The story of community monitoring of health care in India has been told in Global Health Watch 1 & 2 (GHW 2008; GHW 2011). The following account draws on those reports.

The first phase of JSA's Right to Health campaign involved documenting individual instances of denial of health services and recording of structural denial of health care. A national public consultation was organised in Mumbai and attended by hundreds of delegates from sixteen states across India. At the consultation, over sixty cases of 'denial of health care' were presented. Testimonies included the deaths of children from common illnesses and of women due to botched sterilisations in badly equipped camps. The chairperson of the National Human Rights Commission (NHRC) acknowledged the frequent accounts of human rights violations and promised action.

Subsequently 'Jan Sunwais' (People's Health Tribunals) were held in some states: these were public hearings at which people were supported to make public testimonies concerning their experience of being denied health care in front of impartial adjudicators and government health officials. This strategy of holding hearings in front of large audiences publicised health rights violations, put pressure on health systems to become accountable, and raised awareness of health rights among the masses. In 2004, the JSA, in collaboration with the NHRC, organised Public Hearings on the Right to Health Care in all regions of India. Each hearing was attended by hundreds of delegates from various districts and states, along with key public health officials. The hearings were widely advertised in regional newspapers and many people came forward to present their testimonies. This opportunity to share was hugely empowering and the movement began to take on its own momentum.

These hearings culminated in a National Public Hearing on the Right to Health Care that was attended by the central health minister, senior health officials from twenty-two states across the country and the NHRC chairperson and officials. Over a hundred JSA delegates from over twenty states presented numerous health-rights violations, and nine sessions on key areas of health rights were held, including on women's and children's health rights, mental health rights, and health rights in the context of the private medical sector. The hearing concluded with the declaration of a national action plan to operationalise the Right to Health ‑ jointly drafted by the NHRC and JSA.

In 2005, the newly elected government launched the National Rural Health Mission (NRHM), expressing a renewed commitment to strengthen public health systems. The Mission envisages a substantial increase in the national health budget, a woman community health worker in each village of the eighteen focus states, provision of united funds and strengthening of public health facilities at various levels, and decentralised planning of public health services. However, being a programme for 'health system reform in the era of globalisation‑privatisation', it is a mix of policy elements, making provision for semi-privatisation and privatisationof health services. JSA members continued to fight to strengthen the core public health rights in the Mission and introduced a number of monitoring mechanisms to counter the negative provisions leading towards privatisation. In direct response to the NRHM, JSA launched a 'People's Rural Health

Watch' in eight northern states, through which communities actively monitor the quality of care and are enabled to propose suggestions and alternative strategies for the improvement of health.

As a follow-up to the public hearings, JSA represented civil society during national review meetings on health rights organised by NHRC in 2006 and 2007. JSA representatives testified on the state of implementation of the national action plan and on the status of public health services. The idea of developing People's Health Plans has also emerged in discussions in JSA. The Plans were seen as a necessary component in the process of making public health systems work effectively and in a responsive manner. This kind of local, appropriate people's control and planning could pose one of the most definitive challenges to hegemonic globalisation. JSA continues to provide a platform for collaboration among various streams of the health movement dealing with the health rights of various groups.

GHW3 picks up the story:

In parallel with this, advocacy was carried out by certain PHM-India-associated activists to provide an institutional form for the health rights campaign. Carrying this forward, and based on coordination by the NRHM Advisory Group for Community Action, from 2007 onwards an innovative process of 'community-based monitoring of health services' (CBM) was developed; in the pilot phase during mid 2007 to early 2009 this was implemented in 35 districts of nine states. PHM-India member organisations have anchored this activity in certain states. Although this is a broad, publicly organised and funded activity, groups and individuals associated with PHM-India continue to play a key facilitating role in this process in certain states. It is led by networked civil society organisations from block to state levels, with the following key features:

• *Community awareness and activation around health entitlements* have been generated by village meetings, display of health rights posters, expansion and strengthening of village health committees (VHCs), and training of VHC members.

• *Multi-stakeholder community monitoring committees* have been formed at primary health centre, block and district levels, including community members, NGO/CBO representatives, elected political representatives and public health staff.

• *VHC and other committee members periodically collect information about health service delivery* using objective semi-quantitative tools, and rate these through publicly displayed *report cards*, each service being rated as 'good', 'partly satisfactory' or 'bad'. This data is collected at both village level (concerning outreach services) and health facility level.

• *Public hearings with mass participation are organised* at primary health centre, block and district levels, where report cards and cases of denial of health care are presented, and public health officials need to respond regarding remedial actions.

• *Periodic state-level events* enable dialogue between civil society monitoring committee members and the state health department, seeking resolution of critical, unresolved and systemic issues, and help reinforce government support for the CBM process.

As an example of this process, one may consider the western state of Maharashtra, where CBM is being implemented in over 500 villages spread over 23 blocks in five districts of the state.[7] A network of 15 civil society groups including mass organisations, mostly associated with PHM-Maharashtra, have developed this activity to enable people to claim their rights related to rural public health services.

Three rounds of community-based collection of information were organised between mid 2008 and end 2009. Over these one and half years, the *overall proportion of village level health*

services rated 'good' by communities increased from 48 to 66 per cent while the number of *services rated as 'bad' has declined from 25 to 14 per cent*. Community-based data showed that overall PHC services rated as 'good' *improved from 42 per cent in the first round to 74 per cent in the third round*. This has been accompanied by significant increase in utilisation of PHC services, as people have started shifting from dominant private providers to improved public facilities. In Thane district of Maharashtra, during the period 2007/08–2009/10, outpatient, inpatient and delivery-related utilisation of primary health centres in CBM areas increased by 34, 73 and 101 per cent respectively; this was *one and half times to twice as high* as average utilisation increases for PHCs in the district as a whole. Corresponding to this, a wide range of qualitative improvements have also been documented: in most CBM areas, attendance by field staff and doctors has increased, illegal charging by providers has been checked, functionality of PHCs and sub-centres has gone up, and provider behaviour has improved.

Treatment Action Campaign

The World Trade Organization (WTO) was established in 1994. Among the agreements it was to administer was the TRIPS agreement, which included provision for extended patents and patenting products as well as processes. In 1997, 39 international pharmaceutical companies brought a case against the South African government saying that its 'parallel importing' legislation (designed to improve access to cheaper versions of brand name drugs) was against its TRIPS commitments. At this stage the cost of brand name anti-retrovirals for one year was around $10 000 while the Indian generics manufacturer Cipla was selling generic versions of the same drugs to MédecinsSans Frontières (MSF) for US$350 per treatment per year (Oxfam 2002).

Mark Heywood (2009) describes how a small group of activists gathered in late 1998 to affirm the right of access to treatment through litigation, lobbying and social mobilisation. The Treatment Action Campaign (TAC) focused initially on the excessive prices charged by the transnational pharmaceutical companies in South Africa. From the outset TAC sought to build a social movement in which poor people become their own advocates. A critical strategy of this movement was the idea of 'treatment literacy'; education initiatives led by people living with HIV among people living with HIV.

> TAC volunteers who have been trained and have passed an examination are called 'Treatment Literacy Practitioners' (known as TLPs). They are given a small bursary for a year and then assigned to clinics, hospitals, and community organizations where they conduct further training and agitation for the right to treatment. They are also linked to TAC's community branches, the nerve centre for TAC's local organizing, and the treatment literacy programme has an administrative infrastructure that can double up as a means for mobilization and local organization. […]

> TAC's campaigns and court cases have garnered much comment and research. But overlooked has been the fact that the treatment literacy training has been ongoing behind all of them. Treatment literacy is the base for both self-help and social mobilization. Armed with proper knowledge about HIV, poor people can become their own advocates, personally and socially empowered. For example, in interviews conducted during an evaluation of TAC, its volunteers are quoted as saying 'I am living because of TAC', 'TAC puts self-esteem back into people', and 'In TAC you are in a university. You learn and grow with knowledge' (reference in original).

> In the communities where TAC organized, treatment literacy agitators fuelled the demand for access to ARV treatment by people with AIDS at local clinics, leading to higher rates of take-

up and adherence than in comparable communities, where a TAC branch was not present. But, in addition, access to accurate information about health and linking this information to rights empowered marginalized people who began to assume both a public voice and a visibility. (taken from Heywood 2009)

Led by TAC a powerful civil society action emerged against the drug companies. This involved street action in South Africa as well as high-level policy analysis (Knowledge Ecology International and MSF) and solidarity action in the United States (in particular through Health GAP and ACT UP). In May 2001 the companies withdrew their action and paid the costs of the South African government.

In December 2001 in Doha the Ministerial Council of the WTO adopted its Statement on Public Health (WTO Ministerial Council 2001) and agreed to amendments to the TRIPS Agreement that, in theory, would make compulsory licensing more flexible. From 2001 to 2003 the United States stonewalled the adoption of workable protocols for implementing more flexible compulsory licensing. Meanwhile (1999–2000) a new body, the Global Fund to fight AIDS, Tuberculosis and Malaria, was established (mainly through G8 funding but also with Gates Foundation support) with a brief to support wider access to expensive medications (although without compulsory licensing).

UAEM

Universities Alliance for Essential Medicines (UAEM) started at Yale in 2000 at the height of the Treatment Action Campaign in South Africa. One of the drugs at issue in the stand-off was the drug stavudine – an anti-retroviral used in the treatment of HIV – which MSF wanted to use for its projects in South Africa. The drug had been developed by a scientist at Yale and the university had licensed it to the drug company Bristol-Myers Squibb. MSF had approached both Yale and the company but had been unable to convince them to make the drug available. It then contacted some students at Yale and asked them to take on the issue. The students launched a powerful campaign at the university (including a 'TB die-in') and managed to persuade Yale and Bristol-Myers Squibb to export the drug at much lower prices – almost 95 per cent lower. That success inspired students elsewhere in the United States, and UAEM was set up two years later. By 2010 over 50 universities were involved. Three universities in the United States and Canada have since embedded UAEM's core principles into their university constitutions, and numerous other universities are now considering how to better integrate these principles into their work. Those universities that have signed up still grant exclusive licences to pharmaceutical companies for their discoveries, but written into these licences is the requirement that any drug or medical technology relevant to developing countries be made accessible to them. For example, the University of British Columbia is currently ensuring a drug they have developed for leishmaniasis is available to developing countries (UAEM 2010).

Recently UAEM has extended its coverage with the release of a 'report card' grading 54 leading research universities in the U.S. and Canada regarding their commitment to global health in the developing world. Quoting from the UAEM media release:

The new report card assesses these universities on their commitment to researching drugs and technologies to treat "neglected diseases" in the developing world, and to making their medical innovations available and affordable for those who need them most. Advocates publicly called for universities to devote more funding and resources to research on diseases which

predominantly impact the global poor, and for increased use of socially responsible licensing that would help make new medical breakthroughs available and affordable in poorer nations.

The universities were graded on a number of criteria, including whether they invest in medical research that addresses the most neglected health needs of low-income communities worldwide; whether they license their health technologies to for-profit companies in ways that ensure treatments reach developing world patients at affordable prices; and whether schools are educating the next generation of global health leaders about the impact academic institutions can have on global health.

"Nearly a third of humanity does not have regular access to essential medicines, and in the poorest parts of Africa and Asia this figure rises to over 50%, leading to ten million deaths annually from treatable diseases. Meanwhile, universities are public institutions whose medical research is heavily funded by government grants and taxpayer dollars. They have a responsibility to focus on research that meets the most pressing global health needs and to ensure that the results of their research are available to those who need them most," said Bryan Collinsworth, Executive Director of Universities Allied for Essential Medicines. "We need more accessible and responsible research licensing to help life-saving medical innovations reach people who otherwise can't afford treatment, and we also need universities to invest in labs and programs dedicated to global health and, in particular, neglected diseases."

Several top-tier institutions, including Yale, Columbia University, M.I.T. and New York University, scored a C- or below on the rankings. Other schools, like Case Western Reserve University, the University of British Columbia, Johns Hopkins University, and the University of California Irvine, garnered high scores on many metrics, including endorsement of socially responsible licensing, investing higher-than-average resources into diseases that primarily affect the developing world, and offering global health programs that include education on neglected diseases and how intellectual property policies can influence theglobal pricing and availability of new medicines.

Advocates noted that alternative licensing models had no negative impact on schools' ability to fund and conduct research. "We've found that schools that license their research in ways that take into account the needs of the developing world maintain or even increase their licensing activity, while increasing the global availability of the health technologies they're sharing," said Alexander Lankowski, a fourth-year medical student at Boston University and one of the UAEM student leaders who developed the Report Card.

WHO Watch

Since 2000 PHM has actively engaged with the World Health Organisation in different settings and around different issues. Since 2010 a more systematic approach to monitoring and advocacy around WHO has been developed, under the name of 'WHO Watch'.

WHO Watch (WHO Watch 2011) is part of a broader project directed towards engaging with the structures of global health governance. The structures and dynamics of global health governance (GHG) are presently dominated by the big powers (in particular, USA and Europe) and by large transnational pharmaceutical corporations. The big players operate through the UN system, the Bretton Woods system and a plethora of global public private partnerships. They also operate directly through bilateral and regional trade agreements; through the operations of bilateral health-related assistance; and through direct advice and pressure. The operating paradigm of this regime is strongly influenced by the ideology of neoliberalism which is promoted through a much wider range of channels

including the commercial media and various corporate peak bodies (such as at the World Economic Forum).

In many respects the regulatory, financing and policy outcomes of this system reflect the interests of the rich world. This bias is reflected in:

- continuing unimpeded brain drain, in part because the rich countries do not train enough of their own professionals (it is much cheaper to import professionals trained in the developing countries);
- an intellectual property rights regime which is largely focused on maintaining the profits of transnational pharmaceutical companies and discounts the urgent need of millions of people in developing countries for affordable medicines;
- trade policies which sanction the dumping of agricultural produce on developing country markets (which jeopardises the livelihoods of small farmers);
- trade policies which pressure developing countries to cut tariff protection and export duties without regard to the consequent unemployment and loss of government revenues (and public services);
- health system policy models which are oriented to stratified health care delivery with private care for the rich, social insurance for the middle and safety nets for the poor;
- resistance to the kinds of sectoral policies suggested by the WHO Commission on the Social Determinants of Health which could greatly improve population health.

Low and middle income countries are largely excluded from the corridors and forums in which the decisions and policies of the prevailing regime of GHG are formed. Even outside the corridors and forums the voices of most low and middle income countries are muted and dispersed. There are important exceptions; a small number of L&MICs have invested significantly in their intersectoral work (eg between health and trade) and in global health policy advocacy. There are also resources within civil society globally which are well informed and supported by high level analysis and which are sympathetic to the perspectives of L&MICs. Civil society networks which link North and South constituencies also provide an avenue through which the health needs of L&MICs can be brought to Northern consciousness.

There is a strong case for new alliances; for policy research and capacity building with a view to changing in some degree the perspectives which inform GHG and the balance of forces which shape such decision-making.

WHO Watch is a resource for advocacy and mobilisation and an intervention in global health governance. As a resource for advocacy and mobilisation WHO Watch provides a current account of global policy dynamics in relation to a wide and growing range of health issues. While the focus is on issues being considered through the WHO the background documentation provides a more broadly based account of these issues. WHO Watch is also an intervention in global health governance. Partly this is about defending WHO which has been subject to serious financial stresses over several decades. WHO is the paramount health authority at the global level and needs to be strengthened and reformed and properly funded

to play this role. WHO Watch seeks to generate support for a reformed WHO restored to its proper place in global health governance.

WHO Watch also aims to democratise the decision making within WHO, in particular supporting delegations from smaller countries who are seeking to know more about particular issues or are looking for resources regarding issues that they are concerned about.

There are several components of WHO Watch;

- watching (includes documentation, analysis and advocacy as appropriate) at the governing bodies meetings in Geneva;
- watching (documentation, analysis and advocacy as appropriate) at the regional committee meetings;
- watching (monitoring, liaison, collaboration, advocacy) with WHO country representatives;
- liaison with national representatives before their participation at the WHA, EB and regional committee meetings;
- maintenance and development of WHO Watch website providing accessible, high value policy analysis and a portal to other relevant resources;
- collaboration with other CSOs who are involved in health-relevant watching in relation to WHO and other international organisations.

EB Watch and WHA Watch involve mobilising young health activists from around the world (particularly from LMICs) to come to Geneva in January and May to monitor, document, analyse and advocate around the issues being discussed at the Executive Board and the WHA. The Watching includes an orientation workshop before the commencement of the meeting to review the wider GHG picture, the contemporary standing of WHO (and relevant background) and to explore in depth the agenda items. The watching includes documenting the discussion, nightly analyses, statements from the floor, and liaison with the many other CSOs attendng. Watchers are encouraged to liaise directly with official delegates. In a final workshop watchers put together the implications for the various issues in the form of an advocacy resource for PHM at all levels.

Since the launching of WHO Watch in 2010 the project has:

– trained 21 volunteers from 12 countries; trained through hands-on orientation workshops organized prior to the meetings of WHO governing bodies and also through the monitoring and advocacy within those meetings;
– developed a circle of resource people to support the initiative, supporting the watchers' training and the development of the PHM commentaries;
– participated in all (open) WHO governing body meetings in Geneva since May 2010, including the regular and special meetings of the World Health Assembly (WHA) and Executive Board (EB).

Watching the regional committee meetings involves applying the same principles and protocols at the regional level. It is complicated by the variations in protocols for civil society attendance at regional committee meetings between different regional offices of WHO.

Watching at the country level varies widely according to the different situations within countries and local regions. It may involve collaboration between civil society and WHO in countries. A major thrust of country level engagement is to hold member state governments

(in particular, ministries of health, foreign affairs and finance) accountable for their participation in WHO decision making.

The WHO Watch website aims to document current movements in global health policy in terms of events, topics and at the regional offices. One of the objectives of the website is to provide a resource for delegates from countries which have limited policy resources in their own MOHs.

Critical to the work of WHO Watch are the links between the watching processes and the various struggles for health in various districts, states and provinces and at the national level. These links enable local activists to keep in touch with the global policy movements which shape the context for such local struggles. These links also help to ensure that policy analysis and policy advocacy at the regional and global levels is informed by the reality of grass roots activism, both in health systems and around the conditions which shape health.

Reflections on five cases of health activism[3]

These five cases of health activism range from grass roots action in Guatemala and India, through national level action through TAC in South Africa and UAEM in Canada and the USA, through to global engagement through WHO Watch.

Reflecting on these cases we may ask:

- what were the large scale dynamics of social change that the activists were engaging with?
- what were strategies (intentional drivers of change) deployed by these activists?
- which of the 'levers of power' (inspiration, delegitimation, mass refusal, practising differently) can we discern in these episodes?

Dynamics of social change

The dynamics of social change with which these activists have engaged also vary widely although there are significant overlaps. In Guatemala the activists face a continuing history of neo-colonialism and imperialism with indigenous peoples subject to racism, exploitation and exclusion. Civil war and on-going violence and intimidation are part of the context.

Community monitoring in rural Maharashtra deals with some similar dynamics with castism and landlordism playing a salient role. However in the Indian case the long standing neglect of the institutions of public sector health care delivery are also a major feature of the context. The neglect of public sector health care in India reflects the rise and rise of a brutal capitalism increasingly influenced by the ideology of neoliberalism.

The TAC and UAEM cases both deal with the transnational pharmaceutical industry but from two different perspectives. In South Africa the struggle was literally around access to medicines for people who would otherwise die of AIDS. The UAEM case was an expression of solidarity among activists in the USA with the treatment access struggle. UAEM has gone on from there to seek to influence the policies of North American

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3. See also the story of the Green Area of Morro da Policia in Annex 1 of Chapter 10. Also at: http://www.who.int/sdhconference/resources/draft_background_paper24_brazil.pdf

universities with respect to the licensing of intellectual property, challenging one of the underpinning support of big pharma's IP monopolies.

Finally WHO Watch is focused on the structures and dynamics of decision making around health issues at the global level. The 'dynamics of social change' in this case are about the politics of global institutions and big power engagement with and through such institutions.

Activist strategies

The strategies deployed by these different activists also vary widely.

In the Guatemalan, India and South African cases strategies of popular mobilisation, new partnerships and empowerment have featured prominently. Popular education was an important part of this in all three cases.

The UAEM strategies are focused on institutional reform, drawing on the principles of solidarity and educating institutional leaders about the significance of their policies.

WHO Watch is directed at achieving change through forging new alliances and new flows of information. A fundamental strategy of WHO Watch is building closer links between quite specific and local struggles (primary health care in Guatemala, the right to health in India, treatment access in South Africa) and the structures and dynamics at the global level which shape local struggles and are in turn constrained by what happens on the ground.

Levers of power

The levers of power accessed by the activists in each of these cases also vary widely.

We may take the Guatemalan case as an example of 'practising differently' and perhaps also of 'inspiration'. The Chimaltenango project involved health professionals and village health workers practising differently, and inspiring communities to practice differently. The simple act of practising differently was deeply challenging to the established order and has contributed to the processes of change. At another level the Chimaltenango project has been a global inspiration through its significance in the drafting of the Alma-Ata Declaration.

Community monitoring in India involved inspiration ('yes, things could be different; yes'; 'we can make a difference'), delegitimation (shaming the politicians) as well as mass refusal.

Likewise we can see in the TAC case the power of delegitimation, mass refusal and inspiration; treatment literacy education has been fundamental to TAC's work in popular mobilisation: practising differently. The levers of power being exercised through UAEM include education linked to solidarity; education which activates solidarity. WHO Watch likewise seeks to effect change through new alliances (deepened through education and access to information) and popular mobilisation (informed through new channels of information flow).

In this reflection we have focused on inspiration, delegitimation, mass refusal and practising differently as the levers of power, the drivers of change. However, these cases are far more complex than can be captured by such abstract terms and closer study will reveal more complex dynamics. However, the main point of this section has been to elaborate the

principle of learning from case studies of activism; learning through inquiring about the dynamics of change, activist strategies and levers of power.

The logic of the social movement and role of the activist

Social movement activism is predicated upon a set of assumptions about how social change takes place (see Chapter 11) and how political activism can drive social change (see Chapter 12).

In any particular case the activist draws upon an eclectic set of insights about what is happening ('partial stories') and a set of assumptions about the kinds of strategies which might drive change in this particular situation.

The narrative which integrates these partial stories into a sequence of activities is based fundamentally on prior experience informed by theory, judgement; it is mediated through body knowledge (gut feelings) and through rational logic.

This narrative is created in dialogue among comrades; creating a shared story together through the sharing of different perceptions of the situation and options; bringing together different experiences, different ways of seeking the world and different theoretical resources; in a trusting relationship.

Activist practice is based on theories of social change. Not always articulated. One of the benefits of articulating our theories of social change is that we can criticise and develop them and perhaps practise more effectively.

Sustainability

What keeps us going as activists? The sustainers include inspiration, comradeship, solidarity and ethical commitment.

Inspiration can be a response to leadership: 'I could do that'; 'we could do that'. Inspiration is sustained by insightful analyses and feasible strategies including the principles of 'thinking globally, acting locally' and 'the personal is political' which are themselves inspiring when applied insightfully to the specific circumstances.

Activists need to have a sense of accessing the levers of change but commonly the drivers of change only respond to mass pressure. For this reason the activist needs to have a sense of collectivity, of solidarity, of trust. They need to have a sense of trust that they are part of a collectivity which is struggling in the same broad direction. Comradeship including trust, communication and respect, is necessary but not sufficient. Comradeship without strategy will fall apart.

Solidarity, as a source of sustenance arises in the activists' relationship with the people who carry the heaviest burden. A relation of solidarity in this context is a relationship of brothers and sisters. Not pity, charity, duty, productivity or security. Out of solidarity comes a sense that the project I am working on matters to people whom I care about. But while solidarity is necessary it is not sufficient. Solidarity without strategy leads to depression, withdrawal and betrayal.

An ethical commitment is a central component of the activist spine; central but not sufficient. Ethics is the practice of consciously and collectively shaping the people and the

culture that we are becoming. It involves collectively deploying rituals, symbols and icons which are grander, more lasting and more perfect than the pleasures and pains (and seductions) of everyday lives. It involves building the significance of those rituals, symbols and icons so that they can provide guidance to us beyond the fears and inducements of everyday life. However, ethics without strategy, solidarity and comradeship is dry and brittle.

Working beyond role boundaries

Many activists who come from established health professions or from established institutions find it hard to remove the blinkers of professional or institutional socialisation. The customary roles that constitute the institutions of health care, of academia and of government are conservative (in the sense that they reproduce established ways of working) and delegate power to the professional (in the sense that the authority of the profession or the institution is delegated to the role).

To see the world through other people's eyes involves deep listening; being with the other; building relationships of solidarity with the other. But seeing things differently is not enough. The activist needs to work beyond the role boundaries; to form judgements according to different criteria; to practise differently. These all involve ethical choices, individual and collective choices; collectively building the rituals, symbols and icons which will sustain us.

Elements of activist practice

There are many different forms of activism, depending on context and purpose. In this section I present an analysis of the core elements of activism as part of assembling the language that we need to speak about our practice.

Some might argue that the idea of activism is so fluid and so dynamic that there is no purpose to be served in analysing it as a general form of practice. On the other hand analysis can give us a richer library of terms and concepts with which to both describe, critique and improve our practice, recognising context. Activist practice lies at the heart of the people's health movement and there is always scope for improving our practice; there is always scope for improving the ways newcomers to the movement are introduced to the work of PHM.

I shall characterise health activism in terms of: principles, forms of action and core skills.

Principles of activism

The principles of activism include:

- Channelling our passion (distress, anger);
- Shaping who we are becoming, individually and collectively;
- Reflexivity; watching ourselves practice, questioning how and why, exploring new directions;
- Tracing the causes of the causes;
- Sketching scenarios of change;
- Maintaining a broad repertoire of forms of action;
- Working on the issues that matter;
- Working with communities;

- Working across difference;
- Communicating effectively (includes deep listening);
- Working intersectorally;
- Living the personal as political;
- Bridging the local and the global (micro and macro; immediate and longer term);
- Building the movement.

Forms of action

Forms of action include:

- Information strategies, including research, through which the forces for change may be emboldened and the dominant ideologies delegitimized;
- Cultural action which throws new light on the familiar and helps to articulate alternatives;
- Networking and dialogue leading to stronger alliances and more coherent action; for example, alliances between the health movement and the environment movement;
- Community engagement, such as right to health initiatives, through which people and communities gain new confidence in their power to change, while addressing priority issues; campaigns, demonstrations, write-ins etc;
- Policy critique and advocacy;
- Service development reforms, creating health systems that address the structural determinants of health as well as the biomedical;
- Institutional reform, creating institutions that are accountable and responsive and which clear the path for progressive change;
- Personal behaviour change (eg away from patriarchy, away from materialism); changes which are both individual and collective; intentional and cultural; personal and political;
- Movement building.

Skills of activist practice

The skills and knowledges upon which health activism is based include areas which are more or less health specific (covered in some degree by the rest of this book) and areas which are more or less generic to the practice of activism. This latter group includes:

- working in groups
- working with communities
- conscientisation and popular education
- practical skills in organising
- meetings process and governance protocols
- financial management
- using modern information and communications technology
- learning and sharing
- research and evaluation.

Working in groups

We spend a lot of our time working in groups. There are some common principles about making groups work well as well as some common problems. It is useful to have the language to speak about group processes (facilitation, group dynamics, active listening, I statements, etc). There are numerous useful resources on line[4].

Working with communities

The social movement strategy depends on people power as a force for change; in particular the empowerment of the communities who have most to gain from a fairer society. There is a rich literature about working with communities, whether this refers to communities of locality, of culture or of special interest. However, much of this is written for different players who see themselves as 'working with communities', including bureaucrats, politicians and professionals.

We are talking here about health activists working with communities. Some activists are working in their own communities; others are coming in from outside. There are important differences although much of what is written does apply to activists from inside and those from outside.

Trust is fundamental; building relationships and working towards partnerships. How to manage the overlapping interests and perspectives which characterise the relationship between the activist and various different sections of 'the community'? The Australian Aboriginal activist Lillah Watson is credited with saying, *'If you have come to help me, you are wasting your time. If you have come because your liberation is bound up with mine, then let us work together'*.

When the activist is seen as 'coming in from outside' he/she has uncertain standing. What does he know about our lives? What is his/her agenda? Who are you to tell me how I should live? Be wary of assuming you know the right answers. Be wary of thinking of yourself as 'only here to help', as if you have no agenda of your own. Trust can be built even if the activists and their various partners in the community may have different interests and perspectives. 'I know you have different interests and perspectives but I understand where you are coming from; I can work with you.'

The term 'empowerment', widely used in this context, needs to be treated cautiously, particularly where it is used as a verb, 'I empower you'. Empowerment, can be used more safely to describe a social process whereby communities gain access to material resources; gain access to information; break free of assumptions which naturalise oppression and exclusion; build stronger and more meaningful relationships (Benn 1981).

Let us assume that the activist has technical knowledge that might inform an engagement over health care or the conditions for health. But how might such knowledge be applied in *this* community, given its history, culture, stories, divisions, alliances, experiences? Activists can contribute to such 'empowerment' but only through a partnership approach. Fundamentally, the agency, including judgement and drive, must arise within the community.

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4. See for example: http://www.thechangeagency.org/01_cms/details.asp?ID=58

The story of the Green Area of Morro da Policia[5] (Giugliani, Nascimento et al. 2011) provides a very nice illustration of this.

Conscientisation and Popular Education

'Educating the community' arises commonly among the strategies of social movements, including the people's health movement. However, it needs some caution. How to offer new information and skills in ways which enable communities to appropriate and integrate such knowledges into their culture and practice? How to offer new knowledge in ways which respect the norms and values which give the community its identity and dignity? How to teach people that they 'have a right' to a better society?

Paolo Freire's approach to 'the pedagogy of the oppressed' (1971) has inspired and guided activists over several generations in the practice of popular education. Freire was working in the field of adult literacy but insisted on locating the learning of literacy within the wider context of oppression and exclusion. Freire's approach brings together several important principles:

- literacy must provide words and ideas which make sense of the real struggles of daily existence and which expand the range of possibilities in those struggles;
- much of the 'learning' in adult literacy actually involves bringing into discursive form knowledge which is embodied but inchoate; finding (creating) a language which allows this knowledge to be spoken;
- what can be seen and what can be said reflect the prevailing institutions, norms and and power relations; learning to speak differently requires seeing differently and actively reshaping the institutions which shape our lives.

Freire's concept of conscientization involves questioning, researching our reality, finding the words to describe what we find. Far from the teacher filling an empty vessel it involves a dialogue between collaborating learners.

Visit The Change Agency for wide range of activist resources, including activist education[6] and further links.

Practical skills in organising

This chapter is not a manual in practical organising but there are many excellent resources on line[7]. Important issues for attention include: strategic planning, project planning and project management (budgets, timelines, resources, funding) and evaluation.

Meetings

This chapter is not a manual for the conduct of meetings but there are excellent resources on line[8]. Important issues for attention include: structuring the agenda; facilitating discussion; writing the minutes; and follow up. Ensuring that meetings are inclusive, enjoyable and efficient is a cultural issue for everyone; not just for the chairperson/facilitator.

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5. http://www.who.int/sdhconference/resources/draft_background_paper24_brazil.pdf
6. http://www.thechangeagency.org/01_cms/details.asp?ID=36
7. See for example: http://resourcesforsocialchange.org/index.php/publications
8. See for example: http://web.undp.org/comtoolkit/inside-undp/inside-core-concepts-meeting.shtml

Governance

This chapter is not a manual for the governance of voluntary organisations but there are excellent resources on line[9]. Important issues include:

- clarity of mandate
- clarity of constituency
- accountability of governing bodies and office bearers to constituency
- compliance with relevant laws and codes
- effectiveness
- probity (including conflict of interest)

Financial management

This chapter is not a manual for financial management practice in voluntary organisations but there are excellent resources on line[10]. Important issues include: budgeting, accounting, management of cash and bank accounts, accountability, audit and fund raising.

Getting the most out of modern ICT

There are huge productivity gains to be made from the discerning use of modern information and communications technology (ICT). Sometimes it is hard to steer a middle course between technophobia and technophilic indulgence. See the IPHU ICT page[11] as a starting place.

Learning and sharing

Learning from practice is a step towards greater effectiveness. This applies to the individual activist, taking such learning opportunities as arise, and to the organisations which are part of the movement, creating learning opportunities. These kinds of learning opportunities may include:

- sharing our own experiences (problems, causes, strategies, practices, outcomes);
- hearing and reading about other comparable experiences (problems, causes, strategies, practices, outcomes);
- accessing new knowledges, research results, theories, forms of practice, perspectives;
- practice in explaining (problems and barriers); practice in predicting (scenario sketching);
- cultivating mentor relationships;
- debating different understandings, interpretations and strategies; and
- sharing visions, stories and friendships which inspire.

Cognitive knowing and embodied knowing

In thinking about learning in practice it is useful to think about the relationships between cognitive knowing and embodied (tacit) knowing. Theories or principles which are only known cognitively can be regurgitated but not necessarily built into the logic of our

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9. See for example: http://governancecode.ie/code.php
10. See for example: http://www.mango.org.uk/Guide
11. http://www.iphu.org/en/ict

practice. In many situations we act on our embodied understandings and only later are we able to articulate a clear rationale for our actions. The process of integrating new cognitive knowledge into our embodied knowing involves discourse in practice; a cycle of deliberately practising differently, then reflecting and reconsidering, and then further practising differently.

The reverse is also important. Often the knowledge is already there; the challenge is to bring tacit, embodied knowledge into discursive form. This can involve acquiring new languages in which we can voice our experience; it may involve reflecting together on passages of practice and finding the words to share the logic of our practice. Only in discursive form can we collectively reflect upon our experience and collectively explore different ways of being, of practising.

Organisational learning

The idea of organisational learning is also useful for social movement organisations. It provides a framework for thinking about how well we have built evaluation, reflection and redirection into our routines; especially as regards the core functions which are critical to our effectiveness. If a PHM country circle were to articulate its main objectives, and the core functions which need to be carried out to achieve those objectives, then it might be useful to ask, 'how well are we monitoring how well we carry out those core functions and how well do we adjust and redirect on the basis of such evaluation and reflection?'.

Research

Having a research orientation can an important asset in social movement organisations. The treatment literacy focus of the South African Treatment Action Campaign depends very heavily on following current research very closely, including criticising methodology where appropriate and highlighting the policy implications.

In addition to monitoring and accessing published research there is often value to be gained from researching our own practice:

- What am I trying to achieve? Why?
  - how do I review and reflect upon where I put my efforts?
- What strategies am I using? Why?
  - how to I review and reflect upon my strategies?
- Can I improve my practice? How?
  - how can I see what I am doing and see if I could do it better?

The disciplines of participatory action research can be very helpful in systematically reflecting on our practice, collecting and analysing data about our context, our strategies, our practice, developing new forms of action and then recommencing the cycle. The 'participatory' element in participatory action research is commonly interpreted as the participation of the practitioners in researching their own practice. Wadsworth (1984; 1991) argues that it should also refer to the participation of those whom our practice is supposed to be benefitting.

Annex. A note on engaging with policy

Government officials, both elected and appointed, are subject to lots of pressures and enticements. In neoliberal globalised capitalism the corporate sector is engaging with government the whole time, not just in the lead up to elections. Through campaign donations, mainstream media commentary, public relations, foreign pressure and a myriad of other mechanisms the corporate sector exercises its voice at the table. Elections can be a useful tool of accountability but they are a very imperfect way of formulating plans and building consensus around policy directions and steering implementation.

The work of the social movement activist often involves advocacy around government policy and implementation. This will usually involve policy analysis as well popular mobilisation. Some core principles for such engagement include:

- vision matters;
- be prepared;
- be creative; and
- cultivate a fertile policy environment.

In addition I shall comment briefly on the skills of policy analysis and policy development.

Vision matters

Health system development takes place through episodes of change dispersed across time, sector, level and region. *Ad hoc* decisions in different sectors and levels which bear no relation to each other are a recipe for policy incoherence. Social movements can promote coherence across these different sites and times of decision making because advocacy in these different sectors, regions and levels is referenced to the same overarching vision.

Generations of health activists have prized the Alma-Ata Declaration for the vision which it projects including the broad principles which need to be realised in a decent health system. Primary health care is a strategy of social change as well as a framework for health system strengthening and this is makes sense; the struggle for health care is part of the struggle for a decent society, a decent world.

Readiness (be prepared!)

Society is complex and the unfolding of institutional development is always unpredictable. The metaphor of 'windows of opportunity' points to the need for readiness. Readiness involves:

- being prepared with practical policy options;
- building a constituency of support for policy advocacy; and
- addressing a plurality of targets (different sectors, levels, regions, etc).

Being prepared with practical policy options can sometimes mean having well formed policy options fully documented but not necessarily. More importantly it means that there has been a rich conversation about what to do about particular problems with quite specific options being discussed. This conversation has ranged widely across the different sectors, levels of administration and regions where policy responsibilities are different and different policy strategies have been discussed. Across these different discussions there has been a

continuing celebration of the vision which guides policy making with active involvement of those communities who have most to gain from a more equitable and effective health system.

Be sceptical; be creative

The power and risk of generalising are that it foregrounds that which is common and backgrounds that which is unique. Health systems and the countries (cultures, institutions) in which they operate are unique.

Beware one size fits all solutions. Appreciate history. Consider how national culture affects health care delivery. Consider how the design principles articulated in the orthodoxy of health systems science might be realised in the unique institutions inherited from the past.

Respect for contingency does not mean that the models operating in other countries are irrelevant. Rather, we may need to derive general principles from those models before we can start to explore how such principles might be realised in our own unique circumstances. This sometimes calls for a high level of creativity; identifying the general principles perceived to underpin foreign models, and exploring how those general principles operating in quite different settings, might be realised in our own unique domestic circumstances.

Create a fertile policy environment

Institutional reform takes place unevenly; long periods of stasis; short periods of reform. This does not mean that activists do nothing while they are anticipating windows of opportunity. There is much work to be done in terms of unfreezing prevailing institutional relations, creating windows of opportunity, and in being prepared for them when they occur. Some of the key tasks during this period include:

- policy analysis (critically analyse the policy options on offer) and policy; development (developing new policy options and implementation strategies);
- build a constituency for change (work with the people who have most to gain; work with the practitioners who care about their communities);
- support a deep, sustained, inclusive policy conversation (build policy capacity; cultivate policy research);
- develop leadership (leaders who have the record and the standing to guide the movement forward in times of uncertainty);
- build consensus around a long term vision for health care;
- defend the basic freedoms necessary for civil society participation in policy making and monitoring (freedom of association and freedom of speech in particular); and
- demand integrity, accountability and transparency in the structures and processes of governance.

Policy skills

Policy analysis

Policy analysis sounds complex and technical but in essence it involves looking at the policies on offer from three perspectives: technical, political, and personal.

The technical analysis involves tracing the rational narrative underpinning the policies on offer. How have the problems been defined (what values, what boundaries)? What are the causes which are assumed? What options have been considered and what criteria were used to evaluate them? In each case we need to ask about facts, values, evidence and logic.

Then we put aside this technical analysis and explore the politics of the policy. Why is this policy before us at this time? Who is pushing for and who against? Who would be the winners and losers?

Finally we need to examine our own personal relationship with this policy. What prejudices, aspirations and ideologies do we bring to our analysis of this policy? If our analysis is to be sharp and our options practicable we need to be brutally realistic, in particular, sharply critical of the motes in our own eyes.

We need to iterate through these three perspectives repeatedly as we review the facts and logic; unveil the pressures and politics; and confront our own hopes and fears. Initially we may find contradictions between the conclusions of each phase of analysis. We may find that technically, the policy seems quite sensible, but since it is coming from people we do not trust we assume that it is flawed. Maybe we need to reflect on our own prejudices. We may find that technically the policy seems flawed but since it is coming from people we trust we are disposed to supporting it. Maybe we need to work more closely with the people we trust to ensure that their technical work is up to standard. When we come to a judgement which is consistent across all three phases of analysis we may be able to have more confidence in such a judgement.

Policy development

There are three builds and three tasks required for policy development. The three builds are:

- build the argument (the logical, rational narrative; from problem through to preferred options);
- build the constituency of support which will be needed to drive the policy through adoption and implementation; and
- build capacity so that we will be better placed for decision making and for implementation next time around (research, organisational development, training, etc).

The three tasks of policy development are:

- research,
- draft, and
- consult.

Policy development involves many iterations of this 'research, draft, consult' cycle. Research is necessary to understand the problems, to consider and evaluate options and to assess the political environment in which constituency building will be based. Drafting and redrafting allows us to examine and re-examine the logic of the narrative; to identify areas where more research is needed; and to reflect on the likely responses of different stakeholders. (Strategically planned) consultation helps to strengthen the evidence base and logic of the policy narrative; helps to build constituency and helps to identify the risks

regarding to policy adoption and implementation. While exposing your plans to your opponents can have risks, in terms of inviting them to prepare opposing arguments and strategies, their criticisms can also be invaluable in terms of helping to identify weak links in our policy narrative. Opponents are often willing to read policy drafts much more critically than our supporters.

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