

CIVIL SOCIETY ORGANISATIONS AND THE POOR: THE UNFULFILLED EXPECTATIONS

Wim Van Lerberghe
Institute for Tropical Medicine, Antwerp, Belgium

Paulo Ferrinho
Associação para o Desenvolvimento e Cooperação Garcia de Orta (Garcia
de Orta Development and Cooperation Association), Portugal

December 2002

TABLE OF CONTENTS

Introduction	2
On the uses of civil society organisations	4
<i>A good reputation</i>	4
<i>Allies of the poor?</i>	5
health professionals, regulation and civil society	8
<i>Professional self-regulation</i>	8
<i>Bureaucratic regulation</i>	9
<i>Patient involvement: choice and voice?</i>	9
<i>Beyond client choice and voice: pressure from civil society</i>	10
Empowering patients and consumers	12
<i>Helping users know what they are entitled to</i>	12
<i>Helping users choose good providers</i>	13
<i>Helping users handle complaints</i>	13
<i>Helping patients to help themselves</i>	14
Mutual support systems and cooperatives	16
<i>Mutual support for paying for care</i>	16
<i>Co-operatives</i>	17
Civil society organisations as watchdogs	19
Policy influence	21
<i>Putting the interests of forgotten groups on the agenda</i>	21
<i>Informing decision makers and get involved in difficult decisions</i>	21
Priority setting	22
Rationing	23
<i>Pro-poor advocacy</i>	25
State support for CSO?	27
Conclusions	29
References	32

INTRODUCTION

During the last decade incidents of medical neglect have become front-page news in many countries, also, and this is a new development, in developing and middle-income countries¹. Sometimes the scandal is about rationing, as in the case of “Child B” in the UK.² Child B had terminal stage leukemia, and the medical authorities had refused to pay for an experimental chemotherapy and bone marrow transplantation in a private clinic. The father took the case to court, resulting in an emotional and highly politicized debate in the media – and an extensive discussion of rationing in the medical press. Most often, though, newspapers address questions of mismanagement or corruption, of professional incompetence failing regulation and conflicts of interest between providers and the public^{3,4,5,6,7,8}. A typical case is that of the Bristol doctors, two pediatric surgeons who continued to perform open-heart operations even though their case fatality rates were exceptionally high.⁹ The health authorities failed to react until the media picked it up; the doctors were barred after a highly publicized trial. According to the British Medical Journal, this case did more for the future shape of health services than all the reforms suggested in the white papers.¹⁰ Similar headline situations are now occurring also in middle-income countries, such as in Thailand.

The public, the media and the politicians focus on sensational critical incidents: rationing, ‘adverse events’ through medical error or negligence and professional misconduct. At a more fundamental level, however, all this has to do with problems of self-regulation versus the public interest¹¹. The traditional model where doctors regulate their activities themselves is showing signs of strain. The user, the health care ‘consumer’ is becoming increasingly vocal, and trust in the health care system is eroding.^{12,13}

These voices of discontent and mistrust show that civil society de facto plays a role in the way the health care system operates: it is emerging as a major and vocal player in the health field. For all the long-standing lip service and official endorsements of participation^{14,15,16}, the current situation in most health systems, even the most advanced, still reflects a serious democratic deficit¹⁷, with resistance to greater civil society involvement in health issues and health care^{18,19}. On balance, though, civil society involvement in health issues is openly encouraged^{20,21,22,23}. There is a mixture of vast – and at times overly optimistic – expectations, and a large amount of hidden mistrust and skepticism.

This paper reviews the ways civil society intervenes in the field of health. There is a wealth of literature on the subject, but the vast majority consists of papers expressing opinions, and actual

documentation of what “civil society” – a notion that has as many meanings as there are authors²⁴ – actually does or can do is scarce. It is high time to start underpinning opinions with empirical evidence. This paper is an attempt at bringing some systematic in the way one can describe what civil society organizations (CSO) can do to improve the way the overall health care system functions, and particularly, what they can do to make health services serve the poor more effectively and to make sure the needs of the poor are satisfied and their rights respected.

If one makes abstraction of the actual provision of health care by CSO – which we shall briefly touch on again later in the text – one can look at what CSO contribute by focusing on how they interfere – or do not interfere – with the way health care providers operate, be they public, private-for-profit or private-not-for-profit. There are two classical models to talk about regulation of health professionals: professional self-regulation and regulation by the State. We propose to consider Civil Society and its organizations as a third regulatory power that shapes the way health care providers interact with their clients and communities.

After a summary of common knowledge about the benefits CSOs can bring to health care systems and their role as allies of the poor, the paper reviews the ways in which health care providers are traditionally regulated, and the place of civil society in this context. The paper then reviews five potential roles of CSOs (excluding that as service provider, but including the cooperative trend). It ends with some comments on the potential for state support to the development of civil society organizations. The paper merely touches upon two better known areas: that of the involvement of civil society in health care delivery through private-not-for-profit health care organizations, and that of the position of civil society on the international health scene. The focus is on the potential contribution of civil society to what happens in health care delivery at a local or national level.

ON THE USES OF CIVIL SOCIETY ORGANISATIONS

Traditionally, the few attempts to measure civil society involvement in a quantifiable manner have been concerned with progression towards process related objectives (leadership, needs assessment, management, organization, resource mobilization, quality²⁵) rather than with its usefulness in terms of outputs and or outcomes. Still, there is some documentation on contributions resulting from the involvement of civil society in the health arena.

A good reputation

There are numerous examples of the usefulness of civil society involvement in building up of a pool of knowledge about the community and its wants, needs and demands (community diagnosis). One may speculate that this represents the beginning of systems of knowledge management, useful for service development and for ensuring greater professional accountability. It favors a communication and mutual learning. This has been well illustrated by Salber²⁶ through a number of case histories. Bellin and Geiger²⁷ reflect that the advent of a health center, open to community active participation and trying to meet the situational needs (time, cost, convenience) of the health consumers, contributes to a better social integration; the result of this integration is a change in attitudes concerning preventive and promotive care, informed dissatisfaction with inappropriate low standards, and demands for change to meet the newly perceived needs, independent of any formal educational efforts. Consultative decision making processes, and participatory intervention methodologies in CSO interventions are reported to have integrated community knowledge, evidence, views and values and enhanced community involvement in health systems and health policy²⁸. Local CSOs were observed to bridge western and indigenous knowledge in health, with positive impacts on health seeking behavior²⁹. They have been shown to influence the character of the work of the health services, reorienting them to better meet the demands and needs of the community and of the poor.

Although this fall outside the subject of this paper, one cannot overlook the fact that non-for-profit CSOs play a major role in delivery of care. CSOs may act as direct service providers, either in co-operation with the state, contracted by the state, or in areas where the state has ceased to operate. CSO may provide promotive, preventive, curative and rehabilitative health services^{30,31,32,33,34}. They have emerged as major service providers in Africa. With the notable exception of China, CSO play an important role in health care in general: for example, they provide more than 10% of clinical services in India and Indonesia, and are very important in

Africa. The religious sector has also been very active in developing CSO for health care provision^{35,36,37,38}.

Beyond the actual service delivery they may bring in extra elements by extending service outreach within communities or areas of health delivery not well covered by the state or private-for-profit sector³⁹, testing new approaches in national health strategies⁴⁰ and enhancing the speed and effectiveness of primary health care services reform through greater flexibility, autonomy, and responsiveness⁴¹; greater inter-sectoral co-ordination and, consequently, more efficient use of community and other supporting resources; showing that efficiency gains are possible, compared to public or private-for-profit curative, preventive and ambulatory health services⁴².

There have been instances in which the impact of Civil Society Organizations has at least been tentatively documented: improvements in school attendance levels, literacy, immunization, increased use of oral rehydration solution, reduced child malnutrition rates and mortality rates⁴³, improved HIV/AIDS interventions, health services access and environmental health⁴⁴; reduction of maternal mortality, even in areas where specialist referral care is not available, better visibility to women's health issues⁴⁵, better use of existing maternity services in low income women⁴⁶ and increased women's control over reproductive health choices⁴⁷.

Allies of the poor?

However fragmentary the evidence may be, there is clearly a potential for positive contributions, even if it is extremely likely that there is a publication bias favoring positive assessments of the impact of CSOs in health. One should note that not all reports provide positive information on CSO when it comes to pro-poor impacts. CSO coverage of poor communities is patchy, and CSO services have neither resolved the bias against access in the poor nor been more effective in coverage and equity than state services: In Tanzania and Zambia, benefit incidence analysis indicates that the economic level of people served through the non-governmental health sector is higher than that of patients in government facilities⁴⁸.

If poor communities are more susceptible to the successes or failures of health actions, then they have an invested interest in ensuring that valid evidence of their situation reaches policy attention. CSO have played an important role in bridging between researchers-communities-providers-policy makers and, more importantly, in bringing community participation into research, to ensure that evidence judged valid by the poor is brought into policy advocacy^{49,50,51}.

Fuglesang reports on CSO involving youth from poor communities gathering evidence to support advocacy on HIV/AIDS⁵². In the Philippines, CSO took specific measures to enhance the capacity of communities in informal settlements to present evidence and issues to city

governments⁵³. Through informing and organizing communities and by providing services that respond to community values and cultural norms CSO may also help ameliorate the situation of the poor^{54,55,56}. CSO are also less restricted to sectoral boundaries than state bureaucracies. This makes them more responsive to the wider range of employment, production, credit, environment and service inputs needed by poor communities^{57,58}.

But not all that is being done by CSOs is successful. CSO may have internal weaknesses that preclude pro-poor work: inadequate capacities, complex internal politics, unclear legal status, unstable funding, donor dependency, weak mechanisms for monitoring and insufficient clout to ensure adequate scaling up of local experiences^{59,60,61,62}. The leadership of CSO are too often dominated by men and higher income groups, who act to secure their own self-interest and may be unwilling to confront state or funders in the interests of poor people⁶³. These endogenous weaknesses may result in poorly designed inputs that do not ensure the desired improvements for the poor⁶⁴. They may also be reflected in a gap between the rhetoric and reality of substantive mechanisms for participation of vulnerable groups, or in the inadequate impact of such participation^{65,66,67,68}.

Not all the obstacles confronting pro-poor CSO interventions are internal⁶⁹. CSO working towards health equity meet resistance from corporate or state interests, while poorly designed state systems limit their effectiveness in reaching the poor^{70,71,72}. Hence, for example, state health financing tools that should impact on health equity may not reach CSO serving poor communities or protect the poor from the burden of fees. State subsidies to private providers have been found, for example, to be inadequately taken up by CSO serving the poorest communities due to weak demand from these communities, weak management capacities in the CSO that service them and flaws in the design of the subsidies^{73,74}. These problems cannot be solved simply by adjusting the subsidy allocations – it also calls for measures to address other barriers in poor people's use of health services⁷⁵. Analysis of equity impacts of community financing in Benin, Kenya and Zambia found that financing schemes in all countries failed to protect the poorest from the burden of payment for health care. This was traced in part to failures in ensuring that the views of poor communities were heard in decision-making, as a result of the absence of local decision-making structures with representation from civil society groups able to voice the needs of the poorest⁷⁶.

Box 1. Civil Society on the international scene

Globalization has resulted in the emergence of new health policy issues. These new challenges are not exclusively economic or technical. They include, for example, new global information networks that facilitated the growth of a shared human rights framework⁷⁷. This complex environment often weakens the political and practical capacities of national governments to address health risks that arise from within and beyond national boundaries. As a result the focus on the role in and impact on health governance of intergovernmental institutions, transnational business and international CSO has been subjected to renewed attention^{78,79}. There has been increased demand on the UN from CSO for information, access and participation in global policy

issues related to health, such as drug prices and access, the negotiation and implementation of the Framework Convention on Tobacco Control^{80,81,82,83}, patient rights, promotion of breastfeeding and control of infant formula⁸⁴, rights of people with HIV/AIDS, and primary health care, women's health, ethical standards in humanitarian relief and food quality and safety^{85,86,87}.

CSOs have intervened in global health policy in a number of ways. They have provided legitimacy for previously ill-accepted policy options, and mobilized constituencies, resources and actions. CSOs have provided technical expertise to policy development and made processes more publicly accountable through widening public information flow^{88,89,90}. CSO with service provision roles have formed useful intermediaries for wider policy alliances as was the case in the campaigns on vaccination or the International Convention to Ban Landmines^{91,92,93,94,95,96}.

The issues attracting CSO attention - baby foods, pharmaceuticals, tobacco, landmines - are usually health policy issues that derive from corporate practice. CSO intervention focused on balancing corporate interests in policy making in order to make both business and government accountable, particularly as market reforms have made governments less willing to confront big business, or more vulnerable to business pressures, and on strengthening developing country coalitions calling for public health measures, such as the African states lobby on the Framework Convention on Tobacco Control. These achievements spilled into calls for CSO involvement in WHO policy development on its relations with the private sector, and in monitoring and evaluating WHO work with commercial enterprises⁹⁷. HAI, Save the Children Fund, AFRICASO and Oxfam have also intervened around intergovernmental institutions or public-private partnerships, such as the Global Health Fund, seeking involvement of CSO in decision making and raising policy concerns that the fund should not divert attention from more substantive policy issues of drug pricing and health service infrastructures^{98,99,100}.

Beyond policy intervention around corporate and market forces in health, CSO have also intervened in policy on health systems, particularly around the negative impacts of market reforms and in support of primary health care and of equity in health and state health services. CSO have lobbied for the rights of communities with specific health needs, including people with disability and people living with HIV/AIDS. CSO information outreach, research, advocacy and legal action at both national and global level have given visibility to the experience of vulnerable groups and raised important ethical and equity issues around services for such groups^{101,102}. Therefore, the contributions of CSO to global health policy processes include evidence, information exchange, technical expertise, public lobbies and resources. This has generally contributed to positive outcomes and enhanced the public accountability of policy processes. Documented CSO influence is largely exerted through advocacy coalitions, supported by information access and exchange, particularly involving the internet.

HEALTH PROFESSIONALS, REGULATION AND CIVIL SOCIETY

If one makes abstraction of the actual provision of health care by CSO – which we shall briefly touch on again later in the text – one can look at what CSO contribute by focusing on how they interfere – or do not interfere – with the way health care providers operate, be they public, private-for-profit or private-not-for-profit. There are two classical models to talk about regulation of health professionals: professional self-regulation and regulation by the State. We propose to consider Civil Society and its organizations as a third regulatory power that shapes the way health care providers interact with their clients and communities. This goes beyond the analysis of how clients shape provision by exertion of their power of choice and voice.

Professional self-regulation

The traditional model where professionals regulate their activities themselves is showing signs of strain. The health care consumer is becoming increasingly vocal and distrustful of the health care system¹⁰³. The phenomenon is also attracting the attention of the professional world: the number of Medline-articles with keyword ‘trust’ went from 155 in 1990 to 1093 in 1995; from 1997 onwards the average is 2000-2500. But, even now, if questioned, health professionals will tell to leave it to them. *“It is a matter of professional ethics, we can regulate that among our members; after all, we have a reputation to maintain.”* Self-regulation can be effective. Many health professionals are good and honest people. But not all of them are, and all have to look after their own interests as well. The way young doctors, for example, balance their own interests and those of their patients, depends to a large extent on what is considered ‘good professional behavior’ by their teachers and peers. Professional organizations, although in practice they merely look after corporatist self-interests, can also promote professional ethics and positive role models, sanction inappropriate behavior or maintain the technical competence of their members.

For example, the Scientific Association of Flemish General Practitioners in Belgium has been crucial in changing what the average doctor considers ‘good professional behavior’ for the better. In Zimbabwe the (non-governmental) nurses associations play an essential role in maintaining professional ethics and standards among public and private nurses. In Thailand the Rural Doctors Association has had an important similar role in recent years and shaped the commitment – and the presence – of doctors in rural and under-served areas¹⁰⁴. The whole ‘evidence-based medicine’ movement is an example of positive and effective self-regulation, even if it is by no means generally accepted by all professionals¹⁰⁵.

Appeals to honesty goodness, and social control among doctors are no doubt important. In many countries, especially those where health care is provided by the government, the potential of professional organizations and opinion makers among doctors has not been fully exploited as a positive force, and a lot more can be done. Still, economists (and Ministries of Health) would say it is naive to think that self-regulation would be enough to solve all problems. To find a better power-balance between providers and consumers one needs more than that¹⁰⁶.

Bureaucratic regulation

If self-regulation is not satisfactory, one should expect the state health care bureaucracy to regulate the system, to make services accountable for performance and results. Obviously, the way health care is regulated will influence the power balance between provider and consumer and the extent to which providers can take advantage of the asymmetry of information: in a fee-for-service system the temptation to induce over-consumption of costly care is much bigger than in a capitation system. Governments can also protect consumers by trying to ensure that quality standards are respected, e.g. through accreditation. One of the main reasons for thinking in terms of purchaser-provider separation was to replace the reliance on implicit professional judgement with explicit decisions made by purchasers in the light of knowledge about the health care needs of their target populations. This separation, although contributing to greater transparency, in practice, has further eroded the capacity of civil society to participate effectively in the commissioning (rather than the delivery) of health services¹⁰⁷.

On the other hand, one should not underestimate the power of the professional lobbies to resist the bureaucrat's attempts to regulate them - in Belgium the medical lobby has proved strong enough to topple governments - nor the power of bureaucrats to resist the administrative culture of new public management that is necessary for effective regulation¹⁰⁸. Regulating the health sector is one of the important duties of government bureaucracies. But bureaucracies need to be pressurized to act. Even then their real power is limited. In the absence of resources, the existence of regulations is no guarantee that they will be effectively implemented and respected. To find a better power-balance between providers and consumers one needs more than that.

Patient involvement: choice and voice?

The role of patients in shaping the way providers function is often framed in terms of choice – people can vote with their feet – and voice – people can express their wishes and demands to the provider.

Medicine is not just a question of technique. It is also a question of providing guidance and emotional support to the patient, to help him or her decide what the best solution will be for him

or her to deal with his or her problem – taking his or her value system into account. This is not feasible if doctors think they know it all. Junior doctors learn from the role models of their seniors: depending on how their seniors behave, they will tend to be responsible case managers¹⁰⁹ or merely interested in the biomedical aspects of their task¹¹⁰.

There is currently much enthusiasm for a more patient-centered approach to health care, and the involvement of patients in the decisions about their treatment is widely advocated¹¹¹. To do that, doctors need to learn to listen to patients, and involve them in the decisions regarding their health. All too often, listening to patients is something that juniors have not learnt from their seniors, although it is a technique essential to good care. Listening is a technique that can be learnt, but learning the technique is not enough if the conflicts of interest are not addressed so as to achieve a reasonable balance between the user's interests and that of the provider.

If people are to participate in an informed way in the decisions about their treatment, they need information on the relevant options. A number of things can be done to help people communicate effectively with health professionals. These may affect compliance and sense of control, with consequent effects on well being and recovery; satisfaction with care; organization of services; and patterns of litigation¹¹². But the limited evidence suggests that individual consumers cannot usually rely on professional organizations and bureaucracies to help them. If one looks at the information provided by health care organizations themselves or by authorities, one sees that it rarely provides relevant information: most of it seems directed at making patients comply rather than at helping them choose the right service, provider or care.

Beyond client choice and voice: pressure from civil society

The erosion of trust in health care providers is compounded by the erosion of trust in the public system as guarantor of equity, honesty and integrity in the public interest. In other words, it is not enough for services to be responsive. We have to work with a still ill defined notion of “social accountability” of individual and institutional health care providers¹¹³.

But the current understanding, fed by the changing political environment in many developing countries and in the transition economies, by recent health services reforms, by the growing media attention to corruption and medical errors, by the growing professional literature on coping strategies and corruption, by the dilemmas about rationing and equity and by changing public attitudes to national health services and freedom of choice of providers demands a better understanding of the role civil society should play to ensure relevance, fairness, equity, efficiency and effectiveness of health care provision.

It is difficult for the individual consumer to always get the right kind of information at the right

time to be able to exert its powers of voice and choice¹¹⁴. Organized civil society: (consumer groups, user groups, press, advocacy groups, unions, etc.) is in a better position to do so. CSOs can exert pressure on providers, on professional organizations, and on health care bureaucracies to do five things: (i) to put individuals in a stronger position in their relationship with providers; (ii) to function as watchdog to detect things that go wrong; (iii) to assist with resource mobilization; (iv) to help to improve health care provision; and (v) to help reform health care policies.

But, what is civil society? How can its active participation in health care be ensured? What is the meaning of active participation? What is the evidence that active participation positively influences health outputs and outcomes?

EMPOWERING PATIENTS AND CONSUMERS

Health care consumers (and potential health care consumers) do not always have all the relevant information for proper choice and voice. They often do not know what is wrong, where to get help, what will help, what kind of help they can expect, and at what cost. To find that out on their own, as individuals, is hard, difficult and time-consuming work, even for the privileged ones with access to the Internet.

Individual consumers cannot rely on professional organizations and bureaucracies to help them: If one looks at the information provided by health care organizations themselves or by authorities, one sees that it rarely provides relevant information: most of it seems directed at making patients comply rather than at helping them choose the right service, provider or care. Moreover, one should not forget that bureaucracies and professional organizations are not neutral either: there are conflicts of interest there as well.

In this context CSOs can help individuals by empowering them: by helping them to get to know what they are entitled to expect, by helping them choose good providers and by helping them handle complaints. This is particularly important for those who belong to the most fragile and underprivileged groups in society.

Helping users know what they are entitled to

Users who know what their options are, are in a better position to decide what is best for them. Informing the public can be done through self-help organizations, help-lines, contact centers, Internet sites, magazines, etc. A more informed public is less likely to be taken advantage of.¹¹⁵ Information may change things. For example, in Switzerland, an information campaign among the public reduced hysterectomy rates by 26%, whereas it increased by 1% in control areas¹¹⁶. More informed patients may put doctors ill at ease, but they can participate better, and with more self-confidence, in decisions that concern them directly. CSO may have an important role informing the public about these issues.

CSOs can help to empower disadvantaged groups. For example, in societies where the balance of power and control over productive resources are highly skewed toward men, women may gain access from such processes as conscientization through gender awareness, economic change or mobilization for economic or psychological support¹¹⁷, organizing peer groups and mobilizing

community resources and public services¹¹⁸. Useful as this may be in itself, such efforts have a limited scope: they are hard to sustain in the absence of legal, social and economic measures¹¹⁹.

Helping users choose good providers

One can complain about the bad food in a restaurant, but to avoid the aggravation it is better to choose the restaurant with a guidebook, or ask friends, or have a look at the premises and at the menu. If one needs a doctor things are more difficult. Making the good choice may be more important, but we have less information to do so than for a restaurant. There is no medical equivalent to the 'good restaurant guide'. Only in recent years have health services recognized, and only in some countries, that information on where to get good quality care is important.

In most places however, when such information is being made available, it is not by health services themselves. The media, academics and consumer organizations are better placed to get the information and disclose it without conflicts of interest. In the USA the Health Care Financing Administration started publishing such information in 1987¹²⁰. There are now many different league tables, on the Web, with rankings of health care providers in function of different performance criteria¹²¹. One example is the Health Plan Employer Data and Information Set¹²². In the UK the National Health Service provides such information¹²³, in France the lay media¹²⁴ with rankings of HMOs and hospitals in function of different performance criteria.¹²⁵ One example is the *Health Plan Employer Data and Information Set*.¹²⁶ In the UK it is the NHS that provides such information,¹²⁷ and in France the lay media. In 1998 the French health care system reeled when a mass-media monthly published the list of the 50 best and the 50 worst places in the country to get a prostate operation, undergo cardiac surgery or deliver a baby¹²⁸: by now publication of such data has become a matter of a routine.

There is, however, no clear evidence that such information actually impacts on treatment preferences or the final decision on the care received¹²⁹. All the same, and contrary to expectations, consumers do not readily use such information. Information and education seem to be poorly effective means of influencing informed decision making, at least, not as influential as context and social pressures¹³⁰. But information, if adequately framed and presented, may influence consumer knowledge and the processes that lead to the decision. In a study in the WHO, for example, employers appeared to make little use of it for choosing health plans for their personnel. But it does shame providers into improving quality.¹³¹

Helping users handle complaints

One mechanism to deter health care providers from taking advantage of the situation of asymmetry of information that characterizes their interaction with patients is to make sure that

the latter can complain when something goes wrong.

CSOs have a central role in providing assistance to consumers to navigate through the difficult processes of litigation. They should, nevertheless, be aware that the problem with relying on complaints to protect the consumer is that it addresses only the top of the iceberg – gross clinical negligence or financial misconduct – and often comes too late. Litigation answers a justified and real desire for retribution. However, litigation is not an effective tool to deal with errors and accidents that are not caused by negligence. There is some evidence that litigation targets doctors that provide less quality care, or at least, doctors who are less proficient in communicating¹³². But its predictive value in targeting errors is particularly poor.¹³³ There are false positives, many false negatives and 97% of those suffering negligent injury do not sue; those who do are all from the better off social classes; the poor do not¹³⁴. Litigation overwhelmingly focuses on error by omission^{135,136,137,138,139}. Adverse events resulting from interventions, on the other hand, and certainly those due to excessive hospitalization or use of technology rarely lead to claims¹⁴⁰. The result of this focus on omission is defensive medicine, with ever more medical interventions – such as the increasing reliance on cesarean sections¹⁴¹ – and increased costs, as fear of litigation prompts providers to take out ever more expensive insurance policies, that are handed down to patients through increased fees. In the USA this adds 50 billion US\$ to the health-bill, without avoiding between 44 and 98,000 deaths from medical mistakes¹⁴². Litigation has little positive influence on the practice of doctors who are confronted with it¹⁴³, and does not always succeed in changing the behavior of institutions (e.g. failed preventing hospitals from medical dumping¹⁴⁴).

Individual consumers are quite helpless in these situations, and organizations of health professionals are not of much help either – the conflict of interest is too important, and in most countries misconduct is hardly ever sanctioned. The only way out to give complaint mechanisms an effective and reasonable role is to channel them through independent ombudsman structures or consumer organizations. That is what the federation of consumer associations started doing in Thailand around 2000, with its first provincial complaint offices. The European Union (EU) disseminates a consumer complaint form¹⁴⁵ designed to improve communication between consumers and professionals to help reach amicable solutions to problems they might encounter. This form is then channeled to consumer assistance organizations for action.

Helping patients to help themselves

In industrialized countries *self-help* is much more frequent than the use of professional services.¹⁴⁶ Each person can do much to care for his or her own health. Healthy life styles are the basis to prevent a significant proportion of the morbidity and mortality that is seen in many developed and developing countries. Breast-feeding has significant impacts in the well being and health of infants and mothers alike. In Denmark and the UK more than 90% of those visiting a general practitioner have already begun a self-prescribed treatment that is consistent with their

subsequent medical therapy¹⁴⁷. The greatest potential for self-care may actually be in developing countries, with little or no organized health care. An estimated 65-90% of those who fall ill in south and South-east Asia use herbal cures in conjunction with a visit to a traditional healer. Much of this care is worthless and even dangerous, but it should not be dismissed out of hand, and many countries and international organizations are exploring means of integrating effective traditional cures to complement professional medical care¹⁴⁸.

CSOs play a major role in tapping these resources. There are hundreds of self-help associations (of diabetics, handicapped, chronic diseases) even in small countries like Belgium or the Netherlands. The Patient Association in the UK, for example, publishes an Health Address book with the contacts of over 1,000 health support groups whose services include telephone advice, written advice, counseling, advocacy, leaflets, newsletters and books.¹⁴⁹ In the USA alone more than five million people belong to mutual help groups: Alcoholic Anonymous, Migraines Anonymous and Psychotics Anonymous. Some join to change unhealthy life-styles, other to find a supportive community that will help them cope with their problems, but all attempt to deal with their problem without resorting to formal medical care, although, not infrequently, these mutual help programs are initiated by health care providers themselves. Therefore, in developed countries, mutual help groups have varied from the very specific, such as Alcoholics Anonymous to the very broad, the mutual health insurance schemes. They do much more than just informing patients. They help people take charge of their own situation, improve their health, cope better with ill health, increase self-confidence and diminish medicalisation.¹⁵⁰

MUTUAL SUPPORT SYSTEMS AND COOPERATIVES

More important than self-help is the concept of support systems and mutual help. These are a natural extension of self-care and self-help. Support systems are defined as “*attachments among individuals or between individuals and groups that serve to improve adaptive competence in dealing with short term crises and life transitions as well as long-term challenges, stresses, and privations through (i) promoting emotional mastery, (ii) offering guidance regarding the field of relevant forces involved in expectable problems and methods of dealing with them, and (iii) providing feedback about an individual’s behavior that validates his or her conception of his or her own identity and fosters improved performance based on adequate self-evaluation. Mutuality is an important characteristic of support systems*”¹⁵¹.

Mutual support for paying for care

In a number of countries, including developing countries, CSO interventions may be linked to community traditions of mutual support. The most basic are family solidarity systems, based on an implicit moral obligation to help. Other systems include informal saving mechanisms, based on principles of balanced reciprocity, and illustrated by informal sea rescue organizations in Senegal or traditional rotating savings, *tontines* in French speaking Africa¹⁵² or the *abotas* in Guinea-Bissau¹⁵³.

The mutuality model of health insurance functions through self-established management structures, a relative autonomy in its management from state, political parties, employers and other pressure groups and the promotion of individual and collective autonomy¹⁵⁴. In Africa health mutuals are a recent development¹⁵⁵. They do frequently emerge in association with other social movement such as a village association, a trade union (the medical fund of Zimbabwe’s National Engineering Worker’s Union) or a women’s association (as it is the case of the women’s association in Kompienga, Burkina Faso, where a collective field is cultivated in order to finance health expenses of the members of the group and their families)¹⁵⁶. They are usually of small size and are not well documented. They may cover expenses such as outpatient care, drugs, transport to the hospital for emergencies and some of the hospital admission costs¹⁵⁷. The establishment of these mutuality associations may also strengthen the position of communities in their negotiations with other health care providers, including state and for-profit providers^{158,159,160,161}.

Co-operatives

Communities may go beyond mutual assistance for financing health care. A particularly important, and not much spoken of, sector of CSO are co-operatives. Co-operatives have a dual function: as voluntary associations and as productive enterprises. When addressing health needs, the associative component of the co-operative creates a program of health care that it is financially supported by the same cooperative as an enterprise¹⁶². Such an example comes from the Philippines. Following a process of community organization a multipurpose co-operative, of providers and users, was established in order to ensure long-term sustainability of day-care centers. In accordance with the charter of this co-operative, 20% of the profits were channeled to sustain school education and maternal and child care activities. The income generating activities ranged from home-based handicrafts using indigenous materials, day care center based production of secondary foods, to a bakery and workshops for weaving, carpentry and welding, as well as plantations and bee keeping. Health insurance scheme was added only at a later stage¹⁶³.

The potential of the co-operative sector meeting a significant proportion of the health care needs of the world's population has been acknowledged by the International Labor Organization since 1944 and it was reconfirmed by the General Assembly of the United Nations (Resolution 49/155 of December 1994) as well as by the WHO¹⁶⁴. The co-operative movement itself has shown a growing interest in the health care sector. This led, in 1996, to the establishment of the International Health Co-operative Organization¹⁶⁵. The latter suggests the following typology for the co-operative health sector¹⁶⁶.

User's cooperatives are characteristic of countries where health services are under-developed or very expensive, and where a significant proportion of the population is well educated and with an economic situation that favors their organization to develop co-operative health services under their control and which employ professionals to provide members with a contracted package of health care.

Provider's co-operatives tend to emerge where the market is either saturated or the employment conditions in the other sectors are not considered dignifying. This allows doctors and other health professionals, an alternative to private-for-profit work if the public sector is not an alternative. This already happens in many urban areas of developing countries, such as in Brazil.

Mixed providers' & users' co-operatives also exist in Brazil and in Spain. In this situation provider's co-operatives and user's co-operatives are associated into second-degree co-operatives for the building of hospitals and for the organization and provision of the most expensive components of health care. In these cases, the management is a joint management by the representatives of the primary cooperatives with both users and providers in the management structures.

Co-operative insurance. The International Co-operative and Mutual Insurance Federation is a

voluntary association of insurance co-operatives and mutuals. The members are linked by the basic principles, which are common to International Co-operative Alliance and the social Economy – the principle of open membership, democratic management, solidarity, non-exploitation, defense of the economic interests of the members and the use of profits for the benefit of the members. Just in the EU and EFTA countries the membership of these co-operatives and mutual insurance societies approaches 30 million.

Co-operative pharmacies have their origins at the end of the last century. They are particularly developed in Europe. But, even so very unevenly: they are present in Belgium, France, Italy, Holland, Switzerland, the UK and Portugal, with about 3000 pharmacies among them. Legal problems limit their development in Germany, Denmark, Spain, Luxembourg and Greece. In Nigeria and Haiti co-operative pharmacies have made their appearance. In Singapura, the National Congress of the Workers' Union started a chain of pharmacies in their co-operative supermarkets. Most users' and providers' co-operatives usually offer a pharmaceutical service to their members.

CIVIL SOCIETY ORGANISATIONS AS WATCHDOGS

CSO can play a very different – but equally important – role as watchdogs. Consumer organizations, academics, action committees, environmental groups can draw attention, for example, to problems with health hazards of toys, canned goods, powdered milk for infant, etc. That this can be effective is shown by the experience of a consumer organization in Belgium. It started a quarterly health publication, and within the first four years of its existence this led to six royal decrees of protective legislation, just by drawing attention to particular health hazards.

They can also detect and denounce abuse. User committees, consumer organizations, patient groups can help identify mismanagement, e.g. of hospitals, and bring about improvements through pressure on authorities, local or system-wide. The “COSEUR” group, a federation of organizations in 6 European countries, thus channels individual complaints (for example on over-billing), and sends dummy patients to laboratories, GPs, dentists to ascertain quality of care – and cost.

An example of committee work was the community health councils (CHC) of the UK. Established by statute in 1974 the CHC were the main official channel for public concerns about the health service. Its members were appointed by local councils, by the voluntary sector and by the health regions. They were entitled to seek relevant information about the NHS, to access NHS premises, to meet their health authority once a year and to be consulted on substantial service reforms. More recently they started working with purchasers in identifying local needs, developing purchasing strategies and monitoring services and patient satisfaction. A number of problems limits their usefulness: they are supposed to represent individual patients’ interests as well as to help define priorities; they are employed by the NHS and yet required to monitor its activities; they remained with little formal power to hold health authorities to account and none in relation to GP fund holders and they are grossly under-resourced¹⁶⁷. The importance of these voice mechanisms in preventing, for example “corruption”, has been well described from South America¹⁶⁸.

Dialogue with government and professional organizations thus leads to better self-regulation or legislation. Note that all this is obtained more often through pressure, discussion and publication than through representation in committees. Committee work is important, but if action is limited to that, it is often not the most effective way for consumer organizations to promote change.

POLICY INFLUENCE

A fifth function for civil society is to help the build policies, through advocacy and by informing decision-makers and helping to choose priorities.

Putting the interests of forgotten groups on the agenda

Putting the interests of forgotten or discriminated groups on the agenda can be done through advocacy CSO¹⁶⁹ that get those groups together: the homeless, refugees, people with AIDS, chronic patients, people that have bad health infrastructure, or people that do not have the money to access good infrastructure. The first task is really to increase their self-confidence, then to get the issue on the policy agenda by raising awareness among the public and decision-makers. At the same time, advocacy CSOs have a very important role in improving the awareness and sensitivity of individual providers and professional organizations to these problems. Ultimately resources will have to be mobilized. This requires that the advocacy CSO, whenever feasible, tries to work with the government and financing institutions.

The anti-liquor movement that began in the southern Indian state of Andhra Pradesh in 1992-1993, in which thousands of women participated, was prompted by a lesson in an adult literacy primer, portraying the predicament of a landless woman whose husband drank away his paltry earnings at the local liquor shop. The protest created a major political and economic crisis for the state government, which earns vast revenues through licensing of liquor shops and excise duties on alcohol¹⁷⁰.

Informing decision makers and get involved in difficult decisions

An organized civil society can also translate to decision-makers what is of value to citizens and users in health and health care. Health care managers often think that they know what the people want and that it is useless to go and discuss with civil society: “anyway we will learn nothing new”. Experience throughout the world, in the UK, Northern Africa, Lebanon, Thailand or Belgium, shows that when you start asking people what they feel it is important you get answers that may be very different from what the technocrats think. For example, in some cases people do not really mind to have to wait longer on the condition that they can get health care near their homes, whereas in others people may be willing to travel further on the condition they get care that is of

better quality. But you will not get to know what people value unless you ask for it¹⁷¹.

There are many ways of asking. Either by epidemiological survey methods¹⁷², using a more qualitative strategy – qualitative research methods, meetings with CSO or open public meetings - or by including community representatives in the bodies where decisions are taken¹⁷³. It is probably important to ensure that information is obtained through a mix of research methods and reaches decision-makers through a combination of channels –formal and informal, such as the media. Epidemiological survey methods may neglect the needs peripheral social groups, such as the homeless, minority groups and less common diseases¹⁷⁴. The way in which questions are framed seems to influence the responses that are given, suggesting that, given the complexity of some of the choices that have to be made, it may be that an investment in informing and educating the public about the issues involved is needed¹⁷⁵.

Even when information does reach the decision maker the impact may be from negligible, to no impact on decisions but only on the culture of the organization, to decisions based on the evidence presented to the decision makers¹⁷⁶, or in some cases, the information may be used to justify a posteriori decisions already taken¹⁷⁷. The presence of community representatives in the decision-making structures will minimize the risk of ignoring the opinion of the public.

Priority setting

Health care managers will often say that they do not ask people about their priorities, because people are “too emotional and cannot analyze things in a rational and objective way”¹⁷⁸. A couple of years ago the state of Oregon wanted to reduce the health care package for the population that gets state medical assistance, so as to increase the number of people that could benefit from the coverage. They set up a system of dialogue, meetings and consultations with technicians but also with the civil society and the population¹⁷⁹. That proved feasible and effective; moreover, if one compares this experience from that of other states where reform was left in the hands of the technocrats, without dialogue with the population, it is clear that if you want your health care system to improve, you cannot do so without involving the consumer¹⁸⁰. And the consumer may actually be more rational than, for example, the South African doctors who believe in health for all, but oppose cost-containment¹⁸¹.

Individual patients are price-conscious rather than cost-conscious. Furthermore, individuals tend to be effectiveness-driven, whereas society as a whole is cost-effectiveness-driven: it wants to obtain the greatest collective benefit from limited resources. Socially optimal resource allocation requires finding acceptable rationing devices and ways to implement them. Cost-effectiveness analysis (CEA) or cost-benefit analysis (CBA) do not achieve this. They merely inform the decision: in last analysis there remains a trade-off between the pressures from individual and collective rationality. The information from CEA may allow the decision to be based on more

than just intuition. Informing the decision is all the more important since in real-world decisions the limitation of total resources and the possibility and effectiveness of alternative utilization of the resources are often unclear. But making the issues explicit of course does not do away with conflicts of interest.

What, then, is the best way of obtaining public input in setting health care priorities? A first point is that aggregation of individual opinions is not the same as a collective consensus: consensus information obtained from a group is "*when people say collectively what they are unwilling to say individually*", and is better able to incorporate available evidence. Lomas suggests that panels of citizens or patients, convened on an ongoing basis and provided with the opportunity to acquire relevant information and discuss its implications offer the most promising way forward.¹⁸²

Purely rational resource allocation to effective and efficient activities addressing priority problems is an illusion. There is under spending on priorities. This may be because of lack of resources, or merely because of ignorance, lack of 'political will' or awareness of the vulnerability of the problem, or disempowerment of the most afflicted social groups. One example is maternal health: a priority problem for which effective solutions exist, but in many countries the problem is clearly not high on the public agenda, reflecting the limited access to power of women in many societies. In this context CSO have a major role in identifying the issue as a priority issue and putting it on the decision makers agenda.

There is also usually overspending on non-priorities. When non-priority activities are publicly funded, this can be for political reasons; for reasons of human dignity; through ignorance; or through lack of negotiation or debate on what should be funded and what not, or because one gives in to vested interests.

Out of these four categories of irrational resource allocation two are to be accepted (but negotiated): spending for political reasons and for reasons of human dignity. Irrational resource allocation through ignorance or lack of debate or negotiation must be eliminated. This is where the focus of the rationalization should be, so as to liberate these resources to fill the gaps in covering priorities. For the other two the focus should be on a debate within civil society.

Rationing

Very few people would object – at least in theory – to the elimination of ineffective or harmful treatment. Analysis of the available evidence and cost-effectiveness type of reasoning may help to clarify the debate enough for such rationalization to become possible. The situation is much more complicated when we talk about rationing.

Rationalization means eliminating non-priority care, because it is ineffective or because more efficient alternatives exist. Rationing means withholding effective care because resources are limited. If you do not waste your resources on ineffective or harmful treatment, the need for rationing may be less, but it will not be eliminated. In fact, every country in the world rations health care: the difference is the extent, and the way: through democratic debate, through technocratic decisions, or through individual ability to pay.

Most poor countries ration health care de facto, and often quite explicitly, when they define a minimum package: such a package includes a number of items, but by including them, it excludes a number of others. In mid-income countries the need may be less apparent for the general public. But rationing is as much a reality and a necessity in rich countries. In some countries, governments have taken the lead in the debate on rationing health care: in Oregon in the US, in Sweden and New Zealand, or in the Netherlands with the Dunning report¹⁸³. A common characteristic is that in one way or another a democratic debate with the population was organized.

These experiences are also relevant to developing countries. Health and health care are increasingly considered as citizen's rights, as entitlements: witness the 1999 Bamako declaration, or the proposed act on universal coverage in Thailand. The drawback of this evolution is a growing pressure from the middle classes for access to expensive care that society cannot afford in fairness¹⁸⁴.

Public health managers face then two types of difficulties in their attempts at rationalization and at rationing. The first has to do with understanding what care is valued by the sick and the potentially sick in a society. It is obviously naive to pretend that every individual will try to maximize his QALYs⁸⁵. But what exactly individuals do try to maximize is not really known. It changes over time. There may be an epidemiological and a demographic transition; there is also a transition in demand, affecting both content and mode of service delivery.

The second difficulty has to do with the tension between the utilitarian viewpoint of collective priorities and the libertarian viewpoint of individual priorities¹⁸⁶. According to traditional interpretations of economics and Darwinism each individual will first look for its own interest and survival. Modern interpretations do acknowledge that this is counterbalanced by an instinct for solidarity and co-operation. Still, the tension exists. The challenge is to transform the social objective of "maximizing health utilities given the resource constraints" in a system of incentives and disincentives for the institutions and individuals that provide, and for the individuals that use health care.

The issues to be addressed go way beyond evidence-based and cost effectiveness approaches¹⁸⁷: Whose values should be taken into account? Who should undertake rationing? What

accountability mechanisms are appropriate? How explicit should be the principles by which rationing is conducted? What additional information would be required to make rationing more explicit and those responsible more accountable? Is there enough knowledge to implement particular rationing strategies successfully?

Ultimately health care reform is about how people deal with health, how they get help and help themselves, how they cope with ill health and what kind of care they get. It also is ultimately about how the amount of resources allocated to health and the way they are distributed. Reform is thus about priorities and about trade-offs between quality, equity, and coverage. The only way to get to such trade-offs is on the basis of a broad discussion and dialogue. This is more necessary – and more realistic – than is often thought, although CSO have still not made their weight and influence felt in these issues.

Pro-poor advocacy

In the face of persistent inequity at the national and global levels, explicitly articulating values related to fairness and equity in the distribution of health outcomes is argued to be central to shaping pro-poor health policy¹⁸⁸. Lopes de Carvalho describes work in Brazil, for example, to generate dialogue between administrations and committees of citizens about health priorities that is reported to have driven an acknowledgement of the need to fight extreme poverty by society at large¹⁸⁹. The successful CSO led campaign and court action to ban the use of quinacrine for chemical sterilization in India is also cited as an example of CSO use of ethical and value driven approaches¹⁹⁰.

One of the critical means for overcoming the most health-damaging effects of social inequity is dealing with The policies and actions of donors and many governments neglect the "agency" of poor people to create lasting social change, fail to promote participation of the poor in agenda-setting, and stifle systems of public accountability¹⁹¹. Therefore, efforts to strengthen agency and voice should be embedded in CSO programs that address the health needs of the poor.

CSO efforts to promote social rights and participation in poor communities can, however, be undermined by wider political and economic conditions as was the case in Brazil (Lopes de Carvalho 1998). This implies that CSO should go beyond simply 'organizing' or 'providing services' to analyzing and engaging with the political and economic interests that impact on pro-poor policies^{192,193,194,195}. In the Philippines, for example, CSO provided services to low income urban households, but also lobbied for mayors with pro-poor policies and monitored elected leaders¹⁹⁶. Fuglesang note that such political roles call for wider alliances to strengthen CSO voice¹⁹⁷.

Hence if CSO are to move beyond mitigating the consequences of poverty, into raising the political momentum for pro-poor public policy, the evidence calls for a clear, value and rights driven frame of action, grounded in evidence, supporting direct voice and agency of poor communities and the building of alliances. There is a raging debate over whether CSO should be putting their efforts into becoming increasingly efficient at interim strategies for 'serving the poor', or whether they should be building the political momentum for wider challenges and responses to poverty.

STATE SUPPORT FOR CSO?

If there is a real role for CSOs, at least potentially, how should they be supported? The question of state support for CSO has been addressed in a number of papers^{198,199}. Options for encouraging CSO work include the legal framework, taxation policies, funding and other official support, collaborative partnerships and mechanisms for public consultation and information^{200,201,202}.

Subsidies have been a long-standing and common form of state support to CSO. In Rwanda, where missions provide 40% of the health care services, the government reimbursed them for 86% of the salaries of Ruandese staff. In Zimbabwe the government provided missions with 6.6 million USD in 1980-1981 to reimburse them for providing health care to indigents. In Zambia the equivalent subsidy for missions was 9.4 million USD²⁰³. As already discussed, these subsidies have been found, in practice, to be poorly taken up by CSO serving the poorest communities.

New forms of state support have emerged under current health reforms, such as: increasing public co-ordination of private services, including not-profit-providers; encouraging greater CSO participation in preventive services through state financial, equipment and training inputs; and contracting as a method for the integration of CSO health services into the district health system.

An evaluation of a contracting arrangement in Brazil judged by both CSO and the state to be successful found a number of features that contributed to the successful outcome: the contracting was part of a larger national strategy; it involved the CSO in the design of the contracting program; it was backed by a dedicated unit in the state to work with the CSO; the use of mass mailings, website, site visits, and other efforts to maximize transparency and facilitate communication with the CSO. The program built on existing CSO and MOH capacity to implement contracts and provided technical assistance to the CSO in proposal preparation, accounting, monitoring and evaluation. These features are usually not present in most instances of state-CSO collaboration and have been confirmed as desirable from other experiences in Latin America²⁰⁴.

It has also been observed that, contracting arrangements, many times, may not be pursued due to lack of skills and experience in the state itself to design contracts and the possible opposition from public sector unions²⁰⁵.

The action agenda of the CSO may in itself be perceived as a threat by the government. While the primary interest of the state appears to be to extend service coverage, CSO may have wider interests in their collaboration with the state. CSO seek to advance citizen rights, check state power and hold policy makers accountable. Formal mechanisms for enabling this role are far less developed than for encouraging service coverage. This may reflect the ambivalence in the state towards these CSO roles. The state response to such roles ranges from co-operation, to indifference or to open hostility^{206,207,208,209,210}.

Beyond the absence of formal mechanisms, there are also political tensions resulting from the hostility just mentioned. In India, whatever the nature of the state-CSO relations at central level, local level relations were generally characterized by the hostility of politicians, party workers, local elites, lower level bureaucrats, and lower level employees of the state toward CSO activity²¹¹. While at local level this may be traced to power relations between communities, authorities and political leaders, at national level it also traces to a perceived distortion of the national public policy by international CSO. This is documented for example in policy analysis of user fees and drug policies in Uganda²¹². Tensions may also arise where CSO are perceived to compete with government ministries for donor funding²¹³. The state may respond to these tensions positively through structured engagement (such as in the participatory councils of Brazil). On the other hand there are reports of state efforts to regulate 'undesirable' CSO activity through restriction of subsidies and exclusion of CSO from state planning forums²¹⁴.

CONCLUSIONS

Although the absence of a democratic environment is a major obstacle for the effective involvement of civil society in health and health care, it is apparent that the democratic deficit in the health sector is significant even in countries where representative democracy is well established.

This results from a fragmented understanding of what civil society is and of the meaning of its empowerment, as well as from the global inexperience with more participatory forms of democracy. It also reflects the resistance of well-established lobbies, be they professional self-protectionism or powerful economic interests, associated, for example with the pharmaceutical industry. It may also indicate the discomfort of the public sector health bureaucracy with partners not entirely under their control and frequently competing for the same source of resources and raising policy issues that go against the established status quo.

CSO contribute to the health systems, in terms of technical expertise and evidence, institutional and financial resources for health services and in terms of public information. They may enhance the public accountability of policy processes, if not always for the benefit of the poorest communities. They can relay the voice of low-income communities and vulnerable groups within public policy and planning. There is less common evidence that this has translated into real resource shifts into poor communities. Even so, CSO have emerged and grown to become significant partners, not only at local community levels, but also in international forums. As such they cannot be ignored.

Their significance results, partially, from the fact that CSO involvement in health is not new. Community based networks, non-government organizations and other types of CSO have a long history of participation in health, in both policy advocacy and service outreach. As such, as a group, they bring a wealth of experience that cannot be ignored. At national level, while some CSO services have a long historical presence, such as mission hospitals and emergency relief, there is evidence of a widening engagement CSO services in poor communities, remote areas, informal settlements and to meet health needs of specific groups, such as adolescents. There is also growing CSO involvement in organizing, informing and supporting communities towards making services responsive and accountable to their concerns.

Legal, institutional and procedural mechanisms for recognizing and organizing the synergy in health systems between state and civil society are reported to yield positive outcomes, including

better co-ordinated public financing and public mechanisms for joint action, and improved health equity. In contrast, parallel, competitive or poorly managed relations are reported to introduce inefficiencies into the actions of both state and civil society. There is need for a systematic assessment of the most productive forms of legal, political, institutional, financial and service relationships between CSO and the State for improved health outcomes, and what mechanisms, procedures, information and capacities are needed to service such relationships.

REFERENCES

- ¹ Di Tella R & Savedoff WD (editors) 2001. *Diagnosis corruption. Fraud in Latin America's Public Hospitals*. Washington DC: Inter-American Development Bank.
- ² Entwistle,VA, Watt,IS, Bradbury,R, & Pehl,LJ. Media coverage of the Child B case. *BMJ* 312[7046], 1587-1591. 1996.
- ³ Smith,R. All changed, changed utterly. *BMJ* 316 [7149], 1917-1918. 1998.
- ⁴ Cooper-Mahkorn,D. Series of errors led to 300 unnecessary mastectomies. *BMJ* 320, 597. 2000.
- ⁵ Turone F. Italian GPs suspended for accepting bribes. *British Medical Journal* 1998; 316: 1264.
- ⁶ Klein,R. Competence, professional self regulation, and the public interest. *BMJ* 316[7146], 1740-1742. 1998.
- ⁷ Davies,HT & Shields,AV. Public trust and accountability for clinical performance: lessons from the national press reportage of the Bristol hearing. *J Eval.Clin.Pract.* 5[3], 335-342. 1999.
- ⁸ Cooper-Mahkorn,D. Series of errors led to 300 unnecessary mastectomies. *BMJ* 320, 597. 2000.
- ⁹ Dyer,C. Bristol doctors found guilty of serious professional misconduct. *BMJ* 316[7149], 1924a. 1998. Treasure,T. Lessons from the Bristol case. *BMJ* 316[7146], 1685-1686. 1998.
- ¹⁰ Smith,R. All changed, changed utterly. *BMJ* 316[7149], 1917-1918. 1998.
- ¹¹ Klein,R. Competence, professional self regulation, and the public interest. *BMJ* 316[7146], 1740-1742. 1998.
- ¹² Davies,H. Falling public trust in health services: implications for accountability. *J.Health Serv.Res.Policy* 4[4], 193-194. 1999. Davies & Shields, 1999.
- ¹³ Davies,HT & Shields,AV. Public trust and accountability for clinical performance: lessons from the national press reportage of the Bristol hearing. *J Eval.Clin.Pract.* 5[3], 335-342. 1999.
- ¹⁴ McEwen J, Martini CJM, Wilkins N 1983. *Participation in health*. London & Canberra: Croom Helm.
- ¹⁵ Hollister RM, Kramer BM, Bellin SS (editors) 1972. *Neighborhood health centers*. Lexington: Lexington Books.
- ¹⁶ Osborn TWB 1949. Social medicine: a general survey of the problem. *S Afr Med J*; 27 September: 690-693.
- ¹⁷ Cooper L, Coote A, Davies A, Jackson C 1995. *Voices Off. Tackling the democratic deficit in health*. IPPR: London.
- ¹⁸ Freyens P, Mbakuliyemo N, Martin M 1993. How do health workers see community participation? *World Health Forum*; 14: 253.
- ¹⁹ Cooper L, Coote A, Davies A, Jackson C 1995. *Voices Off. Tackling the democratic deficit in health*. IPPR: London.
- ²⁰ Venter EH 1993. Community participation in health service institution. *S Afr Med J*; 83: 290.
- ²¹ Wilson TD, Robb D, Ferrinho P, Ntswanisi D 1991. Insights into community participation. *S Afr Med J*; 80: 372 - 373.
- ²² Shisana O & Versveld P 1993. Community participation in health service institutions. *S Afr Med J*; 83: 5-8.

-
- ²³ Hyde J 1999. Health system reform and social capital. *Development*; 42 (4): 49-53.
- ²⁴ Annex 1 reviews some of the semantics of "civil society", "empowerment" and "participation".
- ²⁵ Rifkin SB Muller F, Bichmann W 1988. Primary health care. On measuring participation. *Soc Sci Med*; 26: 931-940.
- ²⁶ Salber EJ. 1975. Caring and curing. Community participation in health services. New York: Prodist.
- ²⁷ Bellin SS & Geiger HJ 1972. Actual public acceptance of the neighborhood health center by the urban poor, Chapter 16, pp 199-211 in Hollister RM, Kramer BM, Bellin SS (editors) 1972. *Neighborhood health centers*. Lexington: Lexington Books.
- ²⁸ Barnes H 2000 Collaboration in community action: a successful partnership between indigenous communities and researchers. *Health Promotion International* 15:17-25.
- ²⁹ Barnes H 2000 Collaboration in community action: a successful partnership between indigenous communities and researchers. *Health Promotion International* 15:17-25; Field P, Gregory G 2000. Non government organizations to combine for work on chronic disease in aboriginal peoples, Torres Strait Islanders and rural remote populations. *Australian Journal of Rural Health* ;239-242; Sen S 1999. Some aspects of state-NGO relationships in India in the post- independence era. *Development and Change*; 30: 327-355.
- ³⁰ Akbar Zaidi S 1999. Institutional failure, state failure or the failure of "civil" society? The rural water supply and sanitation sector in Pakistan. *The Lahore Journal of Economics*; 5:71-90.
- ³¹ Brinkerhoff D & McEuen M 1999. New NGO partners for health sector reform in Central Asia: family group practice associations in Kazakhstan and Kyrgyzstan. *Special Initiatives Report* 19 ;1-29.
- ³² Carter J 1999. The power of partnership: The eradication of guinea worm diseases. *Cooperation South Journal*; 140-147.
- ³³ Kahssay H, Baum F 1996. The role of civil society in district health systems: Hidden resources. Division of analysis, Research and Assessment, WHO.
- ³⁴ Munishi G, Yazbeck A, Deroeck D, Lionetti D 1995. Private sector delivery of health care in Tanzania. Major Applied Research Paper No. 14. Washington: World Bank.
- ³⁵ Gilson, L., Adusei, J., Arhin, D., Hongoro, C., Mujinja, P. and Sagoe, K. 1997 Should African governments contract out clinical health services to church providers? Chapter 17, pp 276-302. in Bennet, S., McPake, B., Mills, A. (editors) 1997. *Private Health Providers in Developing Countries. Serving the Public Interest?* London and New Jersey: Zed Books.
- ³⁶ Sen PD 1994. Case studies of mosque and church clinics in Cairo, Egypt. Harvar University.
- ³⁷ Van Lerberghe, W., Van Balen, H. and Kegels, G. (1992) [Typologie et performances d'hôpitaux de premiers recours en Afrique sub-Saharienne. *Ann.Soc Belg.Med Trop* 72 Suppl 2, 1-51
- ³⁸ Le Vigouroux A, Okalia R 2000. Les structures confessionnelles privées dans la réorganisation d'un système de santé: le cas du Cameroun. *Afrique Contemporaine* ; 195 : 204-209.
- ³⁹ Delahanty J, Shefali MK 1999. From social movements to social clauses: assessing strategies for improving women's health and labour conditions in the garment sector. *Development* ;42:98-102; Gwatkin D & Deveshwar-Bahl G 2002. Inequalities in knowledge of HIV/AIDS prevention. An overview of socio-economic and gender differentials in developing countries; Harpham T, Burton S, Blue I 2001. Healthy city projects in developing countries: the first evaluation. *Health Promotion International* ;16:111 -125; Hanson K, Hong S, Hopwood I 1999. Implementing health sector reforms in Africa. A review of eight country experiences ; Munishi G, Yazbeck A, Deroeck D, Lionetti D 1995. Private sector delivery of health care in Tanzania. Major Applied Research Paper No. 14 World Bank,

-
- Washington ; Rajbhandari R, Gurung B, Gurung S. (1999) Community medicine in Nepal: opportunities and challenges. *Development* ;42:142-144; Williams B, Houws E, Frohlich J, Campbell C, Macphail C 2001. Lessons from the front: NGOs and the fight against HIV/AIDS in South Africa. *Voices from Africa*;1-5.
- ⁴⁰ Hanson K, Hong S, Hopwood I 1999. Implementing health sector reforms in Africa. A review of eight country experiences.
- ⁴¹ Brinkerhoff D & McEuen M 1999. New NGO partners for health sector reform in Central Asia: family group practice associations in Kazakhstan and Kyrgyzstan. *Special Initiatives Report 19* ;1-29.
- ⁴² Bitran R 1995. Efficiency and quality in the public and private sectors in Senegal. *Health policy and Planning* ;10: 271-283.
- ⁴³ Acharya S, Thomas L 2001 Targeting urban poverty in India- can NGOs and the state cooperate?, London: Government Department for International Development; <http://www.dfid.gov.uk/>; Etemadi F 2000. Civil society participation in civil governance in Cebu city. *Environment and Urbanisation* ;12: 57-72.
- ⁴⁴ Putney P 2001. The Nepal Safe Motherhood Network. *Partnerships for Health Reform*, 1-32. USA. ; Partnerships for Health Reform. (2000) Brazil contracts NGOs to fight HIV/AIDS. *PHR, Report pp* ;1-2. USA; Harpham T, Burton S, Blue I 2001. Healthy city projects in developing countries: the first evaluation. *Health Promotion International* ;16:111-125.
- ⁴⁵ UNFPA 1999. Partnership and Empowerment. The state of world population 1999 Chapter 4 pp 1-2. Geneva: UNFPA.
- ⁴⁶ Putney P 2001. The Nepal Safe Motherhood Network. *Partnerships for Health Reform*, 1-32. USA.
- ⁴⁷ Whelan D, Mahathir M, Homans H 1999. Gender and HIV/AIDS: Taking stock of research and programmes.
- ⁴⁸ Gwatkin D & Deveshwar-Bahl G 2002. Inequalities in knowledge of HIV/AIDS prevention. An overview of socio-economic and gender differentials in developing countries.
- ⁴⁹ Rajkumar A, Swaroop V 2002. Public spending and outcomes: does governance matter? Washington: World Bank.
- ⁵⁰ Raghuram S, Ray, M 1999. The state and civil society: meeting health needs, reaching equity. *Development*; 42: 54-58.
- ⁵¹ Niang S 2001. Reducing African women's vulnerability to HIV/AIDS. UN-NGLS: *Voices From Africa*, Geneva: UN NGLS.
- ⁵² Fuglesang M, Wängborg O, Ragnarsson A 2002. Time to speak up. Youth, HIV/AIDS and political commitment - how can we improve advocacy work? SIDA, Sweden.
- ⁵³ Etemadi F 2000. Civil society participation in civil governance in Cebu city. *Environment and Urbanisation* 12:57-72.
- ⁵⁴ Acharya S & Thomas L 2001. Targeting urban poverty in India- can NGOs and the state cooperate? London: Government Department for International Development; <http://www.dfid.gov.uk/>;
- ⁵⁵ Osmani SR undated. Participatory governance, people's empowerment and poverty reduction. SEPED Conference Paper Series number 7. http://www.undp.org/seped/publications/conf_pub.htm
- ⁵⁶ Etemadi F 2000. Civil society participation in civil governance in Cebu city. *Environment and Urbanisation* 12:57-72.

-
- ⁵⁷ Ron A & Kupferman A 1996. A community health insurance scheme in the Philippines: extension of a community based integrated project. Technical Papers. Macroeconomics, Health and Development Series, number 19. Geneva: World Health Organisation.
- ⁵⁸ Osmani SR undated. Participatory governance, people's empowerment and poverty reduction. SEPED Conference Paper Series number 7. http://www.undp.org/seped/publications/conf_pub.htm
- ⁵⁹ Acharya S & Thomas L 1999. Finding a pathway: understanding the work and performance of NGOs in Ahmeddabad, India. INTRAC Occasional Papers Series 22.
- ⁶⁰ Ahmad MM undated. Donors, the State, Non-governmental Organisations and their clients in Bangladesh. Dhaka: Dhaka University.
- ⁶¹ Osmani SR undated. Participatory governance, people's empowerment and poverty reduction. SEPED Conference Paper Series number 7. http://www.undp.org/seped/publications/conf_pub.htm
- ⁶² Nathan S, Rotem A, Ritchie J 2002. Closing the gap: building the capacity of non-government organizations as advocates for health. *Health Promotion International* ;17:69-78.
- ⁶³ Gomez E 2000. Equity, gender, and health policy reform in Latin America and the Caribbean. Washington: PAHO.
- ⁶⁴ Lewis M, Eskeland G, Traa-Valerezo X 1999. Challenging El Salvador's rural health care strategy. Washington: World Bank..
- ⁶⁵ Ahmad MM undated. Donors, the State, Non-governmental Organisations and their clients in Bangladesh. Dhaka: Dhaka University.
- ⁶⁶ White S 1999. NGOs, civil society and the state in Bangladesh: The politics of representing the poor. *Development and Change*;30:307 -326.
- ⁶⁷ Flower J, Wirz S 2000. Rhetoric or reality? The participation of disabled people in NGO planning. *Health Policy and Planning*; 15: 177-185.
- ⁶⁸ Mitlin D 2000. Civil society and urban poverty- Overview of stage one city case studies. *Urban Governance, Partnership and Poverty Theme paper* 22.
- ⁶⁹ Desai V 1999. Anatomy of the Bombay NGO sector. *Environment and Urbanization*; 11 (1): 247 - 265.
- ⁷⁰ Gwatkin D 2002. Reducing health inequalities in developing countries. In: *Oxford Textbook of Public Health*. Oxford University Press.
- ⁷¹ Leighton C 1995. 22 Policy questions about health care financing in Africa.
- ⁷² Mudyarabikwa O 2000. An examination of public sector subsidie to private health sector: a Zimbabwe case study. *Equinet Policy Series* no 3 ;1-27. Benaby printers, Harare.
- ⁷³ Leighton C 1995. 22 Policy questions about health care financing in Africa.
- ⁷⁴ Mudyarabikwa O 2000. An examination of public sector subsidie to private health sector: a Zimbabwe case study. *Equinet Policy Series* no 3 ;1-27. Benaby printers, Harare.
- ⁷⁵ Castro-Leal F, Dayton J, Demey L, Mehra K 2000. Public spending on health care in Africa: do the poor benefit? *Bulletin of the World Health Organization*; 78:66-74.
- ⁷⁶ Gilson L, Kalyalya D, Kuchler F, Lake S, Oranga H, Ouendo M (2 001. Strategies for promoting equity experience with community financing in three African countries. *Health Policy*; 58:37 -67.
- ⁷⁷ Korten DC 1990. NGO strategic networks: from community projects to global transformation. <http://iisd1.iisd.ca/pcdf/1990/stratnet.htm>
- ⁷⁸ Kickbusch I, Quick J 1998. Partnerships for health in the 21st century. *World Statistics Quarterly*; 51:68-74.

-
- ⁷⁹ Frenk J, Sepulveda J, McGuinness M, Knaul F 1997. The future of world health: The new world order and international health. *BMJ* 314:7091: 1404-1412.
- ⁸⁰ Bond P 1999. Globalization, pharmaceutical pricing, and South African health policy: managing confrontation with US firms and politicians. *International journal of Health Services* ; 29 (4): 765 -792.
- ⁸¹ Demin AK 2001. Tobacco control policymaking in Russia and the role of civil society. <http://www.rpha.newmail.ru>
- ⁸² Mindell J 2002. Lessons from tobacco control for advocates of healthy transport. *Journal of Public Health Medicine*; 23: 2:91-97.
- ⁸³ Yach D, Bettcher D 2000. Globalisation of tobacco industry influence and new global responses *Tobacco Control*; 9: 206-216.
- ⁸⁴ Chapman J 1999. The response of civil society to the globalisation of the marketing of breast milk substitutes in Ghana. *Journal of the Society for International Development*; 42: 4 103-107.
- ⁸⁵ Gordon P & Crehan K undated. Dying of sadness: gender, sexual violence and the HIV epidemic. SEPED Conference Paper Series. http://www.undp.org/seped/publications/conf_pub.htm
- ⁸⁶ Randell A, Whitehead AJ 1997. Codex Alimentarius: food quality and safety standards for international trade, *Rev sci Off int Epiz* 16:2:313-321.
- ⁸⁷ Gostelow L 1999. The Sphere Project: The implications of making humanitarian principles ad codes work, *Disasters*, 23:4:316-325.
- ⁸⁸ Paul JA 2000. NGOs, civil society and global policy making. <http://www.globalpolicy.org/ngos/analysis/analysis.htm>
- ⁸⁹ Sheehan 2000. The role of NGOs in building security in south Eastern Europe. *Central European Issues*; 5: 2:44-49.
- ⁹⁰ Turmen T 1999. Making globalisation work for better health. *Journal of the Society for International Development (SID)*; 42 (4); 8-11.
- ⁹¹ Weiss TG 1999. International NGOs, Global Governance and Social Policy in the UN system. GASPP Occasional paper no 3/1999. Finland.
- ⁹² Willetts P 2000. From consultative arrangements to 'partnerships: The changing status of NGOs in diplomacy at the UN. *Global Governance*; 6: 191-212.
- ⁹³ Muraskin W 2000. The last years of the CVI and the birth of GAVI.« Paper presented at the Workshop on Public-Private Partnerships in Public Health, Dedham, Massachusetts, April 7-8, 2000.
- ⁹⁴ Gates Foundation 2002. Developing successful global health alliances. Gates Foundation, USA, April 2002.
- ⁹⁵ Hardon A 2001. Immunisation for all? *HAI Lights*; 6:1: 1-5.
- ⁹⁶ Fleck F 2002. Children's charity criticizes global immunization initiative. *BMJ* 324: 129.
- ⁹⁷ Raghavan C 2001. NGOs zero in on non-transparent WHO/ Corporate links, *South-North Development Monitor (SUNS)/HAI newsletter* 4899.
- ⁹⁸ Sen S 2002. Africa. AIDS needs more than money and drugs say NGOs. *Third World Network*; April 6 2002.
- ⁹⁹ Machipisa L 2001. African Groups disappointed by UN AIDS Declaration. *IPS*, June 28 2001.
- ¹⁰⁰ Save the Children Fund (UK) 2001. G8 Summit and a global health fund: Issues at a glance, SCF (UK). Media briefing, UK.
- ¹⁰¹ UNAIDS 1998. NGO perspectives on access to HIV-related drugs in 13 Latin American and Caribbean countries. Geneva: UNAIDS.

-
- ¹⁰² Hakkinen U & Ollila E 2000. The World Health Report 2000: what does it tell us about health systems? National Research and Development Centre for Welfare and Health, 7/2000. Finland.
- ¹⁰³ Davies, H. Falling public trust in health services: implications for accountability. *J. Health Serv. Res. Policy* 4[4], 193-194. 1999. Davies & Shields, 1999.
- ¹⁰⁴ Nitayarumphong S, Srivanichakom S, Pongsupap Y. Strategies to respond to health manpower needs in rural Thailand. *Studies in Health Services Organisation & Policy* 2000; 16: 55-72.
- ¹⁰⁵ Robinson R. Rationing health care: a national framework and local discretion [editorial]. *J Health Serv Res Policy* 1997;2(2):67-70.
- ¹⁰⁶ Schacht PJ, Pemberton A. What is unnecessary surgery? Who shall decide? Issues of consumer sovereignty, conflict and self-regulation. *Soc.Sci.Med.* 1985;20:199-206.
- ¹⁰⁷ Cooper L, Coote A, Davies A, Jackson C 1995. *Voices Off. Tackling the democratic deficit in health.* IPPR: London.
- ¹⁰⁸ Moore, M. Public Sector Reform: Downsizing, Restructuring, Improving Performance. (7), 1-23. 1996. Geneva, who. Forum on Health Sector Reform, Discussion Paper. 1996.
- ¹⁰⁹ Hurley RE. Toward a behavioral model of the physician as case manager. *Soc.Sci.Med.* 1986;23:75-82.
- ¹¹⁰ Gustafsson RA. Origins of authority: the organization of medical care in Sweden. *Int.J.Health Serv.* 1989;19:121-33.
- ¹¹¹ Laine C, Davidoff F. Patient centered medicine: a professional revolution. *JAMA* 1996(275):152-6.
- ¹¹² Entwistle VA, Sowden AJ, Watt IS. Evaluating interventions to promote patient involvement in decision-making: by what criteria should effectiveness be judged? *J Health Serv Res Policy* 1998;3(2):100-7.
- ¹¹³ Robinson, R. Rationing health care: a national framework and local discretion [editorial]. *J Health Serv Res Policy* 2[2], 67-70. 1997.
- ¹¹⁴ Leavey R, Wilkin D, Metcalfe DHH 1989. Consumerism and general practice. *BMJ*; 298: 737-739.
- ¹¹⁵ Davidson BN, Sofaer S, Gertler P. Consumer information and biased selection in the demand for coverage supplementing Medicare. *Soc.Sci.Med.* 1992;34:1023-34.
- ¹¹⁶ Domenighetti G, Luraschi P, Casabianca A, Gutzwiller F, Spinelli A, Pedrinis E et al. Effect of information campaign by the mass media on hysterectomy rates. *Lancet* 1988;2:1470-3.
- ¹¹⁷ Mahmud S & Johnston AM 1994. Women's status, empowerment, and reproductive outcomes, Chapter 11, pp 151-173 in Sen G, Germain A and Chen L (editors) 1994. *Population Policies Reconsidered. Health, Empowerment and Rights.* Harvard University Press.
- ¹¹⁸ Batliwala S 1994. The meaning of women's empowerment: new concepts from action, Chapter 9, pp 127-138 in Sen G, Germain A and Chen L (editors) 1994. *Population Policies Reconsidered. Health, Empowerment and Rights.* Harvard University Press.
- ¹¹⁹ Mahmud S & Johnston AM 1994. Women's status, empowerment, and reproductive outcomes, Chapter 11, pp 151-173 in Sen G, Germain A and Chen L (editors) 1994. *Population Policies Reconsidered. Health, Empowerment and Rights.* Harvard University Press.
- ¹²⁰ Marshall, M, Shekelle, P, Brook, R, & Leatherman, S. Public reporting of performance: lessons from the who. *J. Health Serv. Res. Policy* 5[1], 1-2. 2000.
- ¹²¹ O'Malley, C. Quality measurement for health systems: accreditation and report cards. *Am.J Health Syst. Pharm.* 54[13], 1528-1535. 1997.

-
- ¹²² Corrigan, JM & Nielsen, DM. Toward the development of uniform reporting standards for managed care organizations: the Health Plan Employer Data and Information Set (Version 2.0). *Jt. Comm J Qual. Improv.* 19[12], 566-575. 1993.
- ¹²³ Hibbard, JH. Use of outcome data by purchasers and consumers: new strategies and new dilemmas. *International Journal for Quality in Health Care* 10[6], 503-508. 1998. ; Nerenz, DR. Using outcomes data to compare plans, networks, and providers: what is the state of the art? *International Journal for Quality in Health Care* 10[6], 463-465. 1998.
- ¹²⁴ Houdart, P., Malye, F., and Vincent, J. *Hôpitaux et cliniques: spécial maternités. Sciences et avenir* (620). 1998. Houdart, P., Malye, F., and Vincent, J. *Hôpital édition 1998. Sciences et avenir* (610). 1998.
- ¹²⁵ O'Malley, C. Quality measurement for health systems: accreditation and report cards. *Am. J Health Syst. Pharm.* 54[13], 1528-1535. 1997.
- ¹²⁶ Corrigan, JM & Nielsen, DM. Toward the development of uniform reporting standards for managed care organizations: the Health Plan Employer Data and Information Set (Version 2.0). *Jt. Comm J Qual. Improv.* 19[12], 566-575. 1993.
- ¹²⁷ Hibbard, JH. Use of outcome data by purchasers and consumers: new strategies and new dilemmas. *International Journal for Quality in Health Care* 10[6], 503-508. 1998. ; Nerenz, DR. Using outcomes data to compare plans, networks, and providers: what is the state of the art? *International Journal for Quality in Health Care* 10[6], 463-465. 1998.
- ¹²⁸ Houdart, P., Malye, F., and Vincent, J. *Hôpitaux et cliniques: spécial maternités. Sciences et avenir* (620). 1998. Houdart, P., Malye, F., and Vincent, J. *Hôpital édition 1998. Sciences et avenir* (610). 1998.
- ¹²⁹ Estabrooks C, Goel V, Thiel E, Pinfold P, Sawka C, Williams I (2001). Decision aids: are they worth it? A systematic review. *J Health Serv Res Policy*; 6 (3): 170-182.
- ¹³⁰ H Bekker, JG Thornton, CM Airey, J B Connelly, J Hewison, J Lilleyman et al (1999). Informed decision making: an annotated bibliography and systematic review. *Health Technology Assessment*; 3 (1).
- ¹³¹ Nerenz, D. R. Using outcomes data to compare plans, networks, and providers: what is the state of the art? *International Journal for Quality in Health Care* 10(6), 463-465. 1998. Palmer, R. H. Using health outcomes data to compare plans, networks and providers. *International Journal for Quality in Health Care* 10(6), 477-483. 1998.
- ¹³² Charles, SC, Gibbons, RD, Frisch, PR, Pyskoty, CE, Hedeker, D, & Singha, NK. Predicting risk for medical malpractice claims using quality-of-care characteristics. *West J Med* 157[4], 433-439. 1992.
- ¹³³ Rolph, JE, Kravitz, RL, & McGuigan, K. Malpractice claims data as a quality improvement tool. II. Is targeting effective? *JAMA* 266[15], 2093-2097. 1991.
- ¹³⁴ Studdert, DM, Thomas, EJ, Burstin, HR, Zbar, BI, Orav, EJ, & Brennan, TA. Negligent care and malpractice claiming behavior in Utah and Colorado. *Med Care* 38[3], 250-260. 2000.
- ¹³⁵ Hill, M. Failure to diagnose myocardial infarction: the emergency physician's greatest liability in practice. *QRC. Advis.* 6[2], 1-8. 1989. Gwynne, A, Barber, P, & Tavener, F. A review of 105 negligence claims against accident and emergency departments. *J Accid. Emerg. Med* 14[4], 243-245. 1997.
- ¹³⁶ Dewar, MA & Love, N. Legal issues in managing breast disease. *Postgrad. Med* 92[5], 137-4, 149. 1992. Osuch, JR & Bonham, VL. The timely diagnosis of breast cancer. Principles of risk management for primary care providers and surgeons. *Cancer* 74[1 Suppl], 271-278. 1994.

-
- ¹³⁷ Heland, KV & Rutledge, P. Medicolegal issues. *Obstet. Gynecol. Clin. North Am.* 21[4], 781-788. 1994.
- ¹³⁸ Rombouts, JJ & Rombouts-Godin, V. [Delayed detection of hip dislocation: is the physician to blame?]. *Pediatric. (Bucur.)* 48[4], 327-334. 1993.
- ¹³⁹ Classe, JG. Clinicolegal aspects of vitreous and retinal detachment. *Optom. Clin.* 2[3], 113-125. 1992.
- ¹⁴⁰ Cheney, FW, Posner, KL, & Caplan, RA. Adverse respiratory events infrequently leading to malpractice suits. A closed claims analysis. *Anesthesiology* 75[6], 932-939. 1991.
- ¹⁴¹ Localio AR, Lawthers AG., Bengtson JM, Hebert LE, Weaver SL, Brennan TA & Landis JR, Relationship between malpractice claims and caesarean delivery, *JAMA*, vol. 269, no. 3, pp. 366-373, 1993
- ¹⁴² Mayster V, Waitzkin H, Hubbell FA, Rucker L. Local advocacy for the medically indigent: strategies and accomplishments in one county. *Int. J. Health Serv.* 1992;22:317-29.
- ¹⁴³ Entman, SS, Glass, CA, Hickson, GB, Githens, PB, Whetten-Goldstein, K, & Sloan, FA. The relationship between malpractice claims history and subsequent obstetric care. *JAMA* 272[20], 1588-1591. 1994.
- ¹⁴⁴ Enfield, LM & Sklar, DP. Patient dumping in the hospital emergency department: renewed interest in an old problem. *Am. J. Law Med* 13[4], 561-595. 1988.
- ¹⁴⁵ http://eur.opa.eu.int/comm/dg24/policy/developments/acce_just
- ¹⁴⁶ Davison, KP, Pennebaker, JW, & Dickerson, SS. Who talks? The social psychology of illness support groups. *Am. Psychol.* 55[2], 205-217. 2000.
- ¹⁴⁷ Lowell SL 1976. Self-care: an international perspective. *Social Policy*; September/October 1977.
- ¹⁴⁸ Maritoux J, Bruneton C, Bouscharain P 2000. Le secteur pharmaceutique dans les états africains francophones. *Afrique Contemporaine*; 195 : 210-229.
- ¹⁴⁹ The Health address book. A directory of health support groups. FT Health Care, 1997.
- ¹⁵⁰ Segal, SP, Redman, D, & Silverman, C. Measuring clients' satisfaction with self-help agencies. *Psychiatr. Serv.* 51[9], 1148-1152. 2000. Severson, HH, Akers, L, Andrews, JA, Lichtenstein, E, & Jerome, A. Evaluating two self-help interventions for smokeless tobacco cessation. *Addict. Behav.* 25[3], 465-470. 2000.
- ¹⁵¹ Caplan G 1976. Introduction and overview, pp 1-18 in Caplan G and Killilea M (editors) 1976. *Support systems and mutual help. Multidisciplinary explorations.* New York: Grune & Stratton.
- ¹⁵² Criel B 1998. District-based health insurance in sub-Saharan Africa. Part I: from theory to practice. *Studies in Health Services Organisation & Policy*; 9.
- ¹⁵³ Anonymous 1999. *Mutualidades de saúde em África.* Lisboa.
- ¹⁵⁴ Criel B 1998. District-based health insurance in sub-Saharan Africa. Part I: from theory to practice. *Studies in Health Services Organisation & Policy*; 9.
- ¹⁵⁵ Letourmy A 2000. Les mutuelles de santé en Afrique : conditions d'un développement. *Afrique Contemporaine*; 195 : 230-240.
- ¹⁵⁶ Anonymous 1999. *Mutualidades de saúde em África.* Lisboa.
- ¹⁵⁷ Criel B 1998. District-based health insurance in sub-Saharan Africa. Part I: from theory to practice. *Studies in Health Services Organisation & Policy*; 9.
- ¹⁵⁸ Galland B, Kaddar M, Debaig G 1997. Mutualité est systèmes de pré-paiement des soins de santé en Afrique sub-Saharienne. *L'Enfant en Milieu tropical*; 228 : 9-22.
- ¹⁵⁹ Anonymous 1999. *Mutualidades de saúde em África.* Lisboa.

-
- ¹⁶⁰ Ilunga TV, Fournier P, Constandriopoulos AP, Ette J 1997. Mutuelle et assurances rurales de la santé : quelques approches pour l'Afrique. *L'Enfant en Milieu tropical* ; 228 : 23-28.
- 161 Criel B 1998. District-based health insurance in sub-Saharan Africa. Part I: from theory to practice. *Studies in Health Services Organisation & Policy*; 9.
- ¹⁶² Ferrinho HM undated. Cooperativas de saúde, desenvolvimento e reforma do setor da saúde, Lisboa: AGO.
- ¹⁶³ Ron A & Kupferman A 1996. A community health insurance scheme in the Philippines: extension of a community based integrated project. Technical Papers. Macroeconomics, Health and Development Series, number 19. Geneva: World Health Organisation.
- ¹⁶⁴ International Co-operative Alliance 1997. Review of national experiences in promoting and supporting the contribution of co-operatives to social development.. Available in the site of the ICA.
- ¹⁶⁵ <http://www.coop.org/en/health.html>
- ¹⁶⁶ Ferrinho HM undated. Cooperativas de saúde, desenvolvimento e reforma do setor da saúde, Lisboa: AGO.
- 167 Cooper L, Coote A, Davies A, Jackson C 1995. *Voices Off. Tackling the democratic deficit in health.* IPPR: London.
- 168 Di Tella R & Savedoff WD (editors) 2001. *Diagnosis corruption. Fraud in Latin America's Public Hospitals.* Washington DC: Inter-American Development Bank.
- 169 Mayster V, Waitzkin H, Hubbell FA, Rucker L. Local advocacy for the medically indigent: strategies and accomplishments in one county. *Int.J.Health Serv.* 1992;22:317-29. Butler K, Forrest A. Citizen advocacy for people with disabilities. In: Winn L, editor. *Power to the People: the Key to Responsive Services in Health and Social Care.* London: The King's Fund; 1990. p. 59-67.
- 170 Batliwala S 1994. The meaning of women's empowerment: new concepts from action, Chapter 9, pp 127-138 in Sen G, Germain A and Chen L (editors) 1994. *Population Policies Reconsidered. Health, Empowerment and Rights.* Harvard University Press.
- 171 Griffiths I. The battle for the future of health care. The development of primary-care-led purchasing in the English National Health Service, in Glouberman, S. (editor), *Beyond Restructuring,* The King's Fund, London, pp. 96-103, 1996
- 172 Richardson A, Charny M, Hammer-Lloyd S 1992. Public opinion and purchasing. *BMJ*; 304: 680-682.
- 173 Ham C 1993. Priority setting in the NHS: reports from six districts. *BMJ*; 307; 435-438.
- 174 Shanks J, Kheraj S, Fish S 1995. Better ways of assessing health needs in primary care. *BMJ*; 310: 480-481.
- 175 Ham C 1993. Priority setting in the NHS: reports from six districts. *BMJ*; 307; 435-438.
- 176 Ham C 1993. Priority setting in the NHS: reports from six districts. *BMJ*; 307; 435-438.
- ¹⁷⁷ Hensher M & Fulop N 1999. The influence of health needs assessment on health care decision-making in London health authorities. *J Health Serv Res Policy*; 4 (2): 1999.
- 178 Lomas J. Reluctant rationers: public input to health care priorities. *J Health Serv Res Policy* 1997;2(2):103-11.
- 179 Schurman DP. The agony and ecstasy of reform. In: Glouberman S, editor. *Beyond restructuring.* London: The King's Fund; 1996. p. 35-45.
- 180 Robinson R. Rationing health care: a national framework and local discretion [editorial]. *J Health Serv Res Policy* 1997;2(2):67-70.

-
- 181 Volmink JA, Metcalf CA, Zwarenstein M, Heath S, Laubscher JA. Attitudes of private general practitioners towards health care in South Africa. *S.Afr.Med.J.* 1993;83(11):827-33.
- 182 Lomas J 1997. Reluctant rationers: public input to health care priorities. *J Health Serv Res Policy*; 2(2): 103-11.
- 183 Kitzhaber JA. Prioritising health services in an era of limits: the Oregon experience. In: R Smith, ed. *Rationing in action*. London: BMJ Publishing Group, 1993. McKee M, Figueras J. Setting priorities: can Britain learn from Sweden? *BMJ* 1996;312:691-4. National Advisory Committee. *Core services 1993/4*. Wellington, New Zealand: NAC, 1992. *Choices in health care: A report by the Government Committee on Choices in Health Care*. Rijswijk, the Netherlands: Ministry of Health, Welfare and Cultural Affairs, 1992. (AJ Dunning, chairman.)
- 184 Rothman shows that the middle-class desire for sophisticated health care at whatever cost, combined with the political power of that group, has been the driving force behind the reliance on costly technology in the US – in the face of 40 million individuals without health coverage Rothman, DJ. *Beginnings count. The technological imperative in american health care*. Oxford University Press, New York, 1997.
- 185 Weinstein, MC. Risky choices in medical decision-making: a survey. *The Geneva papers on Risk and Insurance*, 11, 197-216, 1986. Cited in: Loomes, G. and L. McKenzie. The use of QALYs in health care decision-making. *Soc Sc Med*, 28, 4, 299-308, 1989.
- 186 We do know that if health care is provided as a public good, this creates a ‘free rider’ phenomenon. A free rider is a person who consumes a good without paying for it. Public goods create a free rider phenomenon because the quantity of the good that the person is able to consume is not influenced by its ability to pay for it.
- 187 New, B. The rationing agenda in the NHS. *BMJ* 1996;312:1593-1601
- ¹⁸⁸ Evans T, Whitehead M, Diderichsen F, Bhuiya A, Wirth M 2001.. Challenging inequities in health. From ethics to action. In: anonymous, eds. *Challenging inequities in health. From ethics to action*.: Oxford University Press; UK
- ¹⁸⁹ Lopes de Carvalho F 1998. Fighting extreme poverty in Brazil: the influence of citizen’s action on government policies. Paris: OCDE, CD/DOC(98)12. <http://www.oecd.org/dev/pub/tp1a.htm>
- ¹⁹⁰ Visvanathan N 1999. Ethics of care and health policy change: Indian women's movement mobilizes against quinacrine sterilization. *Development*; 42:64-69.
- ¹⁹¹ Bangser M 2000. Reframing policies for gender equity: women’s agency, participation and public accountability. Cambridge: Harvard University.
<http://www.hsph.harvard.edu/Organizations/healthnet/HUPapers/gender/bangser.html>
- ¹⁹² Isaacs S & Solimano G 1999. Health reform and civil society in Latin America. *Development*; 42 (4): 70-72.
- ¹⁹³ Bangser M 2000. Reframing policies for gender equity: women’s agency, participation and public accountability. Cambridge: Harvard University.
- ¹⁹⁴ Ranney D, Wright P, Zhang T 1997. Citizens, Local Government and the Development of Chicago's Near South Side. UNRISD Discussion Paper No. 90.
- ¹⁹⁵ Bernal G, Bissell S, Cortes A 1999. Effects of globalisation on the efforts to decriminalise abortion in Mexico. *Development*; 42:130-133.
- ¹⁹⁶ Etemadi F 2000. Civil society participation in civil governance in Cebu city. *Environment and Urbanisation*; 12:::57-72.

-
- ¹⁹⁷ Fuglesang M, Wångborg O, Ragnarsson A 2002. Time to speak up "Youth, HIV/AIDS and political commitment - how can we improve advocacy work? SIDA, Sweden.
- ¹⁹⁸ Gilson, L., Adusei, J., Arhin, D., Hongoro, C., Mujinja, P. and Sagoe, K. 1997 Should African governments contract out clinical health services to church providers? Chapter 17, pp 276-302. in Bennet, S., McPake, B., Mills, A. (editors) 1997. Private Health Providers in Developing Countries. Serving the Public Interest? London and New Jersey: Zed Books
- ¹⁹⁹ Ferrinho P, Bugalho AM, Van Lerberghe W 2001. Is there a case for privatising reproductive health? Patchy evidence and much wishful thinking, in De Brouwere V, Van Lerberghe W (editors). Studies in Health Services Organisation & Policy; 18, 365-394.
- ²⁰⁰ Buturo J. NGOs, democracy and sustainable development in Africa.
<http://www.unsystem.org/ngls/documents/publications.en/voices.africa/number5/vfa5>
- ²⁰¹ Clark J undated. The relationship between the state and the voluntary sector.
<http://www.gdrc.org/ngo/state.ngo.html>.
- ²⁰² Clayton A, Oakley P, Taylor J 2000. Civil society organisations and service provision. Civil Society and social movements Programme Paper number 2. United Nations Research Institute for Social Development.
- ²⁰³ Akin J, Birdsall N, de Ferranti D 1987. Financing health services in developing countries. A World Bank Policy Study. Washington: The World Bank.
- ²⁰⁴ Cardelle A 1998. Democratization, health care reform, and NGO-government collaboration: catalyst or constraint? A North-South Agenda Paper 32. Miami: North-south Center, University of Miami.
- ²⁰⁵ McPake B, Mills A 2000. What can we learn from international comparisons of health systems and health system reform. Bulletin of the World Health Organization;78::811-820.
- ²⁰⁶ Clark J undated. The relationship between the state and the voluntary sector.
<http://www.gdrc.org/ngo/state.ngo.html>.
- ²⁰⁷ Clayton A, Oakley P, Taylor J 2000. Civil society organisations and service provision. Civil Society and social movements Programme Paper number 2. United Nations Research Institute for Social Development.
- ²⁰⁸ Ahmad MM undated. Donors, the State, Non-governmental Organisations and their clients in Bangladesh. Dhaka: Dhaka University.
- ²⁰⁹ Birungi H, Mugisha F, Nsabagasani X, Okuonz S, Jeppsson A 2001. The policy on public-private mix in the Ugandan health sector: catching up with reality. Health Policy and Planning 16:80-87.
- ²¹⁰ Clayton A, Oakley P, Taylor J 2000. Civil society organisations and service provision. Civil Society and social movements Programme Paper number 2. United Nations Research Institute for Social Development.
- ²¹¹ Sen S 1999. Some aspects of state-NGO relationships in India in the post-independence era. Development and Change; 30: 327-355.
- ²¹² Okuonzi S, Macrae J 1995. Whose policy is it anyway? International and national influences on health policy development in Uganda. *Health Policy and Planning*; 10:122-132.
- ²¹³ Kennedy C 1999. Reconsidering the relationship between the state, donors and NGOs in Bangladesh. *Pakistan Development Review* ;38:489-506.
- ²¹⁴ Sen S 1999. Some aspects of state-NGO relationships in India in the post-independence era. Development and Change; 30: 327-355.