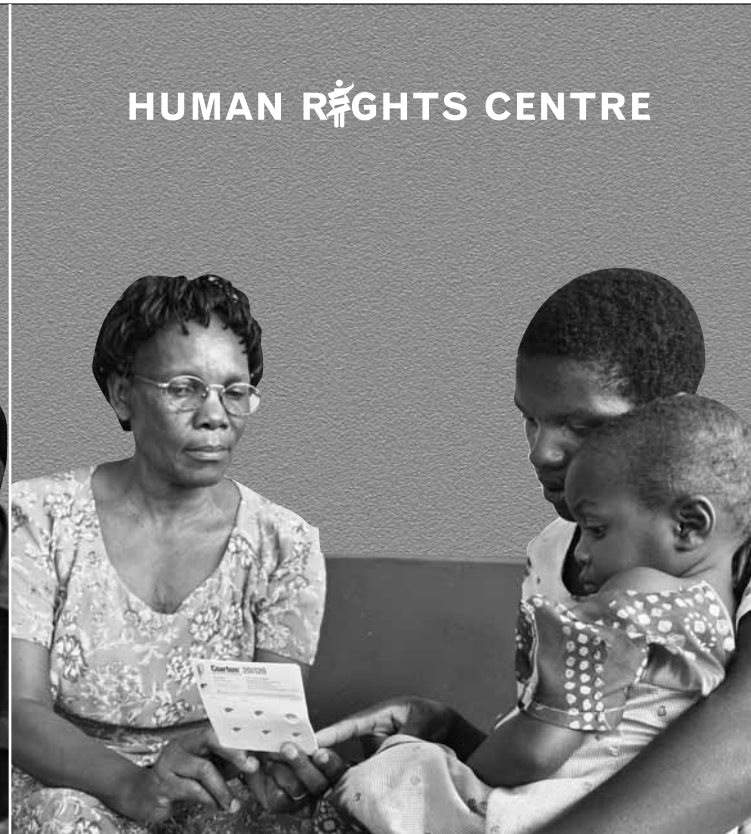




HUMAN RIGHTS CENTRE



PARTICIPATION

AND THE RIGHT TO THE HIGHEST ATTAINABLE STANDARD OF HEALTH

DR. HELEN POTTS



FOREWORD

Participation is a crucial part of the extensive common ground shared by health and human rights.

Many of those working in health-related sectors have long recognised the critical role of participation. Community participation, for example, is one of the themes recurring throughout the Declaration of Alma-Ata.

For its part, the human rights community recognises that participation is an important human right inextricably linked to fundamental democratic principles. Understood to be more than a narrow right to take part in elections, participation is also a component of other human rights. The active and informed participation of individuals, communities and populations, for example, is an integral component of the right to the highest attainable standard of health.

The close relationship between participation, health and human rights is reinforced when we look at health systems. The right to the highest attainable standard of health cannot be delivered without a responsive, integrated health system that is accessible to all. From the perspective of the right to health, a health system must have certain features, such as an up-to-date national health plan and outreach programmes for disadvantaged populations. Moreover, the right to health requires that a health system be non-discriminatory, transparent and participatory.

In brief, active and informed participation is an integral component of health systems, as well as the right to the highest attainable standard of health. States have a human rights responsibility to establish mechanisms that facilitate and enable participation in health-related planning, policy-making, implementation, monitoring and accountability. These mechanisms must be accessible to all those affected, including disadvantaged individuals, communities and populations, as well as patients and health workers. To be effective, the mechanisms will have to be adjusted from one issue and context to another. Because they are not cost-free, more sophisticated participatory mechanisms are demanded of high-income than low-income countries. However, whatever their stage of economic development, all States have a responsibility to ensure a minimum level of participation in their health-related sectors. Monitoring and accountability arrangements are needed to check whether or not a State has done all it can to facilitate meaningful participation.

Active and informed participation can make health interventions more effective, and also deepen participants' sense of responsibility for the health of their communities.

Although recognising its critical importance, health and human rights have not given participation the attention it deserves. While some health researchers have made more headway than those working in human rights, neither community has a widely accepted understanding

of what the process of participation means in practice. One complication is that participation is deeply contextual. Even in the same country, formulation of the national health plan, management of a local health clinic, and the delivery of a campaign on the sexual and reproductive health of adolescents, will require very different participatory arrangements. Also, participatory mechanisms are likely to vary from one culture to another. Because participation has to be seen in context, it is especially challenging to talk about it in general terms.

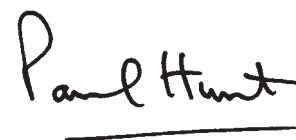
Some people have a naïve view of participation. In reality, effective participation (like access to information) is power. Some traditional elites are likely to resist the active and informed participation of disadvantaged individuals, communities and populations in health-related sectors. This gives rise to another complexity: effective participation is dependent upon the enjoyment of other human rights, such as freedom of expression, and the rights to information, assembly and association.

These are some of the reasons why health and human rights have tended to shy away from a close examination of participation — and this is why this publication is especially valuable. Here is an accessible, practical, timely and original introduction to participation and the right to the highest attainable standard of health.

Because of the complexity of the subject, Dr. Potts focuses on participation in relation to health policy development by States. In this context, she describes various methods of participation and introduces an instructive framework for a fair and transparent participatory process. Also, she identifies some indicators that can be used to monitor and evaluate participation, and she briefly lists the pre-conditions for the incorporation of participation in health systems. The publication provides a number of practical examples, from all regions of the world, of participatory mechanisms in relation to health policy development. In summary, this introductory study is an excellent resource for both health policy-makers and advocates.

As Dr. Potts prepared her study, she benefited from the advice of numerous researchers, policy-makers and representatives of civil society. Colleagues in the Human Rights Centre, University of Essex, advised throughout. I am very grateful to all those who gave their time and shared their insights.

Most of all, however, I am extremely grateful to Dr. Potts for the learning and hard work that she has invested in this original publication, and to the Ford Foundation for their indispensable financial support.



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Abbreviations

ACLAS	Asociación de Comunidades Locales de Administración de Salud
AGBLT	Associação Brasileira de Gays, Lésbicas, Bissexuais, Travestis e Transexuais
AIDS	Acquired Immune Deficiency Syndrome
CERD	Committee on the Elimination of Racial Discrimination
CESCR	Committee on Economic, Social and Cultural Rights
CRC	Convention on the Rights of the Child
DHB	District Health Boards
DSD	Department of Social Development
HIV	Human immunodeficiency virus
HMM	Home management of malaria
HRC	Human Rights Committee
ICCPR	International Covenant on Civil and Political Rights
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
ILO	International Labour Organisation
MoH	Ministry of Health
MSF-CH	Médecins Sans Frontières-Switzerland
NIHE	Northern Ireland Housing Executive
NGO	Non-government organisation
PPR	Participation and Practice of Rights
STMG	Seven Towers Monitoring Group
WHO	World Health Organisation

EXECUTIVE SUMMARY

Participation is a central feature of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health ('the right to the highest attainable standard of health' or 'the right to health'). The right to health places the well-being of people, groups, communities and populations at the centre of a health system. By doing so, implementation of the right can help to ensure that a health system is neither dominated by experts nor removed from the people it is meant to serve. In the context of health systems, this includes active and informed participation in the identification and development of health policy, as well as implementation and accountability. Clearly, participation has wide application in the context of the right to the highest attainable standard of health. In this modest introduction to participation and the right to health, the principal focus is placed on participation in the *development* of health policy to illustrate how active and informed participation can take place.

There are multiple actors involved in the delivery of health services. Developing an understanding of participation in the context of the right to health therefore goes beyond government. However, as with accountability and the right to the highest attainable standard of health, and as a matter of international human rights law, it is the State that has the ultimate obligation to guarantee the realisation of the right to health, and to develop the institutional mechanisms to ensure that participation takes place. Accordingly, the obligations of the State (the government and its agents, for example, health policy makers) are the focus here. The monograph is an introduction to the meaning of participation in health policy development and the process of participation, rather than a detailed toolkit. It is designed to be used as a starting point for health policy makers to develop greater understanding of the area.

Section I

Section I briefly reviews the sources and content of the right to the highest attainable standard of health, to provide the context for the discussion. Included in treaties at the regional and international levels, the right to health contains the freedom to make decisions about one's own health; the entitlement to a system of health protection; available, accessible, acceptable health facilities, goods and services that are appropriate and of good quality; non-discrimination; government obligations to respect, protect and fulfil the right to health; monitoring; accountability mechanisms and remedies; and finally, participation.

Section II

Section II explores the concept of participation in the context of the right to health, focusing on participation in the development of health policy. In the context of the

right to the highest attainable standard of health, individuals and groups are entitled to active and informed participation with government in health related decisions that affect them. This includes participation in identifying overall health strategy, agenda-setting, decision-making, prioritisation, implementation and accountability. Note, however, that the right of people to participate in health decisions that affect them is not to be at the expense of privacy, confidentiality and autonomy. Participation in health policy development is not the same as education, informing or consultation, as none of these concepts guarantees that the 'voice' of individuals and groups will be heeded, or that there will be follow through on any information gathered during the conduct of these activities.

Participation in the development of health policy begins with government ensuring institutional mechanisms are in place for participation, e.g., the presence of accessible and inclusive methods for participation. This means appropriate methods are accessible to different groups; the method for the participation of adolescents will be different to the method for those with physical disabilities. The process of participation should be fair. This means that there is an obligation on the government to ensure that the process of participation is neither directly nor indirectly discriminatory and that all participants have an equal voice. To help overcome barriers to people having an equal voice, fairness in participation encompasses three activities: agenda setting; rule making and facilitation; and discussion. Participation in the context of the right to health allows a preliminary, predetermined agenda because policy discussions have to start from somewhere. However, fairness requires that everyone has an equal chance to put their concerns on the agenda: the preliminary agenda may not be the final agenda.

Our ability to participate can be constrained by a variety of factors, including personal, interpersonal and institutional dynamics. Rules which govern the behaviour of participants, manage discussion, and determine how final decisions will be made can help overcome constraints on our participation. While rules do not guarantee good behaviour, they can help to identify bad behaviour. The appointment of an independent facilitator can help keep the discussion focused, manage the behaviour of participants and encourage comments from quieter participants. Fairness in discussion, encouraged by agenda setting, rule making and facilitation refers to all participants having the opportunity to make their voices heard. This activity overlaps with transparency – the second component of the framework for participation. Transparency is principally concerned with ensuring the best possible decisions are made given the information available to the participants at the time. Transparency refers to the accessibility and availability of information

related to the determinants of health, technical terms, personal experience and so on. For example, information related to epidemiological data, cultural understandings of health, and the right to health may need to be explained to participants to assist them in their decision-making. Also required are indicators that can be used to monitor the process and from which context-dependent benchmarks can be developed. A set of illustrative indicators is provided. Through the development of indicators and benchmarks, the government will be able to show how the 'voices' of people and groups have been heeded in the process and how the final decision was made.

Of course, a participatory process does not aim to ensure that the final decision is in accordance with the views of all people and groups – this is clearly impossible. There will be disagreement within groups and between people – and decisions have to be made. What it does mean, however, is that people and groups are entitled to an accessible, fair and transparent process and also an opportunity to understand how the final decision was reached.

Section III

Section III briefly reviews accountability for participation and participation in accountability. The government has an obligation to ensure that institutional mechanisms are in place to enable the participation of people and groups in a fair and transparent process of health policy development. Participation is a complex area and the methods for undertaking participation are context-dependent. To help government in fulfilling obligations with respect to participation, an independent accountability mechanism should develop guidelines on appropriate methods for undertaking participation. An appropriate accountability mechanism would be a national human rights institution. It is a specific human rights accountability mechanism, and is usually accessible, informal and flexible. Ideally, it would have a mandate to develop the guidelines for participation, and to conduct inquiries on its own initiative into participation as a component of an effective and integrated health system. These inquiries could address issues such as: the appropriateness of the method for undertaking participation; whether a fair and transparent process has

been conducted, and whether representatives are authorised and accountable to those represented. Additionally, this mechanism should have the mandate to receive complaints regarding the process of participation and to provide remedies when necessary.

Participation is also a component of the accountability process: in the monitoring of government activity (e.g., health service provision), in accountability mechanisms (e.g., in judicial, quasi-judicial, political, administrative, and social mechanisms), and in remedies (e.g., court orders for the government and citizens to engage in decision-making). The participation of people and groups will vary within and between the mechanisms. The concepts of accessibility, fairness and transparency also apply to accountability processes. However, how the content of the concepts varies with each mechanism will require further investigation.

Section IV

Section IV, the final section of the monograph notes that for a variety of reasons, it is not possible to provide a simple checklist of what needs to be in place to ensure participation. However, there are some pre-conditions which will facilitate participation, such as a strong commitment and long-term vision on the part of government that the right to health should be incorporated into the day-to-day work of health policy makers; the presence of a national health plan that incorporates the right to health; institutional mechanisms to ensure participation in the development of health policy, e.g., legislation requiring participation and the presence of accessible methods of participation; political will to support, and encourage the involvement of, relevant private actors in participation; sustained funding for capacity building for, and the actual costs of participation to ensure that people, including health policy makers, have the knowledge needed to participate; and, the presence of an independent institutional mechanism such as a national human rights institution or health complaints commission with a mandate over the right to health, to develop guidelines for participation, conduct inquiries into participation and respond to complaints about the process.



Photograph © 2007, courtesy of Participation and Practice of Rights Project. Seven Towers resident Michelle McFarland gives evidence at the Participation and Practice of Rights Evidence Hearing on the Right to Housing, 13 June 2007.

PREFACE

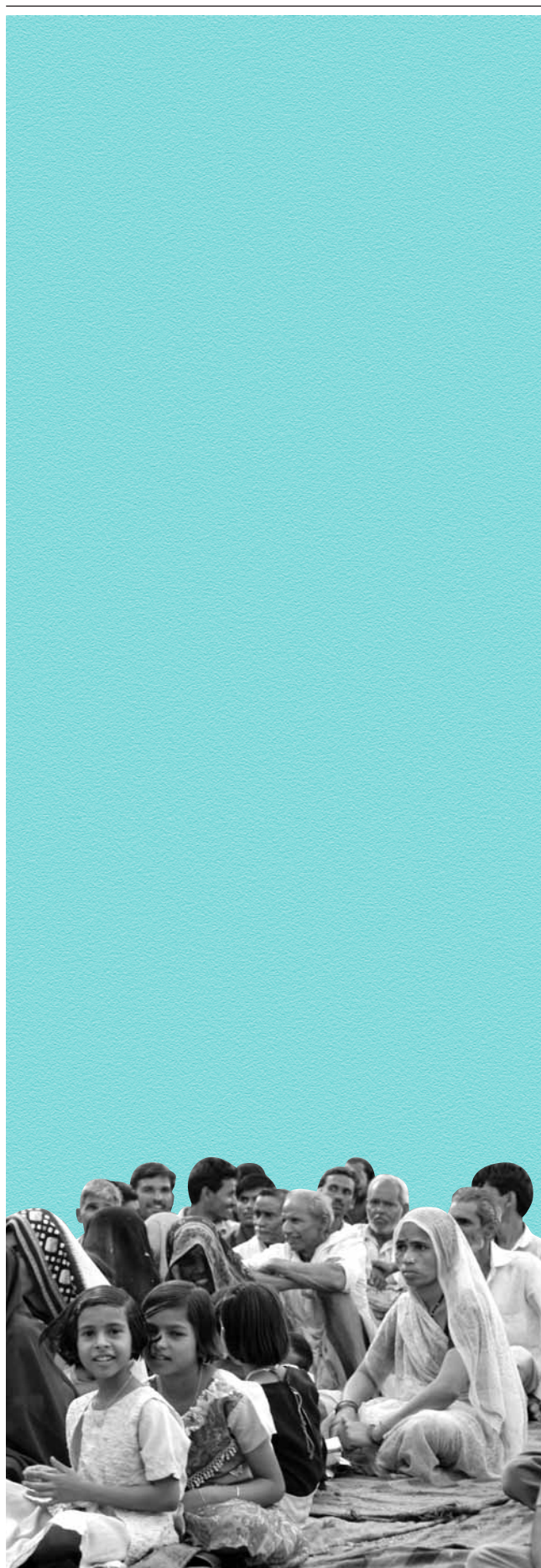
This monograph is an introduction to participation in the context of the right to the highest attainable standard of health. A companion volume to *Accountability and the right to the highest attainable standard of health* (sometimes referred to as the "accountability monograph"),¹ the monograph is intended to assist government health policy makers to understand the content and role of participation in the context of policy making and the right to health.

The active and informed participation of people and groups in all health-related decision-making is a component of the right to the highest attainable standard of health.² The right to health places the well-being of people, groups, communities and populations at the centre of a health system. By doing so, implementation of the right can help to ensure that a health system is neither dominated by experts nor removed from the people it is meant to serve.³ In the context of health systems, this includes active and informed participation in the identification and development of health policy, as well as implementation and accountability.⁴ Clearly, participation has wide application in the context of the right to the highest attainable standard of health. In this preliminary monograph, the principal focus is placed on participation in the development of health policy, as a means of illustrating how active and informed participation can take place.

There are multiple actors involved in the delivery of health services. Developing an understanding of participation in the context of the right to health therefore goes beyond government. It is also clear that the issue of participation has engaged donor organisations, specialised agencies, non-government organisations (NGOs), and academic researchers, as it is equally relevant to the work of these diverse organisations, institutions and individuals.⁵ However, as a matter of international human rights law, the State has the ultimate obligation to guarantee the realisation of the right to the highest attainable standard of health. Hence, as with accountability, it is the State that has the obligation to develop the institutional mechanisms to ensure that participation takes place.

Therefore, the monograph does not examine strategies for participation by individuals and groups in NGO programmes, donor programmes and so on. Nevertheless, developing an understanding of participation in this context will assist donors, NGOs and academics in their work

Photograph © 2005 Anil Gulati, Courtesy of Photoshare. Villagers in the Guna District of Madhya Pradesh State, India, meet as part of a village planning initiative begun by UNICEF, in partnership with the district administration and local NGOs.



to support governments in incorporating this right into their health system. It will also assist donor organisations, NGOs and academics in their work to support civil society organisations in health policy making forums and monitoring mechanisms.

The importance of people's participation is not new to the health sector; it has been a central theme in health-related discussions for many years. It is present in the World Health Organisation (WHO) Constitution, confirmed in the Declaration of Alma-Ata, and reiterated in the Ottawa Charter for Health Promotion (Ottawa Charter), and the Jakarta Declaration on Leading Health

The importance of people's participation is not new to the health sector; it has been a central theme in health-related discussions for many years. It is present in the World Health Organisation (WHO) Constitution, confirmed in the Declaration of Alma-Ata, and reiterated in the Ottawa Charter for Health Promotion (Ottawa Charter), and the Jakarta Declaration on Leading Health Promotion into the 21st Century (Jakarta Declaration).

Promotion into the 21st Century (Jakarta Declaration).⁶ At the same time, it is a contested topic. The meaning of 'participation' varies from the notion that individuals and groups are the passive recipients of information, to the idea that they are actively involved in the decision-making process. While it is frequently reiterated that participation is an essential component of human rights, it is not clear what form participation takes in the context of the right to health. This lack of clarity makes it difficult for governments to fulfil their obligations regarding implementation of the right to the highest attainable standard of health.

As an introduction to participation in the context of the right to health, this monograph covers the following issues:

- **It provides a brief review of the right to health to assist those who may be unfamiliar with the right.** An understanding of the content of the right to health and the essential component of participation is a necessary prerequisite to the incorporation of participation into health systems.
- **It describes the meaning of 'active and informed'**

participation in health policy development. While there are frequent references to the importance of participation in human rights documentation, to date there is no clear understanding of participation. The monograph draws upon United Nations documentation to describe the meaning of 'active and informed' participation.

- **It describes various methods of participation.** There is not one way to conduct participation, and a variety of methods will be required. Whichever methods are selected, they must be capable of ensuring the inclusion of the different and diverse people and groups affected by the policy or issue.
- **It illustrates a framework for a 'fair and transparent' process of participation in health policy development.** Participation applies to health policy development, implementation and accountability; the reality is that the process of participation by people and groups will vary amongst these activities. This preliminary monograph principally focuses on participation in the development of health policy to illustrate how a fair and transparent process can be undertaken.
- **It provides an illustrative list of the kinds of indicators that can be useful for the effective monitoring and evaluation of participation.** Appropriate indicators are essential to monitor whether institutional mechanisms for participation are in place and whether these mechanisms can ensure the participatory process has been fair and transparent. A set of indicators is provided which illustrate some of the issues which may need to be considered and from which context-dependent benchmarks could be developed.
- **It provides examples of participation in action.** Illustrative case studies and text boxes about participation are provided from different regions of the world.
- **Lastly, it provides a list of key factors required for participation in the context of the right to health.** The document provides a list in summary form of the key factors that need to be in place for the incorporation of participation into health systems.

The monograph is a practical information resource and advocacy tool for both health policy makers and health advocates. It can help governmental health policy makers ensure that the State fulfils its obligations arising from the right to the highest attainable standard of health. At the same time, it can operate (either alone or in combination with the accountability monograph) as an information resource to support those advocating for the incorporation of participation by individuals and groups in the development of health policy.

SECTION I: INTRODUCTION

“Participation and active involvement in the determination of one’s own destiny is the essence of human dignity.”

Mary Robinson, United Nations High Commissioner for Human Rights (1997-2002)

The essential requirement of the participation of people in health-related decision-making that affects them has been present in mainstream health discussions for many years at the international and national levels. It is present in the WHO Constitution Preamble, which asserts that ‘informed opinion and active cooperation on the part of the public are of the utmost importance in the improvement of the health of the people.’⁷ Since that time, the notion of people’s participation as a prerequisite to the achievement of the highest attainable standard of health has received widespread acceptance. It was formally endorsed by the member states of the WHO in the Declaration of Alma-Ata and was reiterated in the Ottawa Charter and the Jakarta Declaration. Governments have also endorsed the importance of participation in other international consensus documents. For example, the Programme of Action of the International Conference on Population and Development views the participation of women in reproductive health services as central to ensuring the quality of services and care and the promotion of human rights.⁸ At a national level, it is also possible to find legislation and government health policy

requiring the participation of people and groups in health policy making.⁹

There are significant practical and ethical benefits to be gained from people’s participation in health decisions:

■ **Practical Benefits.** Participation can help to secure the sustainability and effectiveness of interventions by gaining people’s trust, support and internalisation of the goals of health policy initiatives.¹⁰ The participation of those affected by policy decisions in policy development is a key contribution as it will include their distinct personal experience and non-medical understanding of issues which in turn can lead to asking questions that health workers may not have considered.¹¹ This in-turn can help to secure improvements in health outcomes (*see Box 1 opposite*) and the quality of health care (*see Boxes 2 and 5*).

Additionally, participation promotes participants’ understanding of unfamiliar situations or circumstances, i.e., learning about the other side of the story.¹² Through participation, knowledge is acquired on the state of a problem, possible solutions, other peoples’ and groups’ interests and values, and one’s own personal interests and values. This can assist with preventing the manipulation of the process of participation and change the attitude of participants as they learn from each other. It can also assist with developing a sense of self-respect and responsibility to oneself and others. For example, in a citizens’ jury concerned with the development of drugs policy, jurors commented on how they had gained a lot and learned from taking part, particularly from the exposure to different opinions, and as a result changed their opinions regarding drug dealers.¹³ See also the South African Constitutional Court case of *Occupiers of 51 Olivia Road and Ors. v City of Johannesburg and Ors.*, where the Court noted that meaningful engagement had the potential to contribute to the resolution of disputes and to increased understanding and sympathetic care if both sides are willing to participate in the process (*see Box 8 on page 29*).

■ **Ethical Benefits.** Participation places the well-being of individuals, communities and populations at the centre of the health system. Participation promotes accountability, encourages people’s independence and is likely to reduce paternalism associated with health policy. Health policy should be based on people’s priorities and control rather than the priorities and control of health workers.¹⁴ While health policy makers have an indispensable role to play, a more holistic, people centred approach needs to be adopted.¹⁵

Clearly, the concept of participation is not new to the health sector. However, it is a contentious term that can mean everything and nothing. Empirical evidence from development and health literature over the previous



Photograph © 2007
Bonnie Gillespie,
courtesy of Photoshare.
A community health
worker in rural Ethiopia
prepares to distribute
anti-malarial medicine.

three decades shows that participation encapsulates a range of meanings; this has given rise to differing practices, merging of ideas and the emergence of new language.¹⁶ The meanings can vary from allowing community representatives a seat at the table where policy decisions are made; to people being involved in agenda setting, analysing problems and participating in decision-making; to a process of democratisation whereby governments become more accountable and responsive to the needs of the disenfranchised; to a cost-sharing exercise contributing toward sustainable programmes.¹⁷ Approaches vary from the 'top-down', in which participants are passive recipients responding to professional direction; to the 'bottom-up', whereby people identify their priorities and work with government planners

and professionals to address them; to a combination of these approaches.¹⁸

The concept of participation is also not new to human rights; many international human rights treaties recognise participation as a human right. International treaties that have been created to protect the human rights of particular groups, such as women, people with disabilities and those subject to discrimination on the basis of race, all include articles concerned with ensuring the participation of relevant groups in the conduct of public affairs and policy development.¹⁹ The Convention on the Rights of the Child (CRC) contains one of the most explicit provisions for participation in any treaty (see *Box 3 overleaf*) and confirms that participation extends to children and is not restricted to adults.

Box 1: Community-based participatory interventions reduce maternal mortality: Nepal

To address the scarcity of evidence for the effectiveness of participation in the development and provision of health care services, a randomised control trial was conducted in Makwanpur district, Nepal. The MIRA Makwanpur trial was a cluster-randomised, controlled trial of a community-based participatory intervention in a rural mountainous area of Nepal. The trial tested a large-scale intervention, using facilitators to work with women's groups in a population of 170,000 covering 1600 km².

Forty-two village development committees were matched into twenty-one pairs (paired on the basis of topographic stratification, similar ethnic group distributions and similar population densities). A list of random numbers was used to select twelve pairs which formed the study clusters. One cluster in each pair was then randomly allocated to either intervention or control. The average population per cluster was about 7,000, spread over an area of 60 km². A cluster consisted of nine wards. For every intervention cluster, one literate, local female facilitator was recruited. Each facilitator convened one women's group meeting per month in every ward. The role of the facilitator was to activate and strengthen groups and support them through an action research cycle. One supervisor provided support for every three facilitators by attending group meetings and making regular community visits.

The first phase of the trial involved 10 meetings over a period of almost a year. These meetings concerned issues such as the introduction of the study, problem identification (i.e., identifying how women understood maternal and neonatal problems, and learning the frequency of maternal and neonatal problems), problem prioritisation (the sharing of information from other women in the community and the prioritisation of important maternal and neonatal health problems), and joint planning

(i.e., having a discussion of possible strategies for addressing the priority problems, and holding a meeting involving other community members, to discuss the problems and possible strategies and reach consensus). In the following phase, the women's groups implemented and assessed their strategies. An immediate result of the process was that women sought more information about perinatal health.

Typical strategies developed included: stretcher schemes, production and distribution of clean delivery kits, home visits by group members to newly pregnant mothers, and awareness raising with a locally made film. Throughout the process, the groups were also involved in other health-related activities in their communities. Health-service strengthening activities were also undertaken in both intervention and control areas.

Maternal mortality, although not a primary outcome of the trial, was significantly lower in intervention areas. Women in the intervention clusters were more likely than those in the control clusters to have had antenatal care, to have given birth in a health facility, with a trained attendant or a government health worker, and to have used a clean home delivery kit or a boiled blade to cut the umbilical cord. Birth attendants were more likely to have washed their hands. Rates of maternal morbidity were similar between the two groups, but women in the intervention clusters were more likely than those in control clusters to have visited a health facility in the event of illness.

Source: Manandhar, DS., Osrin, D., Shrestha, BP., Mesko, N., Morrison, J., Tumbahangphe, KM., Tamang, S., Thapa, S., Shrestha, D., Thapa, B., Shrestha, JR., Wade, A., Borghi, J., Standing, H., Manandhar, M., Costello, AMdeL., and members of the MIRA Makwanpur trial team, (2004) 'Effect of a participatory intervention with women's groups on birth outcomes in Nepal: cluster-randomised controlled trial', The Lancet 364:970-979.

Box 2: CARE-Perú's improving the health of the poor: A rights based approach

The Care Perú project (in collaboration with Physicians for Human Rights) has developed participatory mechanisms for the planning, provision and evaluation of health services. As part of this process, citizen monitoring of health services has been developed in the Piura and Puno regions of Perú.

Monitoring of hospitals, health centres and health posts by Quechua and Aymara community women

leaders has resulted in a change in attitudes by health workers. The women who conduct the monitoring have noted a distinct improvement in the quality of health service provision in terms of medical treatment, the explanations given by health workers to patients, and how patients are personally treated.

Source: See Accountability and the right to the highest attainable standard of health, page 35).

Photograph © 2001 Guillaume M. Bakadi/CCP, Courtesy of Photoshare. Building partnership with community groups; PRISM, the Guinea Family Planning and Health Project. Here is a group of women representatives in Banankoro. Each one is able to reach at least 200 women through their association, or "Seres." According to Health Center Chief Dr. Daf, out of 100 women receiving prenatal care, at least 90 have symptoms of STDs. At their request, they were given an orientation on STD/HIV/AIDS. They urged PRISM to start targeting males as soon as possible.



In addition, each of the treaty monitoring bodies has also developed general recommendations and general comments which reiterate the importance of participation.²⁰ The International Labour Organization (ILO) Constitution, Article 24, enables industrial associations of employers or workers to make representations that a Member State is not complying with a convention. The governing body appoints a tripartite committee from among its members to consider representations. These procedures (not available to individuals) have been used in more recent years.

The importance of the participation of particular groups in health policy development has also been endorsed by other international instruments. See, for example, the United Nations Declaration on the Rights of Indigenous Peoples, which directs that ways to ensure the participation of indigenous people in decisions that affect them are to be established.²¹ The United Nations Permanent Forum on Indigenous Issues has noted that the recurrent failure to engage indigenous peoples in the development and implementation of health policies contributes to their poor health outcomes.²²

Box 3: Convention on the Rights of the Child, articles 12 and 13**Article 12**

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

Article 13

1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.
2. The exercise of this right may be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:
 - a. For respect of the rights or reputations of others; or
 - b. For the protection of national security or of public order (ordre public), or of public health or morals.

Despite the emphasis placed on participation by both the health sector and the human rights community, it is not clear what participation means nor what its process is, in the context of human rights generally and the right to the highest attainable standard of health specifically. This makes it difficult for health policy makers to evaluate the process of participation to ensure that government is fulfilling its right to health obligations. Indeed, this lack of evaluation also makes it difficult to obtain the evidence that

participation is a viable and reliable concept that leads to better decisions and more effective and sustainable health policy.

This monograph is an introduction to participation in health policy development rather than a detailed toolkit. It is designed to be used as a starting point for health policy makers to develop greater understanding of the area. This understanding can be gained, in part, by a brief review of the content of the right to the highest attainable standard of health.

A. THE RIGHT TO HEALTH AND ITS SOURCES

The right to the highest attainable standard of health is a fundamental human right. The right to health is not a right to be healthy; the government cannot fully ensure good health, as it is influenced by some factors which are in whole or in part outside the government's control, such as individual susceptibility to ill health. As with all human rights, the right to health is interlinked

and related to both civil and political rights (e.g., life, expression, association) and other economic, social and cultural rights (e.g., education, housing, social security, work, culture).

The right to health can be found in laws at three different levels: international, regional and national.

1. INTERNATIONAL

There are many international human rights treaties (also known as covenants or conventions) that recognise the right to the highest attainable standard of health. Though first formulated in the WHO Constitution, the central formulation of the right to health is contained in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR or the Covenant) (see Box 4 below).

The right is also contained in international treaties that have been created to protect the human rights of particular groups, such as children, women, people with disabilities and those who are subject to discrimination on the basis of race.²³ These treaties highlight the emphasis that human rights place on people who are vulnerable to discrimination and marginalisation and who may require special attention.

Box 4: International Covenant on Economic, Social and Cultural Rights, Article 12

1. The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realisation of this right shall include those necessary for:
 - a. The provision for the reduction of the still birth-rate and of infant mortality and for the healthy development of the child;
 - b. The improvement of all aspects of environmental and industrial hygiene;
 - c. The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
 - d. The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

2. REGIONAL

In addition to international standards, the right to health is recognised in regional human rights treaties, including:

- *The African [Banjul] Charter on Human and Peoples' Rights*, Article 16;
- *The African Charter on the Rights and Welfare of the Child*, Article 14;
- *The European Social Charter (Revised)*, Articles 11 and 13;

- The *Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights* (Protocol of San Salvador), Article 10.

Other regional instruments, which do not explicitly recognise the right to health but which offer indirect protections through other health-related rights, include:

- The *American Declaration on the Rights and Duties of Man*;

- The *American Convention on Human Rights*;
- The *Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women*;
- The *European Convention for the Protection of Human Rights and Fundamental Freedoms* and its protocols.

3. NATIONAL

The right to health is recognised in numerous national constitutions.²⁴ When the right to health is enshrined in a constitution or in domestic laws, it creates an opportunity for an individual or group to pursue a complaint and seek a legally binding decision in the national courts if the right has been violated.

The right to health has also been indirectly protected in national courts through its incorporation into another human right. For example, the Supreme Court of India has, in several cases, found that economic and social rights such as the right to health are an integral part of the fundamental rights guaranteed by the Constitution.

B. WHAT DOES THE RIGHT TO HEALTH CONTAIN?

Photograph © 2007, courtesy of the Participation and Practice of Rights Project. Seven Towers high rise complex of flats in North Belfast, Northern Ireland.

The right to the highest attainable standard of health can be understood as a right to an effective and integrated health system, encompassing health care and the underlying determinants of health,

which is responsive to national and local priorities, and accessible to all. The right to health contains the following overlapping and interrelated elements:²⁵



1. FREEDOMS AND ENTITLEMENTS

The right to health encompasses both freedoms and entitlements. The freedoms include, for example, the right to make decisions about one's health, including sexual and reproductive freedom, and the right to be free from interference, such as nonconsensual medical treatment. The entitlements include, for example, the right to culturally appropriate health services and to the underlying determinants of health, such as adequate sanitation, safe water, adequate food and shelter, safe and healthy working conditions, and a healthy environment.

2. AVAILABILITY, ACCESSIBILITY, ACCEPTABILITY AND QUALITY

The right to the highest attainable standard of health also contains four interrelated and essential elements: Availability, Accessibility, Acceptability and Quality (AAAQ).²⁶ While these essential elements are often described in connection with health care services, they also apply to the underlying determinants of health.

The AAAQ framework is summarised here.

Availability

Health facilities, goods and services must be available in sufficient quantity within the country.²⁷ This includes, for example, hospitals, clinics, trained health workers, essential medicines, preventive public health strategies and health promotion as well as underlying determinants, such as safe drinking water and adequate sanitation facilities.

Availability is concerned with the physical presence of health services. It involves, for example, the question of whether there are a sufficient number of health workers and health facilities in rural areas; whether there is a national public health plan; whether there is a health complaints commissioner or similar; whether sexual and reproductive health services are provided.

Accessibility

Health services must be accessible to everyone without discrimination, especially the most vulnerable or marginalised people. They must be physically and economically accessible. For example, while health services may be available at the local level, they may not have been designed in a way that is responsive to local people's needs. If the facility is available but is not responsive to local needs, the facility is not accessible. If the facility charges user fees and those in need cannot pay the fee, the facility is not economically accessible.

Accessibility also includes the right to seek, receive and impart information on health. This latter component of accessibility is particularly important for participation. Protection and enforcement of the right to seek, receive and impart information on health is a prerequisite for participation. It is important to note, however, that this is not at the expense of privacy, confidentiality and autonomy.

Acceptability

Health services must be respectful of medical ethics, culturally appropriate and gender sensitive. For example, medical treatment must be explained in a manner that is understandable to the person who is to receive the treatment. Health workers will need to be aware of cultural sensitivities in the provision of health care; for example, modes of delivery differ with culture. A gender perspective may need to be incorporated into local health facility budgets to identify gender-based gaps in the budget allocation to programmes of the health facility.

Quality

Health services must also be scientifically and medically appropriate and of good quality. For example, there must be access to good quality, essential medicines. If medicines are rejected in the North because they have expired, they must not be recycled to the South. Quality also extends to the manner in which people are treated. Health workers must treat people politely and with respect. Further, the underlying determinants of health must be appropriate and of good quality. Thus, for example, health education, in addition to hospitals and medicines, must be of good quality.

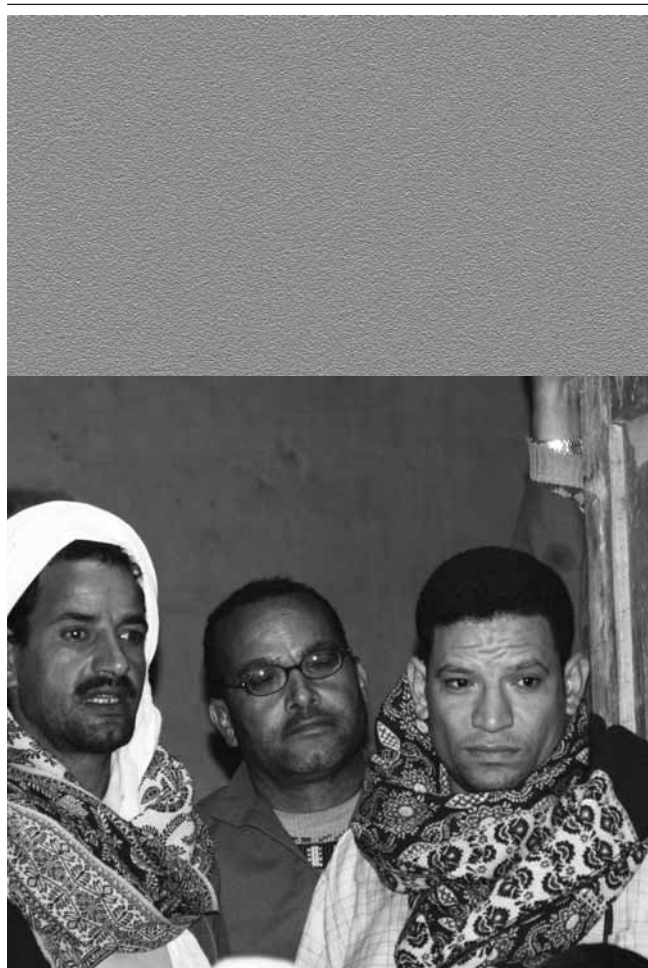
Photograph © 2005 Amrita Gill-Bailey/CCP, courtesy of Photoshare. Men in Minya, Egypt participate in a Dawar meeting, as part of the USAID-funded project, Communication for Healthy Living (CHL). Dawar meetings are held for male leaders at the village level to identify community health problems and solutions.

3. RESPECT, PROTECT AND FULFIL

The State has specific obligations under international law to respect, protect and fulfil the right to health. For example, the obligation to respect places an obligation on States to refrain from denying or limiting equal access for all persons (e.g., prisoners, asylum seekers) to health services. The obligation to protect means that States should take steps to prevent third parties from jeopardising the health of others; the private delivery of health services does not nullify government obligation to regulate those services. The obligation to fulfil requires governments to adopt necessary measures, including legislative, administrative and budgetary measures, to ensure the full realisation of the right to the highest attainable standard of health (e.g., access to primary health care facilities).

4. NON-DISCRIMINATION AND EQUALITY

Central to the right to the highest attainable standard of health is non-discrimination and equality. The right to health belongs to everyone. A person's chances of enjoying good health must not be disadvantaged because of their sex, race, age, language, disability, health status (e.g., with regard to HIV/AIDS), sexual orientation, or socio-economic or other status. In addition, health policy must be developed in a manner that respects cultural diversity. Special attention must be paid to promoting the equality of women, men and disadvantaged groups. Indeed, careful consideration of health resource allocations is required to ensure that health policy and spending promote equality rather than perpetuating inequalities, and this is why participatory budget analysis is important.²⁸



5. PROGRESSIVE REALISATION AND RESOURCE AVAILABILITY

The right to the highest attainable standard of health is subject to progressive realisation and resource availability. Put simply, all countries are expected to be doing better in two years time than they are doing today (progressive realisation), while resource availability means that what is required of a developed country is of a higher standard than what is required of a developing country. Many countries do not currently have the capacity or the resources necessary to implement fully the right to health for all people. Nonetheless, governments must take deliberate and concrete steps toward the full realisation of the right to the highest attainable standard of health for all. The corollary to the obligation to progressively realise the right to health is that there is a strong presumption that retrogressive measures are not permissible.²⁹

Because progressive realisation will not happen spontaneously, the government must have a national health plan, encompassing both the public and the private sectors, for the development of its health system. This plan is to include appropriate indicators and benchmarks in order to monitor whether or not the government is improving the health system and realising the right to the highest attainable standard of health for its population. The indicators must be broken down on the basis of major social classifications (e.g., sex, ethnicity, urban/rural, age, socio-economic status) to identify whether any particular group is disadvantaged. While it is government that has the obligation to develop indicators and benchmarks, indicators which measure progressive realisation can also be developed by civil society (see *Case Study No. 4 on page 34*).

6. CORE OBLIGATIONS

In addition to the obligation to progressively realise the right to health, there are some core obligations of immediate effect. These core obligations require minimum, essential levels of primary health care, food, housing, sanitation, essential drugs, and the preparation of a national health plan. Even in the presence of limited resources, the government is required to give first priority to the most basic health needs of the population and to pay particular attention to protecting the most vulnerable sections of the population.

The preparation of the national health plan is an immediate core obligation and is not subject to resource constraint. The plan is to be prepared in a participatory manner and should address the health concerns of the whole population, while giving particular attention to all vulnerable and marginalised groups. The reality is that it may not be possible for everyone to participate in the development of the plan. However, the government has an immediate obligation to obtain a representation of views, particularly those of the vulnerable and

marginalised. This does not mean simply obtaining the views of representatives. How this is to be done is contextual. An illustration is provided by Brazil's 12th National Health Conference (2003). The then Minister of Health promised that, for the first time in Brazil's history, the national health plan would be based on the conclusions of the National Health Conference. Approximately 3,000 delegates attended the conference. These delegates represented a 'staggering diversity of interests', from the Amazon, remote rural areas and urban slums.³⁰ Delegates were elected through a series of stages, from sub-municipal pre-conferences and state conferences, and many travelled for days by bus to attend the conference in Brasília.³¹ See Case Studies Nos. 2 and 6 (pages 32 and 36) which also describe processes undertaken to ensure the incorporation of a representation of views into the national planning process.

The national health plan cannot include policies for every health issue in a country. Therefore, policies and strategies addressing different health issues will flow

Photograph © 2004 Bangladesh Center for Communication Programs, courtesy of Photoshare. Adolescents work in a small group during a "Know Yourself" Life Skills Workshop in Jessore, Bangladesh, as part of the Adolescent Reproductive Health (ARH) program developed by the Bangladesh Center for Communication Programs (BCCP).



from the development and implementation of the national health plan, e.g., strategies pertaining to HIV/AIDS, nutrition, health for sexual minorities, and adolescent health. The government has a core obligation to ensure

the participation of relevant individuals and groups throughout the development and implementation of these subsequent health interventions, as well as accountability for these interventions.

7. INTERNATIONAL ASSISTANCE AND COOPERATION

In accordance with the obligations envisaged in the United Nations Charter and some human rights treaties (for example, the ICESCR, Article 2, and the CRC, Article 2), developing countries have a responsibility to seek international assistance and cooperation to help them strengthen their health systems. Equally,

developed countries have some responsibilities towards the realisation of the right to health in developing countries generally, and especially with regard to the fulfilment of their core obligations arising from the right to the highest attainable standard of health.³²

8. MONITORING AND ACCOUNTABILITY

People are entitled to an accountability process which requires the government to show, explain and justify how it has discharged its obligations regarding the right. This accountability process is both prospective and retrospective. As a prospective process, it draws attention to the government's potential to improve performance: to identify what works, so it can be repeated, and what does not, so it can be revised. As a retrospective process, it draws attention to the remedies that should be available when the government has failed to fulfil its obligations.

The accountability process necessarily includes monitoring of conduct, performance and outcomes on a continuous basis by government and civil society (either collaboratively with government or independently). Monitoring provides, on an ongoing basis, the information that government needs to determine the areas on which

it should focus in order to reach its targets for the realisation of the right to health. Monitoring also provides rights-holders with the information they need to claim their rights and to hold the government to account when obligations have not been fulfilled.

The accountability process also requires the presence of accessible accountability mechanisms to provide a forum for explanation and justification. This can take place in a variety of settings such as the courts, a national human rights institution, public hearings, and national or local public meetings. In addition, remedies for the non-fulfilment of right to health obligations are to be available. Remedies are broad in nature as they include the modification of monitoring processes, human rights training, and organisational improvements concerning planning, budgeting and policy formulation, in addition to judicial remedies such as compensation.

9. PARTICIPATION

Lastly, the active and informed participation of people and groups in all health-related decision-making is a component of the right to the highest attainable standard of health. It is also present in each of the elements set out above (e.g., the participation of people in the planning for health facilities, will promote the physical and economic accessibility of those health facilities). Equally, the development of culturally appropriate health facilities necessarily implies participation. Participation in the context of the right to health and health systems clearly has wide application. It is important to note that effective participation relies in part upon other rights, such as the right to seek, receive and impart health-related information; the right to express views freely; and the right to basic health education. Full participation on a non-discriminatory basis also requires special attention to sharing information with, and seeking the views of, both women and men, as well as the views of disadvantaged people.

As noted above under the heading Core Obligations,

provision for participation in the development, implementation and review of the national health plan, as well as in the health interventions flowing from that plan, is one of the core obligations with regard to the right to the highest attainable standard of health. In the context of health systems, this includes participation in the identification and development of health policy, as well as implementation and accountability. The participation of people and groups in these activities is clearly a complex area. While the method for undertaking participation is context dependent, steps must be taken by the government to develop institutional mechanisms to enable participation to take place. To assist governments with this obligation, the next section focuses on participation in the development of health policy as a way of illustrating a framework for the active and informed participation of people. The framework is supported by a set of illustrative indicators which are essential for the effective monitoring and evaluation of participation.

SECTION II: PARTICIPATION

Summary

In the context of the right to the highest attainable standard of health, an 'active and informed' process of participation includes the following elements:

- Institutional mechanisms to ensure that people can participate;
- Capacity building for participation (for health policy makers, individuals and groups) where necessary;
- Participation in:
 - setting the agenda for discussion,
 - policy choices;
 - implementation;
 - monitoring and evaluation; and
- Accessible accountability mechanisms and remedies if required.

A. WHAT IS PARTICIPATION?

Participation is an essential component of an effective, integrated health system and an ongoing activity that should be present in the development and implementation of health policy, as well as accountability for health policy. In the context of the right to the highest attainable standard of health, individuals and groups are entitled to 'active and informed' participation with government in health-related decisions that affect them. This includes participation in identifying overall health strategy, agenda-setting, decision-making, prioritisation, implementation and accountability.³³ Health policy which is responsive to the health needs of particular groups, for example, women, children, adolescents, indigenous and ethnic groups, the elderly, and sexual minorities, cannot be achieved without the active and informed participation of these groups.³⁴ But what is 'active and informed' participation?

The Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies (the Guidelines) refer to 'meaningful and effective' participation.³⁵ The Guidelines describe four phases of participation:

1. Preference revelation

In the initial stage of policy development, people should be able to express what objectives they want to achieve or what is of concern to them. In other words, people should be able to place issues on the agenda for discussion. This is possible in both small and large settings.

For an example of a small setting, see the planning process adopted during the hand over of an HIV/AIDS clinic in Coatepeque, Guatemala, from Médecins Sans Frontières-Switzerland (MSF-CH) to the Ministry of Health (MoH). Because a participatory process was adopted, all interested parties had an equal opportunity to place their concerns on the agenda (*see Case Study No. 1 on page 31*). The First National Conference for Lesbians, Gay Men, Bisexuals, Transvestites and Transsexuals (LGBT), held in Brazil in June 2008, is an example of a large setting that provided an opportunity for people to place their issues on the agenda. Over 1,000 people took part in the conference, and 559 proposals for public policies related to LGBT groups were approved (*see Case Study No. 2 on page 32*).

2. Policy choice

Policy choice is concerned with policy formulation, and hence will include difficult resource allocation decisions. The Guidelines consider that it is not necessary for people to take part in all technical deliberations. But people must be allowed to participate in identifying priorities and

developing benchmarks. In practice, this means that while individuals and groups may not be involved in technical deliberations, such as the analysis of data, that form the basis of alternative policy choices, they must be made aware of the implications of the alternative policy choices that are based on the technical deliberations.

Occasionally arguments

Photograph © 2007
Tony Bolaños. Staff of MSF-CH outside the office of MSF-CH, Coatepeque with a banner that reads, "Solidarity, commitment and participation with people living with HIV".



are put forward that the public is too subjective or too uninformed to make complex decisions. However, the deliberations of a Citizens' Jury on genetic testing and insurance in Edinburgh (Scotland) challenge this view. Through a process of knowledge-building, cross-examination and deliberation, 'lay' people were able to assimilate complex information, engage in subtle argument and arrive at well-reasoned conclusions.³⁶

3. Implementation

This phase requires that opportunities are created to enable individuals and groups to exercise their right to participate in the implementation of health policies. This participation is not meant as a way for health policy makers to mobilise community resources (land, labour, money, time and so on) to supplement or off-set the costs of health policies. Home management of malaria provides an important example of participation in the design and implementation of health programmes (see Box 5 below). Community-driven reconstruction or

community-driven recovery (CDR) also provides an example of implementation which enables individuals and groups to exercise their right to participate (see Box 7 on page 22).

4. Monitoring and assessment

This phase is concerned with ensuring that people who are affected by policies participate in monitoring and evaluating the success or failure of those policies and take part in procedures that hold government accountable.³⁷ In practice, this means that people can also be involved in the development of indicators and benchmarks for monitoring and evaluation of policies. For example, in Northern Ireland, the residents of the Seven Towers Flats, with the support of the Participation and Practice of Rights Project (PPR Project), and following capacity building for participation, developed indicators to monitor whether the government was meeting its commitments to progressive realisation of the right to adequate housing and the right to health (see Case Study No. 4 on page 34).

Box 5: Home Management of Malaria in Ghana

The challenge for any malaria control strategy is the development and implementation of effective, sustainable, appropriate interventions. Implementation research from the Special Programme for Research & Training in Tropical Diseases (TDR) has demonstrated that home management of malaria (HMM) is an intervention which is effective, sustainable and appropriate. HMM has become a cornerstone of malarial control in sub-Saharan Africa, and the approach is incorporated into strategic health plans or in applications to the Global Health Fund to Fight AIDS, TB and Malaria.

HMM involves training local mothers and other community members to recognise fevers, provide user-friendly, pre-packaged antimalarial medications, and keep the medicines properly stored and recorded. HMM was developed to increase access to medicines in areas where there is no nearby health facility or provider. With HMM, mothers can get to drug distributors easily and quickly, rather than travelling long distances to get to hospital.

A four-country study (Ghana, Burkina Faso, Uganda and Nigeria) conducted for TDR describes the process adopted in Ghana to develop user-friendly, prepackaged antimalarial (Chloroquine) medications. Community members expressed their preferences on packaging during a baseline survey for the study. The drug prepacks for children aged

6–11 months were white, as children of this age are breast feeding and milk is white. The picture on the drug packets was of a crawling child, as children less than 11 months old are crawling. The drug prepacks for children over 1 year old depicted a walking child and were coloured yellow, which, according to community members, represented the yellow eyes and urine of the malaria victims.

More recent studies in Ghana have revealed that combination treatments for malaria can also be delivered via HMM. Three research studies were conducted in Ejisu-Juaben, Ho and Dangme West districts using one of the new artemisinin-combination treatments in community settings. Mothers, drug distributors and health workers praised the process.

Mothers can get to drug distributors easily and quickly and don't have to travel long distances to get to the hospital, which costs time away from the family and money. Health workers believe their workload has been reduced as a result of the community-level case management of malaria.

Source: Guapong, M. and Garshong, B. Lessons Learned in Home Management of Malaria. Implementation research in four African countries, (TDR/WHO, 2007). Online: www.who.int/tdr/publications/publications/lessons_hmm.htm [accessed 12 August 2008]; and, 'Combination treatments for malaria found safe and effective for children when provided by volunteers', WHO Ghana Press Release, 11 June 2007.

Meaningful and effective participation depends upon two preconditions:

1. Institutional arrangements and specific mechanisms must be provided to ensure this participation at different stages.

2. Capacity-building activities to ensure that people have the ability to meaningfully and effectively participate.

Institutional arrangements for participation need not be developed solely by government. In the absence of

government willingness to develop new participative arrangements, and where current mechanisms are inadequate, civil society can develop these arrangements independently. *ForoSalud*, a civil society organisation in Perú, with the support of Care-Perú and other organisations, developed mechanisms to ensure peoples' participation in the development and implementation of health plans at the national and provincial levels (see *Case Study No. 6 on page 36*). This case study also provides an example of the acknowledgement of the fact that capacity building is necessary to enable people to participate (citizens, health workers and health policy makers within the MoH). The PPR Project in Northern Ireland also provides a good example of a community driven mechanism for participation in the presence of inadequate government arrangements. This case study also identifies the importance of the capacity building provided for the residents of the Seven Towers prior to their participation (see *Case Study No. 4 on page 34*).

The *Report of the United Nations Conference on Environment and Development*³⁸ refers to 'effective', rather than 'active and informed', participation. However, the meaning is essentially the same because 'effective' participation is clearly defined in terms of three elements that are similar to those of 'active and informed' participation: access to information; access to the decision-making process; and importantly, access to judicial redress if a dispute arises or the public wants to challenge a decision.³⁹

As health policies are to be owned by all relevant individuals and groups, 'active and informed' participation in the context of the right to the highest attainable standard of health is equivalent to the notion of a partnership

in the development, implementation and review of health policy.⁴⁰ The intention underpinning this partnership is that the 'voice' of individuals and groups will be heeded in decision-making processes.

In brief, active and informed participation is comprised of the following elements:

- Institutional mechanisms to ensure that people can participate;
- Capacity building for participation (for health policy makers and individuals and groups) where necessary;
- Participation in:
 - setting the agenda for discussion,
 - policy choices;
 - implementation; and
 - monitoring and evaluation.
- Accessible accountability mechanisms and remedies if required.

These components will help to ensure a fair, transparent process of participation.

Governments are ultimately accountable for compliance with international human rights law. Thus, they are obligated to provide an environment which facilitates a process that is not easily manipulated. They are also obligated to ensure that the views of diverse and different groups are heeded in the health policy making process. This will require more than simply proclaiming that health policy must be developed in a participatory manner. It requires the process of participation to be developed systematically on the basis of a clear methodology which includes a strong evaluation component.

B. WHAT PARTICIPATION IS NOT

Participation in the context of the right to the highest attainable standard of health is not the same as:

- Education,
- Informing, or
- Consultation.

None of these concepts guarantee that the 'voice' of individuals and groups will be heeded or that there will be

follow through on any information gathered during the conduct of education, informing or consultation.⁴¹ Education is concerned with teaching or instructing individuals and groups to develop their capacity in a particular area or their knowledge of an issue, e.g., capacity building prior to participation and teaching about human rights. Informing can be similar to education when it involves the process of supplying people with information about a particular issue or fact. It can also be understood as a process wherein tasks are assigned in a project, but those with the power decide the agenda and make the decisions.⁴² Consultation is the process of seeking advice or soliciting information or views about an issue or fact with the aim of obtaining approval from a community for a proposed plan or project.⁴³ People may indeed be heard, but this has not generally meant that people are actively engaged in the process.⁴⁴

Education, informing and consultation clearly play an important role in involving people, but they do not amount to participation.

Photograph © 2007
Bonnie Gillespie,
courtesy of Photoshare.
A nurse in rural Tanzania
explains to a child's
mother how to
administer artemisinin-
based combination
therapy (ACT) as
treatment for adverse
effects of malaria.





Photograph © 2004 Megan Hallahan, courtesy of Photoshare. Participants in the Global Youth Parliament, a global parliament of urban youth in Rome, Italy.

C. UNDERTAKING PARTICIPATION

Summary

Participation in the development of health policy is comprised of four elements:

1. An accessible and inclusive method;
2. A fair and transparent process;
3. Indicators for monitoring and evaluating the method and process; and
4. An independent accountability mechanism and remedies (if required).

Participation in the development of health policy requires an accessible, fair, transparent and continuous process.⁴⁵ This means that participation is to be undertaken via an appropriate method which is accessible to different groups: the method for the participation of adolescents will be different to that for people with physical disabilities, which will again be different from the method for those with an intellectual disability.

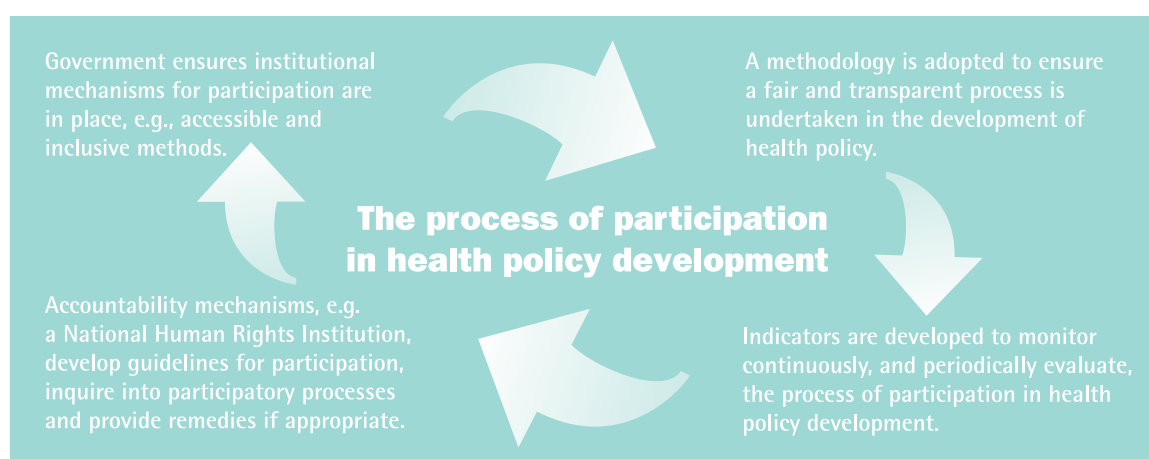
The process is to be fair: all interested, affected participants should have an equal opportunity to be part of the process. The process is also to be transparent: the participants need to understand the information that is related to the issue at hand, in order to make the best possible decisions. For example, epidemiological information or cultural understandings of health may need to be explained.

Also required are indicators that can be used to monitor the process and to develop context-dependent benchmarks. Through these indicators and benchmarks, the government will be able to show how the 'voices' of

people and groups have been heeded in the process and how the final decision was made.

Finally, participation also requires the use of an independent accountability mechanism, for example, a national human rights institution through which the government can explain and justify, to rights-holders and others, how it has discharged its obligations regarding participation. If it is revealed that there has been a failure on the part of government to fulfil its obligations related to participation, rights-holders are entitled to effective remedies to redress this failure (*see Figure 1 overleaf*).

Of course, a participatory process does not aim to ensure that the final decision is in accordance with the views of all people and groups – this is clearly impossible. There will be disagreement within groups and between people – and decisions have to be made. However, people and groups are entitled to accessible, appropriate methods of participation, a fair, transparent process, and an opportunity to understand how the final decision was reached.

Figure 1: The Accountability Process

1. METHODS OF PARTICIPATION

There are many ways of undertaking participation. The purpose here is not to specify each and every possible method, as the appropriate methods selected will always be context-dependent. Irrespective of the methods selected, they must be capable of providing a fair and transparent participatory process.

There is a wide variety of participatory methods that have been utilised for policy decision-making. The variety of methods have increased over the years and include:

- **Regional and national conferences** to develop national health plans. See, for example, Case Study Nos. 2 and 6 (*pages 32 and 36*), which concerned the development of national health plans in Brazil and Perú, respectively.
- **Permanent or time bound forums.** Such forums are used, for example, in the case of the participation of Māori on New Zealand District Health Boards required by the *Public Health and Disability Act 2000* (see *Case Study No.5 on page 35*).
- **Local health committees or teams.** These have included, for example, village health teams (VHTs). In Uganda, the VHTs have a pivotal role to play in providing grass-roots community participation in the health sector (see *Box 6 below*).
- **Focus groups and individual interviews.** For example, the Training and Research Support Centre (Zimbabwe) used open-ended interviews to identify the reproductive health needs of students and to develop an education pack entitled 'Auntie Stella'.⁴⁶
- **Citizens' Jury/Planning Cell.** This method for participation has been adopted in many countries. It draws upon the

model developed by the Jefferson Centre for New Democratic Processes and also the model of a planning cell pioneered by Professor Peter Dienel, University of Wuppertal. A variation on the citizen's jury is the Seven Towers Monitoring Group in Case Study No. 4 (*page 34*), which was developed to address the inadequacy of government arrangements for participation.

- **Public meetings.** An example is that of the public meetings facilitated by the Indian Right to Food Campaign, which brought the issue of accessibility of food to the attention of the government, the public and the media (see *Accountability and the right to the highest attainable standard of health, page 34*).
- **Budgetary oversight.** This includes participatory budgeting, first introduced in Porto Alegre, Brazil, in 1989. The process has now spread to hundreds of cities in North and South America, Europe, Asia and Africa.
- **Local committee elections.** The local committee elections held as part of community driven reconstruction in the Democratic Republic of Congo offer an example. These committees are responsible for the management of reconstruction projects (see *Box 7 on page 22*).

An important purpose of participation in the context of the right to the highest attainable standard of health is to recognise and respect difference and diversity within the population. Accordingly, to ensure inclusiveness in the development of health policy, separate participatory events will need to be undertaken. Depending on the nature of the topic (e.g., sexual and reproductive health) and the cultural context, people will have different priorities based on age, sex, sexual orientation, and so on. The capacity of people to participate will also influence the method selected. People with physical disabilities such as deafness, or those not able to speak the language of the participatory event, will have additional requirements to ensure they can participate. A single participatory event in these situations would result in a non-inclusive process.

Photograph © 2007, courtesy of Participation and Practice of Rights Project. Seven Towers residents Roisin Kelly, Seaneen McKee and Kerry Haddock at the Participation and Practice of Rights Evidence Hearing on the Right to Housing, 13 June 2007.



Box 6: Uganda's Village Health Teams

The Government of the Republic of Uganda actively encourages citizen participation in health decision-making. The Constitution underlines the importance of active participation of citizens and civil society organisations have been involved in the preparation of Uganda's Poverty Eradication Action Plan (PEAP). Decentralisation is also a policy of the health sector. Within the district health system, there are four levels of organization and administration, the lowest being Village Health Teams, also known as Village Health Committees (VHTs). The strategy and guidelines for the implementation of VHTs across the country were finalised during the creation of the Health Sector Strategic Plan (HSSP I) and are being progressively implemented during HSSP II, which includes important commitments to participation. By 2010, the aim is to implement VHTs across the whole of the country, though this will require substantial assistance and resources.

VHTs usually have five members who are volunteers from the community and are trained by the Ministry of Health. When fully implemented, each village will have a VHT of 9–10 people. Women's participation in VHTs is promoted through an affirmative action measure that requires at least one third of the team members to be women. From the right to health perspective, the VHTs have a pivotal role to play in providing grass-roots community participation in the health sector. Effective VHTs can:

- help to dispel the neglect that characterises diseases such as lymphatic filariasis,

schistosomiasis, onchocerciasis, malaria and other neglected diseases common in Uganda;

- help to ensure that health policies and programmes are responsive to local needs and priorities by ensuring that local needs are clearly identified, understood and addressed;
- provide the crucial grass roots delivery mechanisms for community interventions in relation to neglected diseases and health protection generally.

VHTs serve as the first link between the community and the formal health providers; they provide linkages among families, drug distributors and health facilities. HSSP II states that the establishment of functional VHTs is a priority.

Source: Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt. Mission to Uganda. UN Doc E/CN.4/2006/48/Add.2, pp. 11–13; Ministry of Health, Health Sector Strategic Plan II 2005/06–2009/2010, pp. 30–31; Report of the Stakeholders' Meeting with the UN Special Rapporteur on the Right to Health, 8 February 2007, WHO, Sida, UN High Commissioner for Human Rights Uganda; Report from the Health and Human Rights Capacity Building Workshop, 18–19 May 2006, WHO and UN High Commissioner for Human Rights Uganda, pp. 31–32; Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt. Missions to the World Bank and the International Monetary Fund in Washington, D.C. (20 October 2006) and Uganda (4–7 February 2007), UN Doc A/HRC/7/11/Add.2, 5 March 2008, paragraph 61(d).

Numerous other factors operate as barriers to attendance at participatory decision-making events. These factors are also context-dependent and so cannot all be identified. Yet the following barriers to attendance are well documented: socio-economic status, education level, social patterning, gender, sexual orientation, health status, ethnic differences, apathy, low levels of public awareness, lack of a participation culture, a general belief that people's input will not affect the process, lack of skills and resources.⁴⁷ Many of these barriers also operate at the level of representative NGOs and at times limit the ability of these organisations to engage in policy advocacy.⁴⁸ The following three examples of barriers related to attendance indicate the kinds of factors which may need to be considered:

1. Physical accessibility can affect attendance

When participatory endeavours are undertaken in venues that are too far from the relevant population, at infrequent or inconvenient times, or in venues that are not physically accessible, they prevent attendance

and are unfair from the outset.

2. Economic accessibility can affect attendance

Participation is frequently regarded as a voluntary activity, and yet the costs of taking part may be very high. Among individuals and groups that can attend, there can be an inequity between unpaid individuals and groups and the frequently well-paid health policy officials. Consideration should be given to the provision of financial support for individual and group participation. Where resource constraints limit the participants by not allowing for financial support, the evaluation of the process needs to spell this out.

3. Representation

Representation is inevitably necessary, as all individuals and groups cannot be present in all the decision-making bodies whose actions affect their health. In addition, a participatory process with a potentially large number of people will prove either logistically impossible or so cumbersome that over time everyone may lose interest.

It is not the purpose of this document to prescribe how representatives should be selected. It is simply to highlight that representation is itself a process which involves two components: authorisation and accountability.⁴⁹ That is, authorisation of the representative by the constituents and accountability of the representative back to the constituents. As participation is frequently not a single event, the representative needs to report back to the constituents following each episode of participation. When this reporting occurs, the constituents will either continue to authorise the representative or withdraw that authorisation, in which case a new representative will be appointed.

Ideally, it should not be the role of health policy

makers to appoint or select a representative, as the people they would select may not be legitimate representatives.⁵⁰ However, in some situations this is necessary. For example, the *New Zealand Public Health and Disability Act 2000* specifies that each District Health Board (DHB) is to consist of seven elected members, while up to four members can be appointed by the Minister. The Act also provides that there must be at least two Māori members on each Board. However, very low numbers of Māori are elected to DHBs and the compositions of the DHBs following election have therefore permitted the Minister to appoint Māori representatives (see *Case Study No. 5 on page 35*).

Box 7: Community Driven Reconstruction, Democratic Republic of Congo

Community driven reconstruction (CDR) focuses upon building community level institutions and systems that allow recovery to take place in areas (rural and remote) that have been impacted by conflict. CDR recognises that people have a right to direct their own recovery. It attempts to address some of the root causes of conflict (poor governance and poverty) and provide true ownership in decision-making and management of the processes and funds for reconstruction.

The process involves the election (via secret ballot) of community representatives to representative committees at one or multiple levels (village, larger community, regional). The authorised representatives then obtain the views of their constituents and decide on community recovery plans. These plans

outline priority projects against pre-defined budgets. Accountability is obtained through a process which requires the committee representatives to defend the plans to the wider community and obtain their endorsement for the plans.

Once the plans are endorsed, technical and resource support is provided by local officials. An open tendering process for contractors is conducted and overseen by the committees. Once contractors are selected, money is transferred either to contractors or committees, depending on whether banking systems are in place. Project implementation is monitored by separate user groups or community-based organisations.

Source: McBride, L. and D'Onofrio, A. (2008) 'Community-driven reconstruction: A new strategy for recovery' *Humanitarian Exchange*, No. 39, pp. 4-7).

2. A FAIR AND TRANSPARENT PROCESS

Governments are obligated to ensure that institutional mechanisms for a fair and transparent process are in place. This section focuses on the meaning of a "fair and

transparent" process of participation in health policy development, which applies irrespective of the method selected for undertaking participation.⁵¹

> FAIRNESS

Summary

Fairness in participation means that all participants have an equal voice in the participatory process. Participants should have an equal opportunity to:

- Start the discussion;
- Ask for clarification, challenge comments, answer questions and argue;
- Participate in decision-making.

Three activities that take place during participation will assist participants to have an equal voice in the process:

- Agenda setting;
- Rules for and facilitation of the process;
- Discussion.

The first criterion of a right to health approach to participation is fairness. Fairness refers to the equal opportunity of all participants to be a part of the process. That is, to:

- Start the discussion;
- Participate in discussion (ask for clarification, challenge comments, answer questions and argue); and,
- Participate in decision-making.

Attending a participatory event is not the same as having an equal voice. All participants are to have an equal opportunity to make, challenge, debate and decide in the participatory process. However, the ability to have an equal voice can be constrained by personal, interpersonal and institutional dynamics. We may feel awkward, clumsy, unable to say what we really feel, all of which could prevent us from speaking. These barriers could be overlaid with a set of institutional dynamics in the form of attitudes on the part of either lay participants or health policy makers.⁵² The views of lay participants may be politely listened to and then put aside.⁵³ Translating voice into influence involves attitudinal and institutional change, and political will to overcome the significant barriers individuals' and groups' experience in participatory endeavours. The right to health places an obligation on governments to take steps to dismantle these barriers, and to ensure that the process of participation is neither directly nor indirectly discriminatory. In other words, the government is obliged to take all necessary steps to ensure that all participants have an equal voice.

Fairness in participation encompasses three activities that will help overcome these attitudinal and institutional barriers:

1. Agenda setting

The right to health framework for participation allows a preliminary, predetermined agenda because policy discussions have to start from somewhere. However, the framework requires that everyone has an equal chance to put their concerns on the agenda.⁵⁴ The point is that there can be a preliminary agenda, but it is not to be the final agenda. As noted earlier, amendments to the agenda can occur in both large and small settings. See, for example, Case Study No. 1 (page 31) for a small setting and Case Study No. 2 (page 32) for a large setting. See also the Case Study No. 3 (page 33), which describes a scenario where it is the women themselves who set the agenda.

2. Rule making and moderation

Given that our ability to participate is constrained by personal, interpersonal and institutional dynamics, the right to health framework requires that there be rules that govern the behaviour of participants and manage discussion. For example, the rules will require the use of jargon to be avoided. While rules do not guarantee good behaviour, they can help to identify bad behaviour.

Important rules to include are those relating to the decision-making process. These rules overlap with transparency of the process. Unless the process by which decisions will be taken is clearly understood, there cannot be fairness. The participants, and those outside of the process, need to know who will in fact make the final decisions, when these

decisions will be made, and by what criteria.

A related rule concerns how to make a decision when there is disagreement. The reality is that decisions need to be made. At the same time, there will also be disagreement. Proceeding on that basis, the essential point is that at the outset of a participatory event there should be a rule concerning how to decide when there is disagreement, and this rule should be open to challenge via an accountability mechanism.

The appointment of an independent facilitator could also be considered, as this would provide a mechanism to keep the discussion on the final agenda focused, oversee the behaviour of participants and encourage comments from quieter participants. A facilitator is not always required. For example, the Seven Towers Monitoring Group in Northern Ireland is a pro-active group of residents who are fully aware of their rights of participation. Through capacity building and support provided by the PPR Project, they closely monitor and engage with the Northern Ireland Housing Executive (the statutory authority responsible for housing in Northern Ireland (see Case Study No. 4 on page 34). In the hand over of Clinica 12 to the Guatemalan MoH, the planning meeting was facilitated by the MSF-CH representative. Although MSF-CH had been managing the clinic and could therefore be viewed as a nonneutral party, the reality was that their interest coincided with that of the MoH and the hospital administration – the development of a hand over plan for the clinic (see Case Study No. 1 on page 31).

3. Fairness in discussion

Fairness in discussion, encouraged by the two previous activities, refers to all participants having the opportunity to make their voices heard. For example, this happens by ensuring that lay definitions of health are included on an equal footing with biomedical definitions. This activity overlaps with transparency, which is discussed in the next section. Unless information is clearly understood by the participants, there cannot be fairness in discussion. Each of the projects described in the case studies referred to in Appendix III addressed this in different ways. For example, at a conference described in Case Study No. 2 (page 32), the development of a national plan for the promotion of LGBT citizenship and human rights, 559 proposals (which had been developed by the participants) were adopted. Case Study No. 3 (page 33) describes an activity which, by its very nature, ensures that women taking part in coffee evenings have the opportunity to make their voices heard. In New Zealand, ensuring Māori representation on the DHBs attempts to ensure that the views of Māori are included in the policy planning process (see Case Study No. 5 on page 35). The innovative method of policy proposal development adopted by *ForoSalud* and CARE-Perú (which included capacity building for participation; the identification of health issues by local people; the identification of determinants of health which are of concern; the identification of health service provision issues, and the development of suggested solutions) required the participants to be able to express their preferences and views (see Case Study No. 6 on page 36).

> TRANSPARENCY

Summary

A transparent, participatory process is principally concerned with the accessibility and availability of information to ensure the best possible decisions by the participants.

Factors that a transparent process could address include:

- Ensuring that participants have a sufficient understanding of the available information,

e.g., human rights information, epidemiological data, cultural understandings of health;

- Agreement on definitions and explanation of jargon;
- Ensuring open discussion;
- Avoiding a hierarchy of knowledge, i.e., personal knowledge and medical knowledge are equally valid.

The right to the highest attainable standard of health requires that individuals and communities have an opportunity for 'active and informed' participation in decision-making that has a bearing on their health.⁵⁵ Participation cannot be 'informed' if the information required for the development of health policy is not 'transparent', that is, easily understood.

Transparency is principally concerned with ensuring the best possible decisions given the information that is available at the time. It is concerned with the accessibility and availability of information related to determinants of health, technical terms, personal experience and so on. There are a many factors that impact on the accessibility and availability of information, many of which are context-dependent. The following list is illustrative rather than exhaustive.

- To ensure a transparent process, the participants need to understand the information circulating during the discussion. The right to the highest attainable standard of health requires that health policy be based on epidemiological research in addition to other information. This scientific research presents data on relationships between determinants of the issue under discussion and health outcomes. A transparent process will attempt to ensure that all participants have a sufficient understanding of the data to have knowledge of the scope and relative importance of the identified determinants, as well as to know how these determinants can best be influenced in the interest of health. This does not mean that people must understand how to interpret scientific data. However, it does mean for example, that explanations of determinants of health and their impact on the issue at hand are made accessible to everyone in the participatory process.
- A lack of understanding can arise from the use of technical language and jargon. Sometimes words are used that, in practice, exclude some individuals and groups. A transparent process will attempt to ensure from the outset that definitions are agreed on and jargon is explained.
- Adopting a right to health framework for participation offers an opportunity to disseminate information and knowledge on the right to health. A transparent

process will therefore ensure that information about the right to health and its application in the area concerned, is understandable to all. In addition, when health policy choices are made, they need to be consistent with the government obligations contained within the right to the highest attainable standard of health. The participants will need to draw upon human rights materials to determine whether a particular choice is consistent with these obligations. For example CARE-Perú, through a series of cooperative meetings and capacity building exercises, has been able to disseminate the principles of a rights-based approach within the Peruvian MoH (see *Case Study No. 6 on page 36*).

- The participatory process needs to include the views of individuals and groups (or their representatives), and information will be gathered from daily life drawing upon the personal experience of people. For example, research conducted on lay understandings of health reveal interpretations of health that are much broader than the biomedical definition of absence of disease.⁵⁶ Information gathered exclusively on the basis of a biomedical definition would be incomplete and inaccurate as it would not include the economic, social and cultural factors that impact on people's health. For example, *Case Study No. 5 (page 35)* reveals that the *He Korowai Oranga* (Māori Health Strategy) has defined *Whānau ora* (literally, 'health') as healthy Māori families, supported to attain their maximum health and well being. At a local level there is a multitude of understandings of *Whānau ora* which impacts on monitoring the implementation of the *He Korowai Oranga*. This multitude of understandings can also influence what is placed on the health policy making agenda.
- An inclusive participatory process will involve making difficult choices, for example, the provision of harm reduction services or sexual and reproductive health services. It is in the making of difficult choices, that there is likely to be the most disputes and where the hardest questions are raised. It could be that the only decision that can be made is that there can be no decision, or that the final decision is to be determined by other methods. A clear example of how easily

disagreement could arise would be a participatory effort concerned with the provision of health services to people who use drugs. A participatory effort that included people who use drugs and members of the police, as well as health policy makers and others, in efforts to develop a health policy, would potentially involve a substantial amount of disagreement on the acceptability of some interventions. Given this situation, the intention of a transparent process is to encourage open discussion of the choices available. This requires broad-based participation. See for example *Accountability and the right to the highest attainable standard of health*, Case Study No. 2

"High Impact Litigation as an Accountability Mechanism: The unconstitutionality of anti-abortion legislation – Colombia" (pp. 32-33). The example describes how, through media reporting of civil-society mobilisation, a public debate on abortion was reframed. People had the opportunity to hear many different voices. The debate involved doctors, public health experts, members of the women's movement, and pro-choice Catholic women. The debate became one based on public health and human rights, supported by scientific data and constitutional arguments, and moved away from a discussion about church doctrine.

> CONCLUSION

This brief outline of a framework for the process of participation deals with some of the characteristics of what is considered to be an 'ideal' form of participation. It is one that, as a matter of the right to the highest attainable standard of health, participants should work towards and from which indicators and benchmarks could be developed to progressively realise the participatory component of the right to health. There is a large gap between this 'ideal' and decision-making in health policy development. Health policy making is an administrative decision-making process not necessarily conducive to the 'ideal' because there is usually a pre-defined agenda, and health officials are the final decision-makers. However, the development of a framework for the process of participation can serve as a starting point for the development of guidelines that define a process of participation that could challenge the structural barriers that individuals, groups and others face in participating in health-related decisions that affect them.

Adoption of the framework for

participation described in this document can also facilitate a higher level of consistency in practice among the many different players in health policy making and can improve or increase collaborative action. In turn, this can lead to a more coherent, systematic body of practice from which an evidence-base for participation in health policy development, implementation and accountability can be developed. The requirement for inclusion of all interested views compels a deeper investigation into the political, socio-economic, cultural and institutional barriers to participation. While 'trade-offs' during health policy

development may be necessary, the framework for participation ensures that these decisions rely on the obligations contained

within the right to the highest attainable standard of health.

The framework helps shift the focus of analysis to the most excluded and addresses indirect discrimination in health policy development, implementation and accountability. It is an approach that strengthens and does not replace health policy.



Photograph © 2006 courtesy of Care-Perú. Female community leader explaining her views on what human rights mean for her and her community, and how people's mobilisation could influence policy implementation.

3. THE INDICATORS

Effective monitoring and evaluation of participation demands indicators. Indicators for participation will monitor and help evaluate whether institutional mechanisms and processes for participation are in place. They will also highlight where adjustments in the mechanisms or processes are needed. The scope of this monograph does not permit a detailed analysis of which indicators

are needed, as the mechanism and process will vary with the event. However, on the basis of the framework, it is possible to provide examples of process indicators which illustrate how to monitor the 'fairness' and 'transparency' of a participatory event. It is also possible to provide examples of structural and outcome indicators related to institutional mechanisms for participation.

> STRUCTURAL

Structural indicators can assess the following:

- Is there a legislative requirement for participation in policy development?
- Has an independent body (e.g., the national human rights institution) developed a set of guidelines for the conduct of a fair and transparent participation process?
- Does the State require the Ministry of Health to follow the guidelines for participation?
- Are the rights of expression, association, assembly and information protected?

- Has the State included in the legislation a right of review of the participatory process?
- How many jurisdictions (national, provincial, local) have adopted the guidelines for the process of participation?
- How many jurisdictions have legislatively protected the guidelines for the process of participation?
- How many jurisdictions have included a right of review of the participatory process?

> PROCESS

Process indicators can assess the following:

Method of participation and inclusiveness

The method for the conduct of participation should be appropriate to the circumstances and provide everyone with an equal chance of attending.

- Does the process take steps to identify everyone who is potentially affected by the policy?
- Does the process provide for group-specific methods for participation (e.g., in keeping with age, mental illness, or language)?
- Does the process attempt to overcome the costs of attendance?
- Does the process take into account the timing and location of the participatory event?
- Does the process take into account the physical accessibility of the venue?

Fairness

Agenda Setting: The process should provide everyone with an equal chance to put their concerns on the agenda, and to approve the agenda.

- Does the process provide an equal chance for everyone to suggest items for the agenda?
- Does the process provide an equal chance for everyone to approve the agenda?

Rule making and facilitation: The process should provide everyone with an equal chance to propose rules for the process and to suggest a facilitator for the participatory event:

- Does the process provide an equal chance for everyone to suggest rules?
- Does the process include a rule for how decisions will be made?
- Does the process provide an equal chance for everyone to suggest a facilitator?

Discussion: The process should provide everyone (or their duly authorised and accountable representative) who is potentially affected, positively or negatively, by the issue/s under discussion, an equal chance to participate in the process by making statements, challenging and debating the issue/s under discussion.

- Does the process provide an equal chance to make statements about the issue/s under discussion?
- Does the process provide an equal chance to challenge statements about the issue/s under discussion?
- Does the process provide an equal chance to debate the issue/s under discussion?

Transparency

The process should ensure that all information circulating before and during the participatory process is understandable to all participants.

- Does the process make certain that all information relevant to the participatory process is circulated to the participants in a timely manner?
- Does the process make certain that the meanings of all terms, definitions and concepts are made explicit?
- Does the process provide equal access to

documentation, information and training on the right to health?

- Does the process promote the consideration of personal knowledge?
- Does the process provide a mechanism by which the proposed decision options can be characterised relative to obligations contained in the right to health?

> OUTCOME

Outcome indicators usually measure the results achieved. As the focus here is on the process of participation, the outcome indicators are concerned with adoption of the process itself:

- Was the most appropriate method for participation adopted?
- Has the State implemented the framework for the process of participation?
- Have there been any accountability reviews of the participatory process?
- Was participation with other government sectors achieved?
- Was participation by the private sector achieved?
- Were sufficient resources available (funding, time,

capacity building, venues and so on) to undertake the process of participation?

Of course the number of indicators developed needs to be balanced with the resources required to monitor and evaluate participation. However, the essential point is that governments (either alone or in collaboration with civil society) have an obligation to monitor and periodically evaluate participation as part of an effective and integrated health system.

Monitoring and evaluating participation will provide the evidence base that involving people and groups in health policy decision-making will work. Monitoring and evaluation will also identify what is working in the framework for participation, what is not working, what has been omitted and what changes need to be made.



Photograph © 2006 courtesy of Care-Perú. Gloria Corimayhua, leader of rural communities from Huancané and Puno, presenting the health priorities of the communities to the Ministry of Health officers and the general audience at the Third National Health Conference, Lima, July 2006.

SECTION III: PARTICIPATION AND ACCOUNTABILITY

Participation and accountability are interdependent. The government has an obligation to ensure that institutional mechanisms are in place to enable the participation of people and groups in health policy development. Therefore, the government is accountable for the selection of the most appropriate method for

participation and also for the conduct of an accessible, fair and transparent process. Additionally, there is participation in the accountability process: in monitoring for accountability, in accountability mechanisms and in the implementation of remedies (if provided).

A. ACCOUNTABILITY FOR THE EXERCISE OF PARTICIPATION

Participation is a complex area and the method for undertaking participation is context dependent. To assist government in fulfilling obligations with respect to participation, an independent accountability mechanism should develop guidelines on appropriate methods for undertaking participation as well as for undertaking an accessible, fair and transparent process.

An appropriate mechanism would be a national human rights institution. It is a specific human rights accountability mechanism, and is usually accessible, informal and flexible. Ideally, it would have a mandate to not only develop guidelines for participation, but also to conduct inquiries on its own initiative into participation as a component of an effective and integrated health system. These inquiries could address issues such as:

- The appropriateness of the method selected for undertaking participation;
- Whether the process has been fair and transparent; and
- Whether representatives are authorised and accountable to those represented.

Additionally, this mechanism should have the mandate to receive complaints regarding the process of participation. In the absence of a national human rights institution (or in addition), a health complaints commission could also play this role.

The independent accountability mechanism should also have the power to provide remedies when necessary. These remedies may take any one or more of the

Photograph © 2008
Pradeep Tewari,
Courtesy of Photoshare.
Members of a Panjab
University youth group
and Chandigarh municipal
councilors take part in
a candlelight protest
against female feticide
in India on the eve
of International
Women's Day.



following forms: restitution, compensation, rehabilitation, satisfaction, and guarantees of nonrepetition. As the obligation on government is to ensure that institutional mechanisms for participation are in place, it is especially important that the independent accountability mechanism have the power to grant the remedies of satisfaction and guarantees of nonrepetition. This is because these remedies are principally concerned with ensuring the introduction of long term processes, e.g., organisational improvements, legislation, and the conduct of right to

health training. Indeed, participation by government and affected people and groups has been ordered by the South African Constitutional Court as a remedy (see Box 8 below).

At the same time remedies such as restitution are equally important. For example, if legislation or policy has been introduced which limits the ability of people and groups to participate in decisions that affect their health, restitution would involve amendment of the legislation or reversal of the policy.

Box 8: Occupiers of 51 Olivia Road and Ors v City of Johannesburg and Ors.

The case concerned the eviction of more than 400 people (the Occupiers) from two buildings in the inner city of Johannesburg. The Occupiers had applied for leave to appeal against a decision of the Supreme Court of Appeal. They challenged the correctness of the judgment and order of the Supreme Court authorising their eviction.

Two days after the application for leave to appeal was heard, the Constitutional Court issued an interim order which directed the City and the Occupiers to meaningfully engage with each other to resolve the differences and difficulties, and to file affidavits before the Court reporting on the results of the engagement. The Court would take account of the affidavits in the preparation of the judgment in the matter.

The City and the Occupiers subsequently filed affidavits which detailed the terms of an agreement of settlement that had been entered into by the City and the Occupiers. In determining issues that remained for decision, the Court set out the reasons for issuing the engagement order. The Court considered that engagement was a two-way process which would provide the opportunity for the City and those who were about to become homeless to talk to each other meaningfully. Some of the objectives of this process would be to determine: the consequences of the eviction; whether the city could help to alleviate those consequences; whether it would be possible to render the buildings concerned relatively safe for a temporary period. The Court was of the view that meaningful engagement had 'the potential to contribute to the resolution of disputes and to increased understanding and sympathetic care if both sides are willing to participate in the process'. The Court pointed out that those to be evicted were vulnerable, might not understand the importance of engagement and might refuse to participate. This would not entitle the City to walk away from the process, as all reasonable efforts must be made by the City to meaningfully engage. Included in the City's constitutional obligations were the obligations to encourage the involvement of communities and community

organisations in local government, to fulfil the objectives mentioned in the preamble to the Constitution to improve the quality of life of all citizens, and to respect, protect, promote and fulfil the rights in the Bill of Rights.

The Court rejected the suggestion that it would be impractical to expect meaningful engagement with all of the people living in unsafe and unhealthy buildings in the inner city of Johannesburg (approximately 67,000), in relation to whom eviction orders would have to be issued. The Court referred to the City's Regeneration Strategy adopted in 2003 and noted that if structures had been put in place with council workers skilled in engagement, the process of structured, consistent and careful engagement with the 67,000 could have begun when the strategy was adopted. Crucially, the Court also noted that while people who are about to be evicted are vulnerable, they are not and should not be regarded as a disempowered mass. Both sides are to act reasonably and in good faith. People who might be rendered homeless must not, in their turn, nullify the engagement process by making non-negotiable, unreasonable demands or adopting an intransigent attitude. People must be encouraged to be pro-active. Civil society organisations that support peoples' claims have a role to play by facilitating the engagement process in every possible way.

Engagement was undertaken and an agreement was entered into between the City and the Occupiers on 29 October 2007. The agreement was subsequently endorsed by the Court on 5 November 2007. The agreement made explicit and meticulous provision for measures aimed at rendering both properties safer and more habitable in the interim. The agreement also obliged the City to provide all Occupiers with alternative accommodation, pending the provision of suitable permanent housing being developed by the City in consultation with the Occupiers concerned. *Source: Occupiers of 51 Olivia Road, Berea Township, and 197 Main Street, Johannesburg v City of Johannesburg, Rand Properties (Pty) Ltd, Minister of Trade and Industry, and President of the Republic of South Africa, CCT 24/07, [2008] ZACC 1*

B. PARTICIPATION IN ACCOUNTABILITY

Participation is also a component of the accountability process. Included within the accountability process are monitoring of government activity, e.g., the monitoring of health service provision in Perú (see Box 2) and participatory budgeting as a monitoring mechanism.

The monograph *Accountability and the right to the highest attainable standard of health*, classified accountability mechanisms into 5 groups:

1. **Judicial** e.g., judicial review of executive acts and omissions, constitutional redress, statutory interpretation and public interest litigation;
2. **Quasi-judicial** e.g., national human rights institutions, regional and international human rights treaty bodies;
3. **Administrative** e.g., human rights impact assessment;
4. **Political** e.g., parliamentary committee review of budgetary allocations and the use of public funds, democratically elected health councils and healthcare commissions;
5. **Social** e.g., the involvement of civil society in budget monitoring, health centre monitoring, public hearings and social audits.

In each of these mechanisms the participation of people and groups takes place, but the form it takes will vary within and among the mechanisms. How the content of participation varies with each mechanism requires further investigation. For example, in judicial mechanisms, participation will usually be via legal representation. In this case, the accessibility of the process may be principally governed by cost. Fairness and transparency of the process may be governed by court processes and the relationship between the legal representative and the client. In the case of quasi-judicial mechanisms such as a national human rights institution, participation may be direct if legal representation is not required, or it may be through a representative organisation. In the case of political mechanisms, such as parliamentary committees, people could participate via written submissions and by appearing as witnesses. In social mechanisms, there is a wide variety of methods of participation, and with each method, the accessibility, fairness and transparency of the process will vary. Much more work needs to be done in this area to further refine the meaning of accessibility, fairness and transparency for each of these kinds of mechanisms.

SECTION IV: CONCLUSION

The previous sections have aimed to provide health policy makers with an introduction to participation in the context of health policy development and the right to the highest attainable standard of health. Participation in the context of the right to health is much more than this as it applies to implementation and accountability. Further research needs to be done by the human rights community and the health community, working in collaboration, to investigate, understand and further refine participation.

For a variety of reasons, it is not possible to provide a simple checklist of what needs to be in place to ensure participation. However, some preconditions will facilitate participation, such as:

- A strong commitment and long-term vision on the part of government that the right to health should be incorporated into the day-to-day work of health policy makers.
- The existence of a national health plan that incorporates the right to health.
- Institutional mechanisms to ensure participation in the development of health policy, e.g., legislation requiring participation, and the existence of accessible methods of participation.
- Political will to support, and encourage the involvement of the relevant actors in participation.
- Sustained funding for capacity building for participation, as well as for actual costs of participation (e.g. travel, food, opportunity costs) to ensure that people, including health policy makers, have the knowledge to participate.
- The existence of an independent institutional mechanism such as a national human rights institution or health complaints commission, with a mandate over the right to health, to develop guidelines for participation, conduct inquiries into participation and respond to complaints about the process.

Photograph © 2007
Felix Masi, courtesy of
Photoshare. A young
woman cheers alongside
hundreds of other youths
calling for youth leader-
ship in Nairobi, Kenya.



APPENDIX I: THE CASE STUDIES

CASE STUDY 1

The hand over of Clinica 12 from Médecins Sans Frontières-Switzerland to the Ministry of Health: The participatory development and implementation of the hand over plan (Guatemala)

The integrated HIV/AIDS project *Attention to HIV/AIDS* (the project), based in Coatepeque, Guatemala, commenced in 2002 and included three strategies:

1. Sexual education related to HIV/AIDS in 19 schools, grades 4-6 in Coatepeque.
2. Clinica 12, attached to the District Hospital Juan Jose de Ortega, Coatepeque. Clinica 12 commenced taking patients in April 2003 and offered integrated HIV/AIDS services (pre- and post-test counselling, testing, antiretroviral drugs, treatment for opportunistic infections, and psychosocial support); and
3. Edumed Plus – a strategy concerned with the delivery of integrated HIV/AIDS services to the rural areas.

In 2003 the project was transferred to the District hospital, Juan Jose de Ortega, in Coatepeque, but remained under the management of MSF-CH. In 2005, an agreement was reached between MSF-CH and the government to hand over responsibility for the project to the government by December 2006, with follow-up monitoring of the hand over to be conducted by MSF-CH during the first half of 2007. This case study concerns the participatory development and implementation of the hand over plan for Strategy 2 – Clinica 12.

To ensure a smooth hand over, extensive participation was conducted during the planning process. This ensured that all issues were considered, and that everyone was aware of the required activities as well as who was responsible for what and by when. Monthly coordination meetings between MSF-CH, Clinica 12 staff and Gente Unida (the patients' organisation) were already part of the running of Clinica 12. This monthly meeting was to be the vehicle through which the final hand over plan would be progressively developed.

An initial draft plan, which specified the required activities, due dates and persons responsible for those activities, was developed by the hospital director, the hospital administration, the director of nursing, the medical coordinator, Clinica 12 staff, two

NGOs (Proyecto Vida, which worked with Clinica 12, and Gente Unida), the hospice and MSF-CH. This draft plan was presented at a subsequent, larger planning meeting. This meeting was attended by the hospital director, the director of nursing, representatives from the two NGOs (Proyecto Vida and Gente Unida), hospice staff and other hospital staff, such as representatives from administration and the laboratory.

Representatives of Gente Unida, hospital staff and Proyecto Vida requested that this larger meeting commence in the morning, at a time when the patient load was usually the lightest. Not all staff would be able to remain for the entire meeting. Accordingly, it was agreed that there could be a rotation of participants. At any one time during the meeting there were, on average, 50 participants.

The content of the plan was depicted on powerpoint slides projected on a large screen, and explained item by item. It was considered that all of those attending were entitled to have a say and contribute to the progressive development of the plan. As each group was easily identifiable, for example the representatives from Gente Unida, nurses, administrative staff and so on, they could easily be brought into the discussion.

With the support of the hospital director, MSF-CH facilitated the discussion. This participatory event was a long process lasting about 6 hours. While many decisions were made, it was decided that monthly meetings (with a smaller group) would be required as the plan was implemented. Indeed, the necessity for continued monthly meetings was confirmed when new issues arose during the implementation of the plan. Prior to these monthly meetings, the evolving plan was circulated to all groups (and anyone else who was interested), allowing sufficient time for those attending the meeting to obtain the views of those they would be representing.

The representatives of both the MoH and the Global Fund to Fight AIDS,

Tuberculosis and Malaria (Global Fund) had been invited to the larger planning meeting, but they were unable to attend due to prior commitments. The hospital director and the hospital administrator subsequently met with the MoH and representatives of the Global Fund in the capital (Guatemala City), advised them of the process and outcomes of the meeting, provided them with a copy of the plan and asked for their input. The hospital director subsequently reported back to the monthly meeting with the plan, which now incorporated the comments of the MoH and the Global Fund.

In June 2008, the MSF-CH representative

involved in this process returned to Coatepeque to conduct an evaluation of the process. Semi-structured interviews were undertaken with those involved in the planning to obtain their thoughts on the participatory process. While this was a subjective evaluation, important insights were obtained. Those interviewed thought that the planning process had been very inclusive, and they had felt part of the process. Following the hand-over, the monthly meetings between Gente Unida, Proyecto Vida, the MoH, and the hospital continued until late 2007. Many of those interviewed would like to see these meetings reinstated to ensure information sharing and coordination

of treatment and services. Additionally, some suggested that an invitation to the monthly meetings should be extended to the National Human Rights Commission or another human rights organisation, as this would assist with the accountability of the MoH to the HIV/AIDS patients (and indeed all patients) in Clinica 12 and the hospital.

** Source: Prepared in collaboration with Ms Gunilla Backman, Senior Research Officer to the United Nations Special Rapporteur on the right to the highest attainable standard of health (2002-2008) and MSF-CH representative responsible for the management of the project 'Attention to HIV/AIDS', Coatepeque, Guatemala.*

CASE STUDY 2

A National Plan for the Promotion of Lesbian, Gay, Bisexual, Transvestite and Transexual (LGBT) Citizenship and Human Rights (Brazil)

In 1987, João Antônio Mascarenhas, the first homosexual to be invited to speak at the National Congress, proposed that a prohibition of discrimination on the grounds of sexual orientation be included in the new Brazilian Constitution. This proposal failed. As a result, the rights contained in the 1988 Brazilian Constitution do not reach all groups; no law exists regarding the promotion of LGBT citizenship and human rights. Nevertheless, some Brazilian municipalities and cities (e.g., the municipality of Rio de Janeiro and the cities of Campinas (São Paulo) and Juiz de Fora (Minas Gerais)), have included in their laws the prohibition of discrimination based on sexual orientation, in an attempt to restrain discriminatory acts against the LGBT community. Numerous other cities and several of Brazil's 27 states have followed and developed laws that promote LGBT rights.

At present, several proposed laws at the national and state level are related to LGBT rights, such as a proposed constitutional amendment to prohibit discrimination on the basis of sexual orientation, and other laws related to legal unions between individuals of the same sex, divorce, adoption and inheritance. Despite this favourable environment, laws alone are insufficient to ensure the protection and promotion of the rights of LGBT individuals and groups. Also required is an institutional mechanism to ensure that a partnership is established between government and LGBT groups, to promote participation in the development and implementation of plans related to the implementation of the right to health for LGBTs.

A move towards the development of an institutional mechanism was created through the recently held First

National Conference for Lesbians, Gay Men, Bisexuals, Transvestites and Transsexuals, 5th – 8th June, 2008. Convened by Brazil's President Luiz Inácio Lula da Silva, the principle aim of the conference was to propose the guidelines for the implementation of public policies related to LGBTs and the development of a national plan to promote the citizenship and human rights of LGBTs. 1,000 people took part in the conference and 559 proposals for public policies related to LGBT groups were approved.

Not all individuals and groups were able to attend the national conference. However, it was important to ensure that all views and all issues were represented on the agenda. To facilitate this process, an organising committee, comprised of 16 government ministries, the Parliamentary Front for LGBT Citizenship,* and 18 representatives of the LGBT movement, was established and tasked with writing the rules for the national conference as well as the guidelines for the state level conferences held in Brazil's 27 states prior to the national conference. It was at these state conferences that the delegates to attend the national conference were elected and the initial proposals, to be put to the national conference, were developed.

A principal outcome of the national conference

has been Ministerial Ordinance No. 432, dated 2nd July, which directs the Government's Special Department for Human Rights to establish an interministerial technical commission with the purpose of drawing up a draft version of the National Plan for the Promotion of the Citizenship and Human Rights of LGBT (Article 1), to be based on the proposals approved at the Conference. This interministerial technical commission will be comprised of representatives from 18 ministries (including health, education, justice, employment, social security, environment and tourism (Article 2.III)). Once formed, the technical commission will have 90 days to prepare the draft plan. Toni Reis, President of the *Associação Brasileira de Gays, Lésbicas, Bissexuais, Travestis e Transexuais* (ABGLT) has remarked that it is essential that the ABGLT follow the development process closely and that implementation of the national plan is a partnership between LGBT individuals and groups and the government.

** The Parliamentary Front for LGBT Citizenship, comprised of 208 parliamentary representatives and 16 senators, is active in the promotion of LGBT issues in the National Congress and in discussions with the Federal Government.*

Source: Prepared in collaboration with Toni Reis, President of ABGLT and David Harrad, Administrative Director of the LGBT institution Grupo Dignidade. See also the background conference document – Base-Text of the Gays, Lesbians, Bisexuals, Transvestites and Transsexuals National Conference. Human Rights and Public Policies: The path towards guaranteeing the citizenship of Gays, Lesbians, Bisexuals, Transvestites and Transsexuals. Online: www.conferencianacional-glb.com.br/legislacao.php > 22 July 2008.



Photograph © 2008 Ricardo Stuckert. Left to right, Toni Reis, Fernanda Benvenutti, President Luiz Inácio Lula da Silva and First Lady, Marisa Letícia Lula da Silva at the First National Conference for Lesbians, Gay Men, Bisexuals, Transvestites and Transsexuals, Brasília, 5th–8th June, 2008.

CASE STUDY 3

Trust, Marginalisation and 'Coffee with the Mayor' (Bosnia and Herzegovina)

For a person to become an active citizen, he or she requires knowledge, time for reflection and the space in which to discuss experiences and values and to test arguments. Historically, women have been largely excluded from access to these. Their capacity to take part in public discussions has been questioned and they have been prevented from taking part in and shaping the agendas that determine how society is organised. They have been omitted from public discussions of the core issues such as war and peace and security policies. This situation has been undergoing a transition, and today, in many armed conflicts, women are taking initiatives towards peace. While the Dayton Peace Agreement was largely an all-male affair, it did not prevent the women's organisations that had been created during the war from organising themselves in many different ways for the development of society, democracy, human rights and peace. Today in Bosnia and Herzegovina, women's organisations are a strong part of civil society in the country.

Gaining trust and obtaining information

Women's organisations in Bosnia and Herzegovina come into contact with all kinds of women through their different activities and outreach work: refugees, the internally displaced, returnees, domiciles. These organisations actively seek information about the situation faced by these women in order to make correct analyses of their needs and priorities. One example is the NGO *Lara*, based in Bijeljina, which conducted a door-to-door project in villages around Bijeljina to ask women about their life situation and their problems. They followed this up with designing projects and informing the local politicians. By showing the women in their area that they are genuinely interested in their situation, *Lara* was able to gain the trust of the women and receive a great deal of information that is often hard to obtain, such as information on corruption, security issues and violence against women within the family.

Marginalisation of women's organisations by international organisations and the OHR

In many countries, for example, those in post-conflict situations, the government requires substantial assistance to provide essential services such as health services. International donors and non-government organisations are frequently involved in the financing and provision of these services. In the process, it is essential to obtain information about local circumstances and needs, and ensure the involvement of people in the design and delivery of those services. Despite this, women's organisations in Bosnia and Herzegovina were frequently marginalised by the international organisations providing assistance.

By going door-to-door, *Lara*, had obtained extensive knowledge of the situation of women in Bijeljina, their problems and their needs. Despite this, *Lara*, (as with other women's organisations) found themselves marginalised by the international organisations implementing democratisation projects. International organisations working in the country rarely regarded them as a resource. This kind of marginalisation subverts the empowerment of women. It also encourages the development of discriminatory structures, as it sends a signal that the voices and knowledge of women are not important.

A significant example of women's exclusion has been provided by the Office of the High Representative (OHR). The OHR, established by the Dayton Peace Agreement, is the international community's representative in Bosnia and Herzegovina with the responsibility and mandate to oversee the civilian aspects of the peace agreement. In 2005, the OHR and government bodies agreed on the creation of a unified police force. However, women were excluded from this decision-making process despite their extensive experience and knowledge of the problems that people face in urban and rural areas. Their demands to be included fell on deaf ears despite the United Nations Security Council Resolution 1325, which specifically calls on all actors to involve women in all efforts for the maintenance and promotion of peace and security. In 2007, these concerns were raised by women's NGOs at a meeting between women's NGOs and the international community and facilitated by *Kvinna till Kvinna*. Disappointingly, nothing has changed.

Participation in agenda setting and decision making

Women from Bosnia and Herzegovina have largely been excluded from formal decision-making processes in the country despite some progress in recent years in the legislative framework regarding gender equality. This exclusion occurs not only in decision-making, but also in setting the agenda for decision-making. It is a well recognised fact that if an issue is not on the agenda, it will not be discussed. As a result, more than 50% of the population have not had the opportunity to voice their opinions on decisions affecting them.

In the absence of government attempts to address this, women's organisations have developed various strategies to do so, some of which have become quite influential in local political circles.

Lara, like other women's organisations, has never stopped speaking out about the problems faced by women. To assist with ensuring the voices of women were included in issues that affected them, the organisation has, since 2001, arranged weekly meetings called

Coffee with the Mayor. Municipal representatives are invited, and come to the women's centre to answer questions from women and hear their concerns. A crucial component is that the meetings were arranged at a time that was convenient to women. They take place on a Wednesday evening – a time when the men are usually involved in sport. This preoccupation with sport allows women to have a 'free' evening. The meetings provide the opportunity for women to speak directly to the politicians or their representatives. Significantly, the meetings have also contributed to accountability on the part of politicians, as they are questioned by the women as to why decisions were made and also concerning current programmes.

Several campaigns and protests have emanated from these meetings. The most successful campaign was in 2001 and concerned the prevention of trafficking of women and children in the area. The local authorities (the President of the Municipality, the President of the Court and Members of the Municipal Parliament) who were guests at a *Coffee with the Mayor* meeting and who were provided with evidence of trafficking from the 12 Bijeljina nightclubs, also came to support the campaign. After a period of four months, and with the support of local authorities, all of the nightclubs were closed. The evidence is that trafficking in the area has ceased. In addition, the municipality has withdrawn its approval for the opening of new nightclubs.

A second campaign during 2007 concerned the cost of kindergartens. It came to the attention of *Lara* that kindergarten prices varied widely, and that only one was supported through the local municipal budget. As a result it was very difficult to get children enrolled in this kindergarten, and many children missed out. Following lobbying for equal opportunity for all children to attend kindergarten, the local municipality has changed its budgetary decisions and now financially supports all kindergartens in the area.

As a result of these and other programmes, *Lara* has become a significant force in the municipality. Local politicians rarely dare to ignore completely the views coming from *Lara*. Additionally, local politicians have realised that the coffee meetings can be of benefit to them, as they provide a forum for both women and politicians to put issues on the agenda. As a result, politicians themselves ask to attend and meet with the women.

Source: Prepared in collaboration with Mara Radovanovic, Lara, Bijeljina. The case draws upon the experience of Lara and the publication To Make Room for Changes – Peace strategies from women organisations in Bosnia and Herzegovina (Kvinna Till Kvinna, 2006). Online: www.iktk.se/english/index.html (accessed 4 July 2008).

CASE STUDY 4

The Seven Towers Monitoring Group: A non-institutional mechanism for participation — Belfast, Northern Ireland

The Participation and Practice of Rights Project (PPR Project) supports communities in using a human rights-based approach to address social and economic inequalities. In North Belfast, the PPR Project works with a group of residents who live in a high rise complex of flats known locally as the Seven Towers. The flats are in poor condition, and many individuals with children and people with health problems are inappropriately housed there. The problems in the Seven Towers have been repeatedly raised with the Northern Ireland Housing Executive (NIHE), which has responsibility for social housing in Northern Ireland, and has received high profile media coverage. Despite this, little has changed in the thirty years since the Seven Towers were constructed.

In late 2006 local housing and community activists who had identified the situation of the residents in the Seven Towers as a potential example of human rights violations within the local area, approached the PPR Project. Numerous meetings were held with these activists and the New Lodge Housing Forum (the local housing group) to gain a deeper understanding of the issues and strategies used to address residents' issues. The participation of Seven Towers residents in their local housing group was not great.

Therefore, to facilitate the process of engagement between the residents and the PPR Project, a 'Diary Room' event was held in a local community centre to allow residents to voice their concerns about living in the Towers. A short documentary was then compiled and screened for residents.

Following this, the PPR Project conducted training on human rights and a human rights-based approach with a group of residents during January 2007.

The development of monitoring indicators and benchmarks

In April and May 2007, the residents began to devise a set of indicators to measure whether the government was meeting its commitment to progressively realise the right to adequate housing and the right to health in their community over a defined time period – one year. The PPR Project identified that much of the work done to date on setting indicators, is aimed at States who wish to set human rights indicators to evaluate their own progress in realising human rights. Accordingly, the PPR Project adopted a 'bottom-up' approach with the aim of assisting communities in setting *their own* indicators, in relation to *very specific issues selected by that community*. The group chose the following issues: accumulation of pigeon waste in communal areas, sewage ingress and drainage problems, dampness and mould, ongoing housing of families with young children in the Towers, the response of the NIHE to reported problems and complaints, and the participation of residents in decisions which affect their

housing conditions. The group aimed not only to resolve these issues but to structurally change the manner in which the NIHE went about addressing them, in order that the benefits of their work could be felt among other communities with similar problems. Each indicator was linked to a human rights standard, and a benchmark was set. The approach provides the opportunity for residents to articulate in an extremely tangible and measurable fashion what the 'right to adequate housing' and 'the right to health' mean to them and how the relevant statutory agencies could positively act to fulfil these rights – as they are obliged to do.

The Seven Towers indicators are monitored by the Seven Towers Monitoring Group (STMG). The STMG was established in June 2007 following the 'Evidence Hearing on the Right to Housing', hosted by the residents of the Seven Towers.* Following the evidence hearing, the residents were visited by the Minister for Social Development (with responsibility for housing), Ms Margaret Ritchie, on 3rd July 2007. The Minister committed her Department (the Department for Social Development – DSD) to working with the residents to ensure that the human rights indicators and benchmarks would be met over the coming twelve months.

Framework for participation

The main platform for engagement with government is through the STMG. This was deliberately established to avoid being subsumed within existing government 'consultative' structures which have proven ineffective at tackling the problems in the flats for decades. In addition to being responsible for monitoring indicators and benchmarks, the STMG are responsible for the development of periodic progress reports which are submitted to the Minister, the DSD and the NIHE, and to which the NIHE subsequently respond. The STMG meet with the NIHE quarterly to review progress. In addition, a ministerial representative from the DSD receives the reports and attends STMG meetings (see below) when necessary. This approach is fundamentally a rights-based approach, as it is directly tied to the government (the duty-bearer) and not solely to the service delivery body (the NIHE). The reports are also submitted to an international panel of housing rights experts, who validated the unique approach at a residents' hearing in June 2007 and produced findings based on evidence presented at the housing hearing.

Meetings between the STMG, the NIHE and the residents are held on a regular basis. Residents draw up the agenda for the meetings and decide the frequency of the meetings. This agenda is not the final agenda, as it includes the agenda item 'any other business'. This provides an opportunity for participants of the meeting to raise other relevant issues of concern to them.

Representation via the STMG

The STMG has four members: two residents of the Seven Towers, one community activist and one member of the PPR Project. To attempt to ensure that these four individuals legitimately represented the residents of the Seven Towers, the STMG have from the outset tried to build accountability to other residents into their activities. Acknowledging the historic alienation of residents from consultative processes, the group have attempted innovative means and activities to involve residents in a substantive, as opposed to tokenistic, change process. Through these activities they have also indirectly addressed the issue of an 'authorised' representative. The activities include:

- widespread resident engagement (sixty-two residents participated out of approximately three hundred and fifty) to identify issues and establish indicators and benchmarks;
- six month monitoring of the indicators and benchmarks in which sixty seven residents participated;
- focus groups with ten residents carried out in March 2008 to explore barriers to the right to an effective remedy when reporting problems to NIHE;
- 'block' meetings with twenty-one residents in May 2008 to inform residents of monitoring results, future activities, and recruit to the group;
- an art project with eight children resident in the Seven Towers in May 2008 on the 'right to housing';
- carrying out a satisfaction survey of residents in May 2008 among residents of one tower where the sewage system was replaced.

Future plans include:

- the production of a quarterly news sheet;
- the conduct of focus groups on participation and accountability (November 2008);
- public meetings on issue-related concerns, including planned asbestos removal (the presence of which was discovered through a freedom of information request), to be held over the summer;
- targeted growth of representation within the residents' committee to include senior citizens, singles, and couples;
- an oral history project with residents to chart historical context and developments over time;
- monitoring of indicators and benchmarks for the past twelve months;
- convening a second Right to Housing hearing in November 2008;
- the setting of new or additional indicators and benchmarks (January and February 2009).

Barriers to participation

Despite the existence of this framework for engagement, the STMG has experienced substantial barriers to their participation, as the mechanism for participation has not been welcomed by the NIHE. These barriers have included:

- Non-acceptance by the NIHE of the participatory structure: There seem to be a number of reasons for this. First, the NIHE does not want to operate outside the parameters of their current consultative structures. Secondly, they do not like the direct involvement of the Minister in operational issues. This is compounded by the particular circumstances in Northern Ireland: a lack of effective political accountability for decades and a civil service culture of unaccountable decision-making processes.
- Non-availability of information: The NIHE has regularly not supplied requested information either in advance of meetings nor following meetings. Accordingly, the STMG has consistently had to rely on *Freedom of Information Act 2000* requests to obtain information

necessary to engage properly in processes with the NIHE.

- Attempts to by-pass the structure: The NIHE has continuously attempted to undermine or bypass the STMG structure through a number of channels. For example, the NIHE established a separate forum to deal with Seven Towers issues that was made up of NIHE members and local housing workers, but without the direct involvement of residents; and it only delivers reports to the STMG on indicators progress when the Minister's office has become directly involved (usually following the release of the STMGs official progress reports).
- Decision-making without participation: Since the commencement of the project, the NIHE has committed to spending GBP 900,000 on a maintenance scheme for the Seven Towers and over GBP 7 million on cladding the exterior of the Seven Towers to address dampness and structural problems. A serious and legitimate concern that residents have is that both of these decisions were taken, plans made, tenders drawn up,

and contracts awarded without the involvement of residents. These circumstances provide an example of the statutory authority being prepared to spend money but not allow participation.

The future

To date, the indications are that the NIHE is co-operating with the structure out of duress and only really substantively engages with the group when pressure is applied through campaigning and the direct involvement of the Minister's office. While this is a problem for the STMG, it is also a problem for the NIHE, as the DSD has confirmed that the Minister is eager to continue working with the residents, and there has been an agreement to extend the monitoring structure beyond the initial 12 months.

**For further information on the Seven Towers project and the evidence hearing, go to <http://www.pprproject.org/> and follow the links.*

Source: Prepared in collaboration with Dessie Donnelly of the Participation and Practice of Rights Project, Belfast.

CASE STUDY 5

A legislative requirement for Maori Participation in District Health Boards (New Zealand)

In 2001, the New Zealand government introduced reforms to the structure of New Zealand's health and disability sector. Pursuant to the *New Zealand Public Health and Disability Act 2000* (the Act), the government introduced a number of measures to guide the health and disability sector and to fulfil its obligations to recognise and respect the principles of the Treaty of Waitangi: partnership, participation and protection.

Included in the measures to recognise and respect the principles of the Treaty of Waitangi, was the establishment of 21 District Health Boards (DHBs). The DHBs are to function as local organisations responsible for population health and for the purchasing and provision of health and disability support services at a local level. The Act specifies that each DHB governing board is to consist of seven elected members, while up to four members can be appointed by the Minister (s.29). The Act also provides that there must be at least two Māori members on each Board, and preferably the number of Māori on each Board is to be proportional to the number of Māori in the DHB resident population, s29(4). One of the purposes of the Act is to provide a community voice in matters relating to personal health, public health and disability support services.

The Act also explicitly provides mechanisms to enable Māori to contribute to decision-making on, and to participate in, the delivery of health and disability services (s4). DHBs must establish and maintain processes to:

- enable Māori to participate in, and contribute to strategies for, Māori health improvement, s23(1)(d);

- continue to foster the development of Māori capacity for participation and for providing for the needs of Māori, s23(1)(e);
- provide relevant information to Māori to meet these ends, s23(1)(f); and,
- provide for Māori membership of DHB committees (ss34, 35, 36).

Between 2002 and 2005, the Health Services Research Centre* undertook research to chart the progress of, and to evaluate, the reforms (the Review).** The Review found a significant degree in variation in the manner in which DHBs honour their responsibilities in relation to the Treaty of Waitangi principles.

Partnership

The principle of partnership contained in the *He Korowai Oranga* (Māori Health Strategy) requires working with Māori, *Iwi*, *Hapū* and *Whānau* communities to develop appropriate strategies and health and disability services. The partnerships that have been developed vary across DHBs, as no single partnership model suits every board or community group. The models include formalised arrangements such as Memoranda of Understanding, partnership boards, steering groups, strategic planning processes and jointly developed work plans.

Participation

The principle of participation contained in the *He Korowai Oranga* requires the involvement of Māori at all levels of the sector, in decision-making, planning, development and delivery of health and disability services. The arrangements for

participation in the DHBs vary and include: membership of the DHB, partnership boards, advisory staff in different parts of the DHB, Māori leadership roles which offer technical and cultural support and policy review, and Iwi and Hapū feedback on District Strategic Plans. While many of the participants in the review were clear about the benefits of participation, important issues relevant to the process of participation were identified:

- Participants in the review thought that in some DHBs there was little understanding of the Treaty of Waitangi and hence of the principle of participation and the requirement for Māori participation.
- Inappropriate behaviour and racism had been displayed by some DHB members;
- There was a lack of clarity on definitions. *Whānau ora* is defined in *He Korowai Oranga* as healthy Māori families, supported to attain their maximum health and well being. The Review found that there was a multitude of understandings of *Whānau ora* at the local level. While a multitude of meanings may work to encourage the development of local ways of working, it makes it difficult to monitor implementation of *He Korowai Oranga*, particularly at the national level.
- Some participants perceived a lack of resources (human and financial) for Māori participation. Despite the formal relationships between the DHBs and Māori, some participants felt that Māori members were under-resourced, and that they had little decision-making authority.

Protection

Protection of Māori health, cultural concepts, values and practices is the remaining principle of the Treaty of Waitangi. *He Korowai Oranga* clearly defines this principle as working to ensure Māori have at least the same level of health as non-Māori, and safeguarding Māori cultural concepts, values and practices. This principle of protection is to be fulfilled through mechanisms to enable Māori to contribute to decision-making and participate in the health and disability sector, in order to protect Māori interests. Often referred to as 'active protection', the principle implies more than a superficial acknowledgement of the requirement by the Crown to provide equity and equality for Māori. The Crown is to be pro-active in health promotion and the development of preventative strategies for Māori. This may mean putting in additional resources to address issues of capacity building of all parties. This might include, for example, assisting all participants in developing a thorough understanding of the requirements of the Treaty of Waitangi and combating issues such as racism.

Representation

The Act specifies that each DHB governing board is to consist of seven elected members, while up to four members can be appointed by the Minister (s.29). The Act provides there must be at least two Māori members on each Board, and preferably the number of Māori on each Board is to be proportional to the number of Māori in the DHB resident population. However, election does not always provide good representation or guarantee local participation in decision-making. The election turnout is relatively modest, and very low numbers of Māori are elected to DHBs. The composition of the DHBs following election have therefore permitted the Minister to appoint (mindful of skills and experience, including Māori skills and experience) Māori to various DHBs.

Despite this pro-active power, concerns were expressed over the appointment process, the

ability of Māori to participate, and the accountability of representatives:

- With regard to the appointment process at the Ministerial level, some participants in the Review expressed frustration at the lack of transparency. Chairs of boards also expressed a desire for greater input into the appointment process.
- Concerns were also expressed about the ability of Māori to participate, given the limited number of Māori with the necessary expertise. What expertise is available is spread even more thinly if devolved to 21 DHBs. Participation, particularly in a formula driven model, e.g., with prescribed minimum numbers determined by legislation, may not equate with health gains. While there may be governance requirements to include Māori representation, if there is not the capacity, these requirements cannot be implemented and so risk tokenism.
- During the Review, concerns were raised regarding the accountability of Māori board members. A related concern is whether Māori interests are truly represented. Accountability of representatives is essential and is also relevant to other, non-Māori board members, as board members can also be employees of the health sector. In this situation there is a definite potential for a conflict of interest. To whom are the board members accountable? The Review found that there were mixed views as to whether board members are primarily accountable to government or local communities. DHB members who identified as Māori had mostly been appointed to their DHB, and agreed that their role was to ensure the interests of Māori were advanced. At the same time, the majority of the participants considered themselves accountable to a number of people or groups – to the Crown, the DHB, Māori DHB personnel, Māori provider organisations, and Māori communities more widely. Some felt they could not adequately participate in decision-making, in part as a result of

perceived multiple accountabilities. As a result, some unease was expressed over whether the views of all Māori were adequately represented at the board table.

Despite the concerns and barriers indicated above, a range of initiatives have been carried out within the DHBs and have been identified as achievements for Māori health. These include:

- Treaty workshops for staff;
- Māori representation on each of the statutory committees;
- Community consultations with Māori;
- The opportunities provided by the DHB model, such as:
 - the development of a greater understanding of community needs;
 - the promotion of innovation and scope to try different models of practice; and
 - the establishment of the Treaty relationship between a DHB and Iwi.

Source: Prepared in collaboration with Chris Cunningham (Ngāti Raukawa and Toa Rangatira), Director, Research Centre for Māori Health and Development, Massey University and by drawing upon the following documents: Interim Report on Health Reforms 2001 Research Project, November 2003 (Health Services Research Centre/ Te Hikuwai Rangahau Hauora, Victoria University of Wellington/ Te Whare Wananga o te Upoko o te Ika a Maui, 2003) and Health Reforms 2001 Research Project, Report No. 6. Maori Health and the 2001 Health Reforms (Health Services Research Centre/ Te Hikuwai Rangahau Hauora, Victoria University of Wellington/ Te Whare Wananga o te Upoko o te Ika a Maui, 2007).

**The Health Services Research Centre/ Te Hikuwai Rangahau Hauora, Victoria University of Wellington/ Te Whare Wananga o te Upoko o te Ika a Maui.*

***A series of reports were subsequently produced and are available at: www.victoria.ac.nz/hsrc/reports/new-reports.aspx*

CASE STUDY 6

Strengthening participation in the development of the national health plan (Perú)

A significant factor in strengthening Peruvian civil society's ability to influence the development and implementation of more responsive health policies has been the role played by the major civil society network, *ForoSalud*. Established in 2002, *ForoSalud* is comprised of over 100 national, regional and local organisations (professional organisations, nongovernment organisations, and academics) and individuals. The organisation, known at the regional and national level as a 'network of networks', has been elected as the civil society representative in the National Health Council and Regional Health Councils. Together, these bodies are responsible for formulating national and regional health policy proposals and monitoring their implementation. In these spaces, *ForoSalud* has succeeded in ensuring peoples' participation

in health policy decision-making. In turn, *ForoSalud* has received support in its role from long term collaboration with CARE Perú's 'Improving the Health of the Poor: A Rights Based Approach Program', and other nongovernment organisations, such as *Movimiento Manuela Ramos*, and *Consortio de Investigación Económica y Social* (CIES), as well as DFID and USAID.

The process of ensuring people's participation in health policy decision-making has required substantial organisation and commitment from all parties. *ForoSalud* and others recognised that citizens, health workers and policy makers within the Peruvian health system had a poor understanding of human rights and the right to health. Discrimination on grounds such as ethnicity,

socio-economic status, sex, race, and citizenship in access to health services also occurred.

Additionally, health workers and policy makers were reluctant to make the institutional shift from a process of informing and consulting people to one which would allow peoples' participation in health policy development. Accordingly, a process of capacity building for health workers, policy makers and the general population was required if people's voices were to be heeded and included in health policy.

Capacity building at the community level

During 2004, *ForoSalud*, CARE Perú and other organisations implemented 'bottom-up' processes for the participatory construction of health policy

proposals. First a series of capacity building workshops were held in 12 of the 24 regions of Perú to explain issues such as human rights, the right to health, the rights contained in Peruvian law, and how people have a right to participate in decisions that affect them. This was followed by a second wave of capacity building, this time with the national directorate of *ForoSalud* and the twelve regional *ForoSalud* networks, in preparation for the development of national and regional health policy proposals that would use a 'bottom-up' approach. This capacity building process involved training *ForoSalud* on participatory methodologies to ensure that local health issues would be identified by the local people. Successive capacity building workshops focused on the potential of participation in the realisation of people's right to health and on building workshop participants' capacity to participate in spaces such as the Regional Health Councils. People received training on topics such as how policies are constructed, the identification of different groups involved in policy development and implementation and the power relations that exist within the process. A particular concern of the *ForoSalud* Directorate, shared and supported by CARE Perú, was bringing representatives of the rural communities and provinces in the regions to the workshops, to increase the representativeness of *ForoSalud* itself. To that end, workshops in Huancavelica and Puno regions (the poorest Andean regions of Perú) were conducted in the Quechua language.

These workshops were also the participatory mechanism by which local health priorities and their potential solutions were identified. Issues and solutions were developed under three headings:

- health issues, such as maternal mortality and infectious diseases;
- social determinants of health issues, such as contamination of water by mining companies, and the absence of sanitation; and
- health service provision, such as responsiveness of health services to people in need.

The issues were included in proposals presented to regional health authorities in regional health conferences organised by *ForoSalud*, as part of a policy construction process. The regional policies were then incorporated into a national health policy proposal, which was presented and discussed at the Second National Health Conference (August 2004) and attended by more than 2,000 civil society delegates coming from most of the 24 regions. At the conference, policy issues brought by the regional representatives were discussed in conference workshops, the results of which were summarised in a common proposal discussed at the final plenary of the conference. The plenary was facilitated to promote participation and to ensure that any remaining issues not discussed in work-shops were included in the final conference proposal to government. A similar process was followed prior to the Third National Health Conference (July 2006). This innovative methodology was later adopted by the Ministry of Health (MOH or the Ministry) for the development of the 2006-2007 National Health Plan.

As a result of this 'bottom-up' policy design

process, health policy proposals have been constructed with the participation of a wide range of local health organisations, and openly discussed at regional and national forums, thus ensuring that citizen's policy proposals are on the regional and national health agenda.

Capacity building within the MoH

Strengthening people's capacity to participate is essential. However, on its own it is insufficient to ensure that people's views are incorporated into health policy decision-making. Both CARE Perú and *ForoSalud* recognised that capacity building was also required in the MoH. To that end, CARE Perú linked up with the MoH to undertake capacity building with health workers and policy makers.

In early 2004 there was a "window of opportunity" to overcome the reluctance on the part of health policy makers to involve citizens in development of health policy. The visit to Perú by the United Nations Special Rapporteur on the right to the highest attainable standard of health, together with the appointment of a new Minister of Health, provided an environment in which CARE Perú could meaningfully engage with the MoH to address institutional shortcomings within the Ministry. Through a series of capacity building and cooperative meetings, the principles of a rights-based approach were disseminated and endorsed by the Ministry. During the following years, positive change occurred within the MoH, especially regarding the relationship between the Ministry and civil society.

Programs designed to promote inclusion and cultural appropriateness of health service provision became a priority. Technical units within the Ministry commenced working on the incorporation of the right to health into the work of the Ministry. With the support of CARE Perú and others, nationwide training for regional health officers on human rights and health and the promotion of citizen participation was conducted during 2004-2006. Additionally, the MoH created a technical unit concerned with the promotion of health rights, gender equity and cultural adaptation of health care. This unit has been concerned with the development of an institutional understanding of what a rights-based approach officially means for the MoH.

Important outputs of these MoH efforts to introduce a rights-based approach into organisational practices have been the development of new standards of care, such as the incorporation of cultural preferences within primary health care practices (e.g., vertical birth delivery for rural areas). The MoH has also opened new spaces for citizen participation. For example, prior to the 2006 Third National Health Conference, the Minister of Health asked *ForoSalud* to include MoH officers within the conference working groups that were responsible for health policy proposal discussion during the conference. Additionally, the MoH 'Shared Administration Program' strategy (Asociación de Comunidades Locales de Administración de Salud, ACLAS), which promotes co-management (citizens and government) of primary care health facilities, was given legislative support through the passing of the Health Co-Management and Participation Law

29124, October 2007. This law will support the development and extension of the program.

The future

These changes, both within and external to the MoH, have indeed advanced citizen participation in health policy development and have obtained sound results. Among these are the following:

- In 2004, sexual and reproductive health policies were developed which authorised the use of contraceptive methods such as the 'morning after pill';
- Agreements were reached among 17 political parties in the run up to the 2006 national election, that included commitments by each of these political parties to improve the health of the population, and to promote citizen participation and universal access to health care. These agreements were presented to *ForoSalud*, the Peruvian Ombudsman's Office and the National Health Council, as the national actors responsible for the oversight of the fulfilment of the political parties agreement.
- The CARE Perú, *ForoSalud* and Physicians for Human Rights monitoring program initiated in the Puno region in 2007, has led to greater accountability of health service providers.

Despite these improvements in citizen participation, there is still a long way go. Civil society faces substantial challenges to ensure it has an effective influence on health policy development, due in part to MoH institutional weaknesses. Peruvian public institutions are still learning to incorporate a systematic, participatory approach to policy-making. New government officers and the Minister for Health have a wide discretion regarding prioritisation of health policy issues. Additionally, there is a frequent turnover of MoH staff due to the lack of a career path within the Peruvian public sector. These factors impact on the capacity of the MoH to understand and implement its right to health obligations and agreed commitments.

An important issue which is currently being address is the composition of the spaces for participation in the National Health Council and Regional Health Councils. Currently civil society has only 'one seat' at an '11 seat table' (made up of health providers and health worker organisations). *ForoSalud*, with the support of the recently appointed Minister of Health (December 2007), has proposed a law to increase the presence of civil society. The law also includes the establishment of a national health convention which would require the Minister of Health to present and discuss at a national health assembly, new government policy guidelines. The Minister would also be required to account to the population for the implementation (both positive and negative) of national health policy in biannual national meetings.

* Source: Prepared in collaboration with Dr Ariel Frisancho, National Coordinator, Health Rights Program, CARE Perú: afrisancho@care.org.pe / afrisanchoarroyo@yahoo.es

APPENDIX II: GLOSSARY

Government

Government is used in a broad sense. It covers the law and policy-making sections of departments, as well as the government institutions that are responsible for the implementation of policies. It also includes all levels: local / municipal, regional / state/ province / territory and national government. While all levels of government have obligations to ensure that human rights are respected, it is the national government that has the final obligation.

Hapū

Hapū means sub-tribe in Māori.

Health workers

Health workers is a generic term and includes all those developing, delivering, monitoring and

evaluating preventive, curative and rehabilitative health 'plans' in the private and public health sectors. It also includes traditional healers, whether or not they have been incorporated into the health sector. Pursuant to the obligation to protect, the State has an obligation to ensure that traditional healers are aware of, and carry out, their responsibilities regarding the right to health.

Health policy maker

The term 'health policy maker' is defined broadly and includes health policy researchers, legislators, decision-makers and professionals concerned with developing, implementing and analysing health policy.

Iwi

Iwi means "Tribe" in Māori.

Policy

Policy is used as a generic word and includes programmes, plans and strategies.

Underlying determinants of health

Underlying determinants of health are defined broadly to include factors such as safe and potable water, adequate sanitation, an adequate supply of safe food, housing, healthy occupational and environmental conditions, access to health-related education and information, discrimination and the impact of poverty.

Whānau

Whānau means Family.

APPENDIX III: RESOURCES

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The Participation Rights of Adolescents: A strategic approach (UNICEF, 2001), www.unicef.org/adolescence/files/Participation_Rights_of_Adolescents_Rajani_2001.pdf

Wallerstein N (2006). 'What is the evidence on effectiveness of empowerment to improve health?' *Health Evidence Network Report* (WHO Regional Office for Europe, Copenhagen, 2006), www.euro.who.int/Document/E88086.pdf

The World Bank Participation Sourcebook (Washington D.C., 1996), www.worldbank.org/wbi/sourcebook/sbhome.htm

ORGANISATIONS, AND ACADEMIC INSTITUTIONS

Ford Foundation
www.fordfoundation.org

Institute of Development Studies
www.ids.ac.uk

Jefferson Center
www.jefferson-center.org

Kivinna Till Kivinna
www.iktk.se/english/index.html

Open Society Institute
www.soros.org

Participation and Practice of Rights Project
www.pprproject.org

Special Programme for Research and Training in Tropical Diseases, www.who.int/tdr/

UNICEF
www.unicef.org

UNFPA
www.unfpa.org

WHO Healthy Cities
www.euro.who.int/healthy-cities

The Health Services Research Centre / Te Hikuwai Rangahau Hauora, Victoria University of Wellington / Te Whare Wananga o te Upoko o te Ika a Maui
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