

# Women's and Children's Health: Evidence of Impact of Human Rights

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Sofia Gruskin, Asbjørn Eide, Linsey McGoey, Sujatha Rao, Francisco Songane, Daniel Tarantola,  
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# Preface

Public health, medicine and human rights share a common goal: to improve the health, life and well-being of individuals, communities and populations. Moreover, they are deeply complementary. The right to the highest attainable standard of health cannot be realized without the expertise of health professionals. Equally, the long-established objectives of public health and clinical care can benefit from the dynamic discipline of human rights.

Human rights, as well as the relationship between health and human rights, have matured greatly in recent years. Today, it is universally accepted that human rights include not only classic civil and political rights, but also economic, social and cultural rights, including the right to the highest attainable standard of health. This right, which is enshrined in the Constitution of the World Health Organization, is to be realized progressively and subject to the availability of resources. More than ever before, it is now understood that human rights can be used by health workers to achieve their professional goals. As human rights become more operational, they become more effective as tools to help governments strengthen their health systems, deliver health care for all and improve health. However, the right to the highest attainable standard of health, and other human rights, can only be made operational if health professionals and human rights experts work closely together and are ready to learn from each other.

These are some of the issues that this report explores in relation to women's and children's health.

The past two decades have seen significant reductions in maternal and child mortality. The number of maternal deaths in the world decreased from 543 000 in 1990 to 287 000 in 2010. The maternal mortality ratio declined from 400 maternal deaths per 100 000 live births in 1990 to 210 per 100 000 in 2010, representing an average annual decline of 3.1%.

The number of deaths among children under five years declined from 12 million in 1990 to 6.9 million in 2010. The under-five mortality rate fell from 73 per 1000 in 1990 to 51 per 1000 in 2011. In many regions, the under-five mortality rate fell by at least 50% between 1990 and 2011. There is evidence that the rate of decline is accelerating as we approach 2015.

Recent initiatives, such as the UN Secretary General's Global Strategy for Women's and Children's Health, have provided greater opportunities for guidance and coordination, and generated commitments to allocate more resources to the achievement of Millennium Development Goals 4 and 5 on child and maternal health. The subsequent establishment of two Commissions – on Information and Accountability and on Life-Saving Commodities – has also benefited women's and children's health.

Nonetheless, the health challenges for women and children remain enormous in all countries. These challenges have to be viewed across the life-course. Interventions in childhood, adolescence, the reproductive years and beyond affect health later in life and across the generations. There is an interplay between biological and social determinants of health, such as equality and non-discrimination. Women's health needs go beyond sexual and reproductive concerns, while children's health needs extend beyond under-five mortality. Chronic diseases, injuries and mental ill-health take a terrible toll on women. United Nations studies have highlighted the magnitude of the problem posed by violence against women and children.

Crucially, these are not just health challenges – they are also human rights challenges.

Most States are legally bound by the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination Against Women. In 2009, the Human Rights Council adopted by consensus a historic resolution on preventable maternal mortality and morbidity and human rights, triggering a process that led to the preparation of technical guidance on the application of a human rights-based approach to reduce maternal mortality and morbidity. Completed in 2012, this technical guidance was prepared by the Office of the High Commissioner



for Human Rights in close cooperation with the World Health Organization. Earlier this year, the Human Rights Council adopted a resolution on the right of the child to the enjoyment of the highest attainable standard of health, and the Committee on the Rights of the Child adopted an authoritative statement on the same issue. The World Health Organization recently embarked on a fresh initiative to mainstream gender, equity and human rights across all levels of the Organization.

In short, the issues of human rights, women's health and children's health are gathering momentum.

This report contributes to these developments in several distinctive ways. It finds that applying human rights to women's and children's health interventions not only helps governments comply with their binding obligations, but also contributes to improving the health of women and children. It also shows that few human rights-shaped women's and children's health policies are accompanied by research and evaluation that is well equipped to capture many of the human rights dimensions of the interventions. These and other findings have important implications and the study suggests what needs to be done, especially by States and international agencies.

We hope this report will inspire and guide members of governments, parliamentarians and public health professionals engaged in policy development, monitoring, evaluation and research in the field of women's and children's health, and also generate discussion among, and papers from, policy-makers on a human rights-based approach to health.

We also hope it will be taken into account in the current discussions about the post-2015 agenda, because human rights and universal access to quality health care are mutually reinforcing.

In conclusion, human rights are maturing. They are more than slogans and aspirations. Of course, they do not provide easy solutions to complex health issues. However, as this report demonstrates, they can contribute to health gains for women and children. This contribution will increase if health professionals and human rights experts maintain and extend their respectful collaboration. For our part, we warmly welcome engagement with a wide array of actors who are committed to realizing the right to the highest attainable standard of health for all.

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Professor Paul Hunt was the Project Director. A Steering Group met twice and provided indispensable guidance and support throughout the life of the project. The members of the Steering Group were:

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# Abbreviations and acronyms

|           |   |
|-----------|---|
| AARR      | average annual rate of reduction  |
| ACSD      | Accelerated Child Survival and Development (Malawi)                     |
| AIDS      | acquired immunodeficiency syndrome                                      |
| ARI       | acute respiratory infection   |
| ART       | antiretroviral therapy  |
| ARV       | antiretroviral  |
| BMZ       | German Federal Ministry for Economic Cooperation and Development        |
| CB-IMCI   | community-based Integrated Management of Childhood Illness              |
| CEDAW     | Convention on the Elimination of Discrimination Against Women           |
| CF        | Consultori Familiari (Italy)  |
| CHW       | community health worker   |
| CRCT      | cluster randomized controlled trial                                     |
| DFID      | Department for International Development (UK)                           |
| DHS       | Demographic Health Survey   |
| EHP       | Essential Health Package (Malawi)                                       |
| HIV       | human immunodeficiency virus  |
| HRBA      | human rights-based approach   |
| HRC       | Human Rights Council  |
| HSA       | health surveillance assistant   |
| IMCI      | Integrated Management of Childhood Illness                              |
| M&E       | monitoring and evaluation   |
| MDG       | Millennium Development Goal   |
| MGDS      | Malawi Growth and Development Strategy                                  |
| MHRC      | Malawi Human Rights Commission  |
| MMC       | maternal mortality committee  |
| MMR       | maternal mortality ratio  |
| NGO       | nongovernmental organization  |
| NSMNH-LTP | National Safe Motherhood and Newborn Health – Long Term Plan (Nepal)    |
| NWC       | National Women's Commission   |
| OC        | oral contraceptives   |
| OHCHR     | Office of the High Commissioner for Human Rights                        |
| PAISM     | Programme for Comprehensive Assistance to Women's Health (Brazil)       |
| PHPN      | Programme on Humanized Assistance to Pregnancy and Childbirth (Brazil)  |
| PLS       | Community-Based Paediatricians (Italy)                                  |
| PMTCT     | prevention of mother-to-child transmission (of HIV)                     |
| PNAISM    | National Policy for Comprehensive Assistance to Women's Health (Brazil) |
| PNDSR     | National Sexual and Reproductive Rights Policy (Brazil)                 |
| PRSP      | Poverty Reduction Strategy Paper  |
| PSF       | Family Health Programme   |
| RCT       | randomized controlled trial   |

|        |   |
|--------|---|
| SDIP   | Safe Delivery Incentive Programme (Nepal) |
| SSN    | Servizio Sanitario Nazionale (Italy)      |
| STI    | sexually transmitted infection            |
| SUS    | Unified Health System (Brazil)            |
| SWAp   | sector-wide approach                      |
| TBA    | traditional birth attendant               |
| TOP    | termination of pregnancy                  |
| U5MR   | under-five mortality rate                 |
| UN     | United Nations                            |
| UNICEF | United National Children's Fund           |
| UNFPA  | United Nations Population Fund            |
| WHO    | World Health Organization                 |

*President Nelson Mandela addresses the joint session of Assembly and Senate. South Africa, 1996.*



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## Executive summary

Human rights are recognized in a number of legal instruments and other documents of the World Health Organization, including the WHO Constitution, the Declaration of Alma-Ata, the International Health Regulations and the WHO Framework Convention on Tobacco Control. Member States of the United Nations have negotiated and agreed the Universal Declaration of Human Rights, the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination Against Women.

Today, binding national human rights standards are commonplace, and are protected by numerous national and local bodies, including constitutional courts, ombudsmen-style national human rights institutions and democratically elected assemblies. Moreover, countries have put in place policies, programmes and other measures to ensure that human rights move beyond laws and institutions to actually improve the lives and well-being of individuals, communities and populations.

The first of its kind, this report asks: what evidence is available to policy-makers that human rights have helped to improve women's and children's health? It considers whether or not evidence of beneficial impact supplements the compelling moral, political and legal reasons for adopting a human rights-based approach (HRBA) to women's and children's health.

By way of an initial assessment, the report concludes that applying human rights to women's and children's health policies, programmes and other interventions not only helps governments comply with their binding national and international obligations, but also contributes to improving the health of women and children.

### Audience

This report is intended primarily for members of governments and public health professionals engaged in policy development, monitoring, evaluation and research in the field of women's and children's health. It will also be of interest to parliamentarians, foundations and civil society organisations that collaborate with public health policy-makers, and researchers in public health and human rights.

### A focus on governments' human rights-shaped health interventions

Many stakeholders contribute to the implementation of a human rights-based approach to health, and there is compelling evidence that their contributions have a beneficial impact. This study focuses on the evidence of impact of governments' human rights-shaped health interventions, with particular attention to the initiatives of the executive branch. There are two reasons for this.

First, governments have the primary legal responsibility for implementing human rights; and second, very little attention has previously been given to the evidence of impact of governmental human rights-shaped initiatives on women's and children's health.

## What is a human rights-based approach to health?

This study uses the understanding of a human rights-based approach adopted by WHO and the Office of the High Commissioner for Human Rights (OHCHR). This approach aims to realize the right to the highest attainable standard of health (or "right to health") and other health-related rights. It underscores that the right to health includes timely and appropriate health care, as well as the underlying determinants of health, such as safe and potable water, health-related information, and gender equality. A human rights-based approach is based on seven key principles: availability, accessibility, acceptability and quality of facilities and services, participation, equality and non-discrimination, and accountability. The approach is not only about achieving certain goals or outcomes; it is about achieving them through a participatory, inclusive, transparent and responsive process.

## Learning from country experiences: Nepal, Brazil, Malawi and Italy

A number of countries have begun to apply elements of a human rights-based approach to women's and children's health, and there is much to learn from their rich and diverse experiences. Given constraints of time and funding, this report focuses on the experiences of Nepal, Brazil, Malawi and Italy, and asks two research questions. Has a human rights-based approach explicitly shaped the laws, policies and programmes related to women's and children's health? If so, what is the evidence that these explicitly human rights-shaped interventions have contributed to improvements in women's and children's health?

While united by these two central questions, each country report has a different theme. The report for Nepal looks at maternal and child health; that for Brazil looks at sexual, reproductive and maternal health; that for Malawi looks at children's health; while that for Italy looks at women's and children's health. The reports are not intended to be comprehensive; each considers aspects of the selected theme.

The studies found that, in all four countries, human rights have, to one degree or another, explicitly shaped the laws, policies, programmes and other interventions related to women's and children's health.

While the studies do not attribute improvements exclusively to the use of a human rights-based approach, there is plausible evidence that human rights contributed positively to health and health-related gains for women and children in the four countries, such as increased access to emergency obstetric care (Nepal), increased access to modern contraception (Brazil), reductions in early childhood mortality (Malawi) and increased vaccination coverage (Italy).

The studies mainly draw from existing quantitative data collected for other purposes, but these data do not capture many of the distinctive elements of a human rights-based approach. This underscores the urgent need for more research and evaluation on a human rights-based approach to women's and children's health, as well as fresh thinking on the appropriate disciplines and methods to be used.

Although major challenges remain in relation to women's health, children's health and human rights in Nepal, Brazil, Malawi and Italy, the governments deserve great credit for their leadership in taking human rights beyond the law books and beginning to apply them to women's and children's health policies and programmes.



## Participation and human rights: impact on women's and children's health – what does the literature tell us?

The monograph also reports on findings from a review of a specific subset of the academic literature on participation, human rights, and women's and children's health. This review sought to illustrate the impact of one principle of a human rights-based approach – participation – on women's and children's health, while retaining a focus on other human rights principles.

The overarching review question was: “What evidence is there that the participation of women in the design, implementation, management and/or evaluation of their community health services/systems leads to greater access to, and use of, acceptable and quality reproductive, maternal and child health services, and/or improved outcomes?” In addition to this overarching question, the review process identified more specific subsidiary questions.

The key findings of the review included the following.

- There was evidence of an association between women's participation and improved health and health-related outcomes.
- The studies in the review highlighted the benefits of attention to additional HRBA principles alongside participation.

- No study reported systematic attention to all elements of a human rights-based approach to health.

The scarcity of literature available for this review highlights the need to ensure that research is conducted, and accessible evidence generated, so that the strengths, weaknesses and impacts of a human rights-based approach can be better understood. Specific suggestions for further research include:

- intervention studies that explicitly consider participation within the framework of a human rights-based approach; and
- an explicit study of how non-discrimination can be used as a framework for addressing inequities in health.

## An enabling environment for a human rights-based approach to women's and children's health

One of the themes emerging from this report is that a human rights-based approach to women's and children's health is supported by an enabling environment with a number of features, including high-level political leadership and advocacy for a human rights-based approach, and a dynamic civil society. Steps that governments can take towards such a positive environment include ratifying key international human rights treaties, endorsing other global commitments,



*A mother and her child attend a free clinic in Port-au-Prince's impoverished Cité Soleil neighbourhood.*



recognizing the right to health in the constitution, establishing non-judicial human rights oversight bodies, and ensuring policy coherence and effective coordination among multiple stakeholders. Although their mix and sequencing may vary from one country to another, these steps may be instructive for those countries committed to implementing a human rights-based approach to women's and children's health.

### **A scarcity of research on, and evaluation of, the impact of a human rights-based approach on women's and children's health**

Another theme is the scarcity of research on, and evaluation of, the impact of a human rights-based approach on women's and children's health. There may be a number of reasons for this scarcity; for example, there are various interpretations of what constitutes a human rights-based approach and these conceptual uncertainties may discourage researchers from undertaking impact evaluations. Also, donor interest is relatively limited and there is a lack of funding for research of this sort. In addition, there is a lack of clarity about the methods and tools needed to carry out the appropriate research and evaluation.

### **Multidisciplinary and multi-method approaches**

In response to this last-mentioned methodological problem, the report emphasizes the importance of multidisciplinary and multi-method approaches to research on, and evaluation of, the impact of a human rights-based approach on women's and children's health. Several disciplines have a significant contribution to make, including epidemiology, clinical medicine, demography, social and behavioural sciences (e.g. sociology and anthropology), political science, law and economics. A multidisciplinary approach underlines the critical importance of using a broad and diverse array of methods and tools, encompassing quantitative and qualitative, including ethnographic, methods.

### **The importance of plausible levels of evidence**

The study also suggests that plausibility will often be the most compelling and feasible level of evidence for researchers and evaluators to use when assessing the impact of a human rights-based approach on women's and children's health, although adequacy and probability may also have a role.

### **Creating a platform for policy-makers seeking to implement a human rights-based approach to women's and children's health**

While this report has highlighted experiences in Nepal, Brazil, Malawi and Italy, many other countries are endeavouring to operationalize a human rights-based approach to women's and children's health, and there is much to learn from their rich experiences. Unfortunately, policy-makers sometimes find it difficult to locate documentation about these diverse country experiences. They would benefit from a platform, or other arrangement, that facilitates the exchange of documentation about country experiences, and offers an opportunity to discuss ideas and provide advice, support and encouragement on the implementation of a human rights-based approach to women's and children's health. Although mainly directed towards those working in the executive and legislative branches of government, the platform or other arrangement should include a wide range of stakeholders from different disciplines.

### **An agenda-setting process to strengthen research and evaluation**

An agenda-setting process is needed to strengthen research on, and evaluation of, the impact of a human rights-based approach on women's and children's health. A coherent and manageable agenda will help stakeholders from different disciplines to collaborate, coordinate and make strategic choices about what to prioritize. This agenda-setting process might include the following five steps.

- Conduct situational analyses of the health and human rights of women and children to establish a baseline.
- Find out what research on, and evaluation of, the impact of an human rights-based approach on women's and children's health have already been carried out.
- Set priorities for new research on, and evaluation of, the impact of a human rights-based approach on women's and children's health.
- Establish a multidisciplinary network of policy-makers, practitioners and scholars interested in research on, and evaluation of, the impact of a human rights-based approach on women's and children's health.
- Disseminate the findings of research on, and evaluation of, evidence of impact of an HRBA on women's and children's health so that the knowledge and evidence become well known and are used to advance the health and human rights of women and children.

## Conclusion

This report demonstrates plausible evidence that a human rights-based approach contributes to health improvements for women and children. It shows that the constitutional and international right to health can be translated into improved health services and health status through laws, policies and programmes that are explicitly shaped by health rights principles, such as accessibility, quality, participation and accountability. Applying human rights to women's and children's health policies and other interventions not only helps governments comply with their binding national and international obligations but also contributes to improving the health of women and children.

The study found few human rights-shaped women's and children's health policies and other interventions that were accompanied by research or evaluation that was well equipped to capture many of the human rights dimensions of the interventions. The observed scarcity of evidence may be attributable not to lack of impact but to a scarcity of appropriately designed research and evaluation.

There is a need for a multidisciplinary network of policy-makers, practitioners and scholars interested in research on, and evaluation of, the impact of a human rights-based approach on women's and children's health. WHO has an important role in helping to establish such a network.

There is also a need for a platform, or other arrangement, that facilitates the exchange of documentation about country experiences, and offers an opportunity to discuss ideas and provide advice, support and encouragement on the implementation of a human rights-based approach to women's and children's health. There is an important role for WHO, in close collaboration with OHCHR and other stakeholders, in helping to ensure the setting-up of such an arrangement, mainly directed towards those working in the executive and legislative branches of government.

Finally, human rights-shaped women's and children's health interventions can help governments comply with their binding human rights obligations, health workers deliver their professional objectives, and individuals, communities and populations improve their health, life and well-being.



*Ante-natal care in Ukraine.*



WHO

## Chapter 1

### Introduction

The opening article of the Charter of the United Nations (UN) establishes the promotion of human rights as one of the four purposes of the Organization (1). Human rights are also specifically recognized in a number of documents and legal instruments of the World Health Organization, including the WHO Constitution (2), the Declaration of Alma-Ata (3), the Bangkok Charter for Health Promotion in a Globalized World (4), the International Health Regulations (5) and the WHO Framework Convention on Tobacco Control (6).

In line with their commitments under the UN Charter, Member States have negotiated and agreed the Universal Declaration of Human Rights (7), and a number of human rights treaties, including the Convention on the Rights of the Child (8) and the Convention on the Elimination of All Forms of Discrimination Against Women (9). Of 193 UN Member States, 190 are legally bound by the Child Rights Convention and 187 by the Women's Rights Convention.

Today, binding national human rights standards are commonplace, and are protected by numerous national and local bodies, including constitutional courts, Ombudsmen-style national human rights institutions, democratically elected assemblies, civil society organizations, such as health professional associations, and the media.

Designed to deepen national and global governance, the extraordinary flourishing of human rights is one of the most remarkable achievements of the period since the establishment of the UN.

Moreover, countries have put in place policies, programmes and other measures to ensure that human rights move beyond laws and institutions to actually improve the lives and well-being of individuals, communities and populations. International agencies offer advice, assistance and support to governments as they seek to put their human rights commitments into practice. Implementation of human rights is the key contemporary challenge.

While strongly affirming the moral, political and legal authority of human rights, this monograph addresses an important question: what evidence is available to policy-makers that human rights have helped to improve women's health and children's health?

The first of its kind, this report concludes that applying human rights to women's and children's health policies, programmes and other interventions, not only helps governments comply with their binding national and international obligations, but also contributes to improving the health of women and children.

While this monograph focuses on the evidence of impact of a human rights-based approach (HRBA) on aspects of women's and children's health, it has to be emphasized that conformity with human rights is required by binding national and international law. In short, the report considers whether or not evidence of beneficial impact supplements the compelling moral, political and legal reasons for adopting a human rights-based approach to women's and children's health.

### 1.1. Aims, structure and research questions

This monograph analyses the evidence of impact of a human rights-based approach on aspects of women's and children's health, considers some of the implications of this analysis, and suggests some practical next steps.

Many stakeholders contribute to the implementation of an HRBA to health, and there is compelling evidence that their contributions have a beneficial impact. Gauri & Brinks and Yamin & Gloppen, for example, have shown that judicial decisions based on human rights have had a beneficial impact on women's and children's health (10-12). There is also evidence of the beneficial impact of human rights-shaped health interventions designed and implemented by civil society organizations. While not the focus of this report, Chapter 4 provides examples of the contribution of law courts and civil society to the implementation of human rights in relation to women's and children's health (Boxes 4.1 and 4.2). Such contributions, and the evidence of their impact, are very significant, and merit close attention and sustained research.

This study focuses on the evidence of impact of governments' human rights-shaped health interventions, with particular attention to the initiatives of the executive branch, such as ministries of health. There are two reasons for this. First, governments have the primary legal responsibility for implementing human rights; and second, very little attention has previously been given to the evidence of impact of governmental human rights-shaped initiatives on women's and children's health. This results in a critical gap in knowledge, which this report highlights and addresses.

Numerous countries have begun to apply elements of a human rights-based approach to women's and children's health. In light of constraints of time and funds, Chapter 2 looks at the instructive experiences of

just four such countries – Nepal, Brazil, Malawi and Italy – and asks two questions. Have the laws, policies and programmes relating to women's and children's health been explicitly shaped by an HRBA? If so, what is the evidence that these interventions have contributed to improving women's and children's health? It will be important in the future to ensure that lessons can be drawn from the rich and diverse experiences of other countries (see Chapter 5).

Chapter 3 presents the results of a literature review on participation, which is widely recognized as an important public health principle and is one element of a human rights-based approach. The review examined the evidence that the participation of women in the design, implementation, management or evaluation of their community health services and systems leads to greater access to, and use of, acceptable and quality reproductive, maternal and child health services, or improved health and health-related outcomes. While participation provided the main "entry point", the review considered participation in the context of other human rights principles, such as accessibility, quality and accountability.

Chapter 4 outlines the key features of an enabling environment in support of a human rights-based approach to women and children's health, drawing on the experiences of Nepal, Brazil, Malawi and Italy. It also highlights the scarcity of research on the impact of a human rights-based approach on women's and children's health, and suggests several reasons for this scarcity, focusing in particular on the lack of clarity and agreement about the methods and tools needed to carry out meaningful research in this area. In response to this methodological problem, a number of multidisciplinary and multi-method approaches to much-needed research and evaluation are set out.

Building on the findings and discussion of the previous chapters, Chapter 5 introduces two initiatives designed to promote a human rights-based approach to women's and children's health: first, a platform for policy-makers seeking to implement a human rights-based approach to women's and children's health; and, second, an agenda-setting process to strengthen research and evaluation on the impact of a human rights-based approach on women's and children's health.

This initial assessment provides an introduction to these important issues.

## 1.2. What is a human rights-based approach to health?

This study considers the evidence of the impact of a human rights-based approach on aspects of women's and children's health. It adopts the understanding of a human rights-based approach promulgated jointly by WHO and the Office of the High Commissioner for Human Rights (OHCHR). This is based on seven key principles: availability, accessibility, acceptability and quality of facilities and services, participation, equality and non-discrimination, and accountability (see Annex 1) (13).

This approach aims to realize the right to the highest attainable standard of health (or "right to health") and other health-related rights. It underscores that the right to health includes timely and appropriate health care, as well as the underlying determinants of health, such as safe and potable water, sanitation, health-related information and education, and gender equality (14, 15). It also emphasizes that health-related services and facilities have to be available, accessible, acceptable and of good quality, and that human rights standards and principles, such as participation, equality, non-discrimination and accountability, should guide

programming in all health-related sectors and at all stages of the process. A human rights-based approach is not only about the achievement of certain goals or outcomes; it is about their achievement through a participatory, inclusive, transparent and responsive process.

This WHO-OHCHR understanding of a human rights-based approach resonates with definitions adopted by other UN organizations, national development agencies and nongovernmental organizations (NGOs) (see Box 1.1). While more attention needs to be given to the different articulations of a human rights-based approach, with a view to promoting greater consistency, this is not the aim of the present report (see 1.7).

In summary, this study takes the position that, after agreeing to be bound by the right to health, and other health-related rights, a government has to take measures to implement these commitments. Such a government has a legal obligation to take steps to ensure that its health policies and other interventions reflect the key principles understood to be part of a human rights-based approach. Moreover, it is accountable in relation to this obligation.

### Box 1.1

#### Illustrative definitions of a human rights-based approach

##### **The concept of a human rights-based approach adopted by the United Nations Population Fund (UNFPA)**

[A] human rights-based approach is a conceptual framework for the process of human development that is normatively based on international human rights standards and operationally directed to promoting and protecting human rights ... the application of a human rights-based approach alters the way that programmes are designed, implemented, monitored and evaluated.

##### **Key benefits to implementing a human rights-based approach**

- Promotes realization of human rights and helps government partners achieve their human rights commitments;
- Increases and strengthens the participation of the local community;
- Improves transparency;
- Promotes results (and aligns with Results Based Management);
- Increases accountability;
- Reduces vulnerabilities by focusing on the most marginalized and excluded in society; and
- More likely to lead to sustained changes as human rights-based programmes have greater impact on norms and values, structures, policy and practice.

*Reproduced from reference 16.*

##### **The concept of a human rights-based approach adopted by the German Federal Ministry for Economic Cooperation and Development**

A human rights-based approach involves explicit alignment of development policy with commitments to human rights under international and regional human rights conventions and the human rights principles of non-discrimination and equal opportunity, accountability and transparency, and participation and empowerment. It is the basis for an emancipatory understanding of development cooperation which views and promotes people everywhere as subjects and actors of their own development. "Target groups" and "people in need" are recognized as right-holders, government partner institutions as duty-bearers.

*Reproduced from reference 17.*

##### **The concept of a human rights-based approach adopted by the International Initiative on Maternal Mortality and Human Rights**

Emphasise the processes as well as the outcomes of programming; focus on the most marginalized populations; work towards equitable service delivery; ensure meaningful participation of affected communities; ensure local ownership of any initiative; seek to strengthen the accountability of all actors.

*Reproduced from reference 18.*

### 1.3. Women's health and children's health

WHO's Constitution defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (2). This definition, including "social well-being", is the understanding of women's and children's health adopted in this monograph. Health has to be understood across the life-course; interventions in childhood and adolescence, during the reproductive years and beyond can affect health later in life and across the generations (19). There is an interplay between biological and social determinants of health; for example, gender inequality can increase the exposure and vulnerability of girls and women to risks, limit access to health care and information, and have an impact on health outcomes. Similarly, children's health and development depend to a large extent on their family, community and environment (20).

In this initial assessment, it is not feasible to address all aspects of women's and children's health, and a selection of particular aspects has had to be made. As research and evaluation of women's and children's health interventions shaped by human rights become deeper and more widespread, they will need to collectively encompass a holistic understanding of health, the continuum of care, and all aspects of women's and children's health.

While women and children are distinct populations with distinct health issues and human rights, this report mostly uses "women's and children's health" as a shorthand for "women's health and children's health".

### 1.4. Explicitly or implicitly shaped by human rights?

Policies, programmes and other interventions can be either explicitly or implicitly shaped by human rights. Both are important. Overall, the emphasis of this study is on interventions explicitly shaped by human rights. The four reports of country experiences in Chapter 2 consider initiatives that were explicitly shaped by human rights, while the review of participation (Chapter 3) includes initiatives that were either explicitly or implicitly shaped by human rights. For the purpose of this study, an initiative is explicitly shaped by human rights if there is either an explicit reference to human rights, suggesting their formative role, in the documentation supporting the intervention, or an unambiguous oral or written statement from an authoritative person, such as a minister, confirming that human rights considerations played a formative role.

### 1.5. Key terms

Box 1.2 provides working definitions of some key terms. Together, research and evaluation can generate knowledge on the impact of a human rights-based approach on women's and children's health that can be generalized within and across countries. Of particular relevance to this study is impact evaluation, which gives attention to attribution and causality. Monitoring is closely linked to research and evaluation, but is beyond the scope of this study.

#### Box 1.2

#### Working definitions of some key terms (21-24)

**Evidence:** the available body of facts and information, generated through scientific or analytical methods, that indicates whether a proposition or assertion is valid or true. Evidence can come from many sources, such as controlled trials that compare one intervention with another, ethnographic observations of community involvement in health programming, case studies and legal testimonies, as further discussed in Chapter 4.

**Research:** a systematic investigation, using scientific methods (e.g. research development, testing and evaluation), designed to develop or contribute to generalizable knowledge. For example, research can produce new information on selected components and impact of a policy.

**Evaluation:** a systematic assessment of an activity, project, programme, strategy, policy, etc. It should be as impartial as possible, and should focus on expected and achieved accomplishments, examining the results, processes and contextual factors of causality, in order to understand achievements and failures. The purpose of an evaluation should be to improve understanding of whether planned results were achieved and how to optimize the impact on stakeholders.

**Outcome:** the likely or achieved effects (positive or negative) on women's and children's health and human rights that could result from a specific intervention, e.g. a law, policy or programme.

**Impact:** changes (short- and long-term, intended and unintended, positive and negative) affecting the target populations of a policy, programme or project, other members of their community, and the policy or project environment that are attributable to a particular intervention.

**Impact evaluation:** evaluation of the effects (positive and negative, primary and secondary, short- and long-term) produced by a particular intervention, directly or indirectly, intended or unintended. Impact evaluation seeks to attribute impacts, i.e. the effects produced by an intervention and what the effects would have been in the absence of the intervention. For example, an impact evaluation can assess the increase in access to emergency obstetric care as a result of a particular human rights-shaped policy.

**Monitoring:** the routine collection and analysis of data to determine if policies, programmes or actions are on track to achieve their intended purposes in a timely manner. Monitoring may reveal barriers to progress.

## 1.6. Audience

This report is intended primarily for members of governments and public health professionals engaged in policy development, monitoring, evaluation and research in the field of women's and children's health. This is a diverse group, including ministries of health and official development agencies, whose main task is to draw on evidence and experience to design, implement, monitor and evaluate policies, programmes and projects. The report assumes some familiarity with the various disciplines concerned with policy evaluation, research methods and the use of findings, as discussed in Chapters 4 and 5. It does not look deeply into technical issues that are more appropriately dealt with by textbooks and similar publications. The study will also be of interest to parliamentarians, as well as foundations and civil society organizations that collaborate with, and support, public health policy-makers. It is hoped that the monograph will stimulate interest and action among researchers in public health and human rights, so as to expand the knowledge base on which sound public policy and programmes can be formulated, implemented and evaluated.

## 1.7. Methodological and other challenges

The first of its kind, this report begins to address the critical gap in knowledge about the impact on women's and children's health of governmental human rights-shaped initiatives. Such an undertaking faces major methodological and substantive challenges, some of

which are examined in later chapters. However, in a report of this length, it is not possible to examine in detail all the relevant methodological and other issues. A number of issues that could not be dealt with in detail are briefly mentioned below.

Rather than analysing the various competing definitions of a human rights-based approach, this report adopts the understanding promulgated jointly by WHO and OHCHR (see section 1.2), and focuses on the neglected issue of evidence of impact of human rights on women's and children's health. However, it has to be acknowledged that the OHCHR–WHO understanding was primarily designed for use by UN agencies, whereas the main focus of this report is governmental initiatives. The most appropriate understanding of a human rights-based approach for use by ministries of health in implementing human rights and assessing the evidence of impact needs further attention.

Chapter 2 suggests that the human rights provisions of some constitutions have helped to shape health policies, programmes and other interventions (see, for example, Figure 2D.1, in the report on Italy). Chapter 4 takes this idea further by outlining key features of an enabling environment in support of a human rights-based approach. However, closer analysis is needed to better understand the processes by which constitutional provisions influence health interventions at the national and community levels. This analysis will benefit from the growing literature on theories of change.



*One of the drafters of the Universal Declaration of Human Rights, Mrs. Eleanor Roosevelt of the United States holds a poster of the Declaration in Spanish. [November 1949]*



While the report finds plausible levels of evidence that human rights have contributed to health gains for women and children, it emphasizes that other factors have also contributed, such as the development of political will, proactive measures to reduce health disparities, and increased investment (see section 2E). A challenge for future research may be to isolate and analyse the discrete and specific impact of human rights on women's and children's health.

These and other issues raised in this report require further analysis. The report identifies research that will deepen the initial assessment provided by this study, sets out multidisciplinary and multi-method approaches to such research, and introduces initiatives designed to clarify what constitutes a governmental human rights-based approach to women's and children's health.

### ► Key messages

- The Charter of the United Nations establishes the promotion of human rights as one of the four purposes of the Organization.
- The flourishing of human rights standards and processes is one of the most remarkable achievements of the period since the establishment of the UN.
- Today, implementation of human rights is the key challenge.
- While strongly affirming the moral, political and legal authority of human rights, this monograph asks: what is the evidence that human rights have helped to improve women's and children's health?
- Primarily designed for governments and public health professionals engaged in policy development, monitoring, evaluation and research, the report focuses on the evidence of the impact of governments' interventions on women's and children's health that are explicitly shaped by human rights.
- The monograph analyses the impact of a human rights-based approach on aspects of women's and children's health, considers some of the implications of this analysis, and suggests practical next steps.

*Nurses treat HIV positive patients at Nepal Government Hospital which has an influenza isolation unit.*



WHO /Tom Pietrasik

## Chapter 2

### Evidence of impact of a human rights-based approach in countries: Nepal, Brazil, Malawi and Italy

A number of countries have begun to apply elements of a human rights-based approach to women's and children's health, and there is much to learn from their rich and diverse experiences. This section considers the experiences of Nepal, Brazil, Malawi and Italy. After looking at a number of countries, these four were selected because they provide instructive examples of evidence of the impact of a human rights-based approach on aspects of women's and children's health. They are also diverse in geography, income and health outcomes for women and children.

In looking at the experiences in the four countries, two questions were asked. First, has a human rights-based approach shaped the laws, policies and programmes related to women's and children's health? Second, if so, what is the evidence that these explicitly human rights-shaped interventions have contributed to improvements in women's and children's health? Particular attention was given to large-scale interventions.

While united by these two central questions, each

country report has a different theme. The report for Nepal looks at maternal and child health; that for Brazil looks at sexual, reproductive and maternal health; that for Malawi looks at children's health; while that for Italy looks at women's and children's health. The studies are not comprehensive; each considers aspects of the selected theme.

In summary, the studies found that, in all four countries, human rights have, to one degree or another, shaped the laws, policies, programmes and other interventions related to women's and children's health. While the studies do not attribute improvements in women's and children's health exclusively to the use of a human rights-based approach, there is plausible evidence that human rights contributed positively to women's and children's health gains in the four countries.

The country studies were based on reviews of existing material, such as laws, policies, programmes, and quantitative and qualitative health data, supplemented by discussions with key health policy professionals and

other informants. Each study applied the OHCHR-WHO human rights-based approach outlined in Chapter 1, giving particular attention to the seven underlying key principles (Box 2.1). These principles provide a human rights “lens”, through which selected health policies and programmes were examined. Supplementary information on the human rights principles related to selected health interventions in the four countries is given in annexes 2-5.

**Box 2.1**  
**Key principles of a human rights-based approach to health**

- Availability
- Accessibility
- Acceptability
- Quality
- Participation
- Equality and non-discrimination
- Accountability

These principles are inter-related and sometimes overlapping.

*\* Based on the WHO-OHCHR human rights-based approach to health outlined in Chapter 1.*

80-year-old Ratna Maya Thapa from the Central Region of Nepal shows her voter registration card after walking for one and a half hours to cast her ballot in the Nepalese Constituent Assembly elections.



UN Photo/Nayan Tara

## Chapter 2A.

### Maternal and child health in Nepal\*

Akshay Patel, Sudha Sharma, Audrey Prost, Genevieve Sander, Paul Hunt

Nepal has a recent history of political conflict, is ranked 157 out of 187 on the Human Development Index (1), has a challenging topography, and has over 100 caste and ethnic groups (2). This complex socioeconomic, environmental and political context makes the recent improvements in maternal and child health in the country all the more remarkable: the maternal mortality ratio (MMR) decreased from 539 to 281 per 100 000 live births between 1996 and 2006, while the under-5 mortality rate (U5MR) fell from 125 to 54 per 1000 live births between 1991 and 2011 (3, 4). Recent data suggest that the MMR continues to fall, with data from eight districts in 2009 indicating an estimated MMR of 229 per 100 000 (5). This achievement was recognized by the United Nations in 2010 with a Millennium Development Goal (MDG) Award (6).

Many factors may have contributed to these striking gains: the development of political consensus around the importance of maternal and child health, the emergence of maternal health champions (7), increasing investment (8), and increased overall

coherence in aid (9) have complemented a package of interventions to improve maternal and child health. In the past decade, a human rights-based approach has increasingly been incorporated into laws, policies, programmes and other interventions related to maternal and child health in Nepal.

#### 2A.1 Research methods

A review of the literature was conducted to identify significant maternal and child health laws, policies and programmes. PubMed, ScienceDirect, JSTOR and SpringerLink databases were searched for peer-reviewed articles, and grey literature sources were reviewed. Key informants in the health and policy sector in Nepal were also consulted. All laws, policies and programmes relevant to maternal, newborn and child health in Nepal over the past 15 years were reviewed. From these, five illustrative case studies were selected with an explicit human rights-based approach in their goals, design, implementation and, where available, evaluations of impact on health outcomes.

\* Acknowledgements are due to Professor Dharma Manandhar and Jyoti Shrestha (Mother Infant Research Activities, Nepal), and Professor Anthony Costello and Dr Joanna Morris (UCL Institute for Global Health, London, England).

## 2A.2 The Nepali context

### Maternal and child health

Maternal and child health indicators in Nepal have improved over the past 20 years. For example, between 1991 and 2011, the total fertility rate declined from 5.1 to 2.6 children per woman of childbearing age. The skilled birth attendance rate increased from 11% to 36% between 2001 and 2011, while the under-five mortality rate decreased from 125 to 54 per 1000 live births between 1991 and 2011 (4).

Concerted efforts to increase immunization coverage, as well as increased access to, and improved quality of, management of acute respiratory infections and diarrhoeal illness, have also contributed significantly to gains in child survival. Although maternal and child mortality remain unacceptably high and significant work is required to meet Nepal's own targets, particularly to reduce neonatal mortality, the country's recent achievements are commendable.

### Increasing legal recognition of human rights

Nepal was an absolute monarchy until 1991, when it became a constitutional monarchy. In 1996, caste, religious, geographical, economic and political marginalization contributed to sociopolitical unrest, fuelling an insurgency led by the Communist Party of Nepal (Maoist), which lasted 10 years (2). During this period, both sides in the conflict faced criticism about rights violations and their negative impact on health (10). Despite internal instability, during the 1990s Nepal ratified several key international human rights treaties with a bearing on maternal and child health. Following the success of the People's Movement in 2006, directed against the King's seizure of power, a Comprehensive Peace Agreement was signed between Nepal's seven political parties and the Maoists. The Agreement committed the signatories to establish a republican system of government and included groundbreaking constitutional recognition of human rights, including "civil rights in education, health, shelter, employment and food security" (11).

In 2007, Nepal adopted an Interim Constitution that enshrines civil and political rights, as well as economic, social and cultural rights, including the right to health (12). Demonstrating a commitment to the promotion of women's health and children's health, the Interim

#### Box 2A.1

##### The Nepali Interim Constitution (2007)

- Article 16(1) and (2) guarantees every citizen the right to live in a healthy environment and the right to basic health services free of cost from the State, as provided in law.
- Article 20(2) guarantees every woman's right to reproductive health and other reproductive matters.
- Article 22(2) guarantees children's rights to nourishment, basic health and social security.

Constitution recognizes women's reproductive rights, as well as children's rights to nourishment and basic health (see Box 2A.1). It also recognizes several economic, social and cultural rights that are enforceable by courts, including those in Box 2A.1. For example, in *Prakash Mani Sharma & Others vs Government of Nepal* (13), a case seeking accountability for the Government's failure to address the high incidence of uterine prolapse, the Supreme Court ruled that the Government had violated women's constitutional right to reproductive health by failing to develop and implement policies and programmes to effectively address this severe form of maternal morbidity. Besides the Supreme Court, other Nepali human rights oversight bodies include the National Human Rights Commission and the National Women's Commission. Despite significant progress in human rights, the rule of law in Nepal, upon which a human rights-based approach depends, needs strengthening.

#### ► Key messages

- While maternal and child mortality rates remain high and significant work is required to meet Nepal's own targets, the country's recent achievements are commendable.
- Nepal's Interim Constitution (2007) includes the right to health, women's reproductive rights, and children's rights to nourishment and basic health; the Supreme Court has ruled on cases on the basis of some of these human rights.

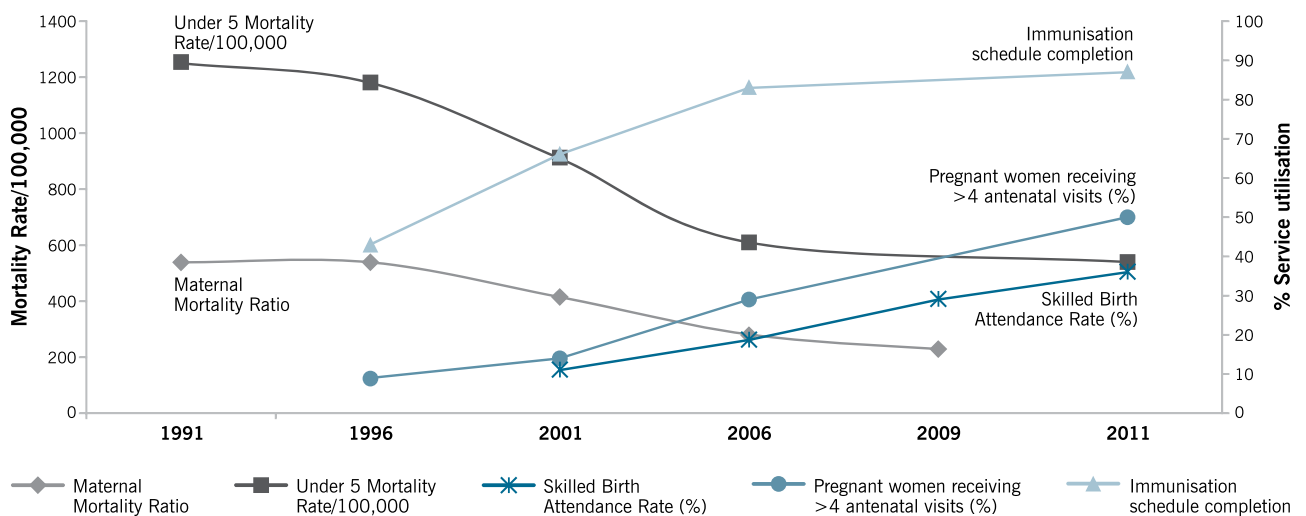
### 2A.3 Emerging recognition of a human rights-based approach to maternal and child health policies

Approaches to health programming evolved during the period of intense political change, from a focus on basic needs in the early 1990s, to poverty reduction strategies and, more recently, an emerging human

rights-based approach (14). The past two decades have witnessed a shift from absent or implicit human rights influences on maternal and child health policy, to adoption of a clear and explicit human rights-based approach. Figure 1 shows the laws, policies and plans relevant to maternal and child health that were introduced under the influence of a human rights-based approach,

Figure 1.

Trends in mortality rates and service use, and introduction of policies and plans shaped by human rights considerations, Nepal, 1991-2011



|                      | 1991-1996   | 1997-2006  | 2007-Present  |
|----------------------|---|--|---|
| Law                  |   | Muluki Ain 11th Amendment Bill (legalizing abortion 2002)                                      | Nepal Interim Constitution (2007)   |
| Policy               | National Health Policy (1991)   | National Safe Abortion Policy (2002)   | Free Health Care Policy (2007)  |
|                      | National Safe Motherhood Policy (1994)                                | National Policy on Skilled Birth Attendants (2006)   | Nepal Health Development Partnership<br>International Health Partnership Compact (2009) |
| Strategies and plans | Eighth Five Year Plan (1992)  | Second Long Term Health Plan (1997-2012)   | Three-Year Interim Plan (2007)  |
|                      |   | National Adolescent Health and Development Strategy (2000)                                     | National Reproductive Health Commodity Strategy (2007)                                  |
|                      |   | 10th 5-Year Plan/ Nepal Poverty Reduction Strategy Paper (2002-2007)                           | Five-year Strategic Plan of National Women's Commission (2007)                          |
|                      |   | National Safe Motherhood - Long Term Plan (2006-2017)  | Health Sector Gender Equality and Social Inclusion Strategy (2007)                      |
|                      |   | National Neonatal Health Strategy (2004)   | Nepal Health Sector Programme Implementation Plan II (2010-2015)                        |
|                      |   | National Human Rights Action Plan (2004)   |   |
|                      |   | National Health Sector Strategy – An Agenda for Reform (2003)                                  |   |
|                      |   | National Health Sector Programme, Implementation Plan (2004-2009)                              |   |
|                      |   | National Nutrition Policy & Strategy (2004)  |   |
|                      |   | Vulnerable Community Development Plan for Nepal Health Sector, Implementation Plan (2004-2009) |   |
|                      | Revised Safe Motherhood and Newborn Health Long-term Plan (2006-2017) |  |   |

Legend for Strategies and plans:

- Absent rights focus
- Implicit rights focus
- Explicitly rights-based

as well as changes in relevant health indicators and outcomes, from 1991 to 2011.

During the 2011 review by the UN Human Rights Council under the Geneva-based Universal Periodic Review mechanism, Nepal was commended for the notable decline in maternal mortality. The Government recommitted itself to “continue its holistic and comprehensive approach to the promotion and protection of human rights and to put in practice a rights-based approach to [the] development of all sectors” (15). Dr Praveen Mishra, Secretary of the Ministry of Health and Population, recently confirmed in a letter to WHO: “Reframing basic health needs as health rights has remained the main thrust of the policies of the Government of Nepal. ... Many government strategies and policies related to safer motherhood, neonatal health, nutrition and gender are anchored in the principles of human rights” (5 March 2013). By way of illustration, the revised National Safe Motherhood and Newborn Health – Long Term Plan (2006–2017) (NSMNH-LTP) is the major instrument setting out the Government’s safe motherhood and newborn package of health care. The revised plan places explicit emphasis on a human rights-based approach:

Rights-based approaches are therefore included as fundamental and cross-cutting to all outputs of the NSMNH-LTP, with the aim of increasing accountability for maternal and neonatal health, strengthening local capacity of duty-bearers to fulfill women’s rights, strengthening women’s voices and their ability to demand their rights to maternal health and transforming the distribution of power and resources that maintain inequalities across society, in families, communities and health systems... (16)

The National Health Development Partnership – International Health Partnership Compact (2009), which is designed to coordinate development funding in Nepal, confirms the partnership between external development agencies, who accounted for approximately 55% of the health sector budget in 2008, and the Government of Nepal (17). The Compact pledges to “advance citizens’ rights” and recognizes that “citizens of Nepal have a constitutional right of access to free basic health care, and universal access to reproductive care”. It also recognizes the need to “increase access and service delivery effectiveness”, “advance equity and social inclusion”, and “strengthen governance and

accountability” (17). Gender equality strategies, which are part of a human rights-based approach, have been incorporated in government departments (18), and recent amendments to labour laws have increased the duration of paid maternity leave, and introduced paternity leave, the mandatory provision of breastfeeding time for working women, and the provision of crèches (19).

#### ► Key message

- The last two decades have witnessed a shift from absent or implicit human rights influences on maternal and child health policy, to the adoption of an explicit human rights-based approach, such as in the National Safe Motherhood and Newborn Health – Long Term Plan (2006–2017).

## 2A.4 The influence of a human rights-based approach on maternal and child health programmes, and evidence of impact

Preceding sections have outlined the increasing legal recognition of human rights and the emergence of a human rights-based approach to maternal and child health policies. The current section focuses on maternal and child health programmes. Using five illustrative case studies, it explores how a human rights-based approach has been employed to address maternal, newborn and child health priority programmes, and considers the evidence of their impact. Four of the case studies focus on maternal and newborn health, while the fifth focuses on child survival. While only two of the programmes are national, all have involved the Government and have influenced other maternal, newborn and child health services in Nepal.

### Women’s Right to Life and Health Programme: emergency obstetric care

The Women’s Right to Life and Health Programme contributes to the implementation of the revised 2006–2017 National Safe Motherhood and Newborn Health Long-Term Plan. The Government aims to provide comprehensive obstetric care in 60 districts, and basic emergency obstetric care in 80% of primary health care centres, by 2017 in order to reduce maternal and neonatal mortality (16).

Emergency obstetric care in districts was pilot-tested at the start of the millennium by the Nepal Safer Motherhood Project and the UNICEF/Government of Nepal Women's Right to Life and Health Programme (20). The Women's Right to Life and Health Programme supported a human rights-based approach in four districts, while the Safer Motherhood Project supported a pilot-test in nine districts. Annex 2, Table A2.1, summarizes some of the human rights-based elements of the Women's Right to Life and Health Programme from 2004 to 2010, and indicates some of the outcomes. For example, by improving availability and accessibility, the Programme led to a five-fold increase in met need for emergency obstetric care, and a significant increase in institutional delivery rates (3.8% to 8.3%). There was an observed decrease in the case-fatality rate from 2.7% to 0.3% (21).

Following the success of these initial pilot studies, the Government scaled-up the services. Data from 2011 suggest that significant progress has been made nationally; for example, availability of comprehensive obstetric services increased from 34 facilities in 26 districts in 2005 to 99 facilities in 43 districts in 2011 (22). Furthermore, data suggest that, in areas where services are available, utilization has increased, with one in five births taking place in facilities that can provide emergency obstetric care; 23% of the need for emergency obstetric care is now being met, compared with 2–3% in 2000 (21). The met need for caesarean section has increased to 46.6% in these areas,

representing an increase in met need of 2–9% per year between 2004 and 2011 (22).

### Equity and Access Programme (23)

The Equity and Access Programme, part of the Support to Safe Motherhood Programme, was established in 10 districts through a partnership between the Government of Nepal and the UK Department for International Development (DFID)/Options. This Programme explicitly adopted a human rights-based approach, aiming to “empower women, their families and local stakeholders to secure maternal and newborn health rights”, and specifically targeted the poor and excluded (23). As a demand-side initiative, it focused on behaviour change strategies in two districts, and on strengthening village development committees in eight districts by, for example, mobilizing women's groups.

Annex 2, Table A2.2, summarizes some of the human rights-based elements of the Equity and Access Programme, and indicates some of the outcomes. Results were striking, with an increased uptake of antenatal care visits (45% to 60%), an institutional delivery rate twice the national rate, significant increases in iron tablet intake (12.3% to 65.5%), functioning community emergency fund mechanisms, and increases in knowledge, awareness and participation (23). The Government is currently expanding the Programme to a further ten districts.



*Primary Health Care  
in Nepal.*



### Skilled birth attendance: Aama Surakshya Karyakram Programme

In recent years, a range of initiatives have been developed to increase skilled birth attendance rates as part of Nepal's strategy for reducing maternal mortality. The National Policy on Skilled Birth Attendance outlined plans to increase the training of skilled birth attendants, but with no explicit reference to a human rights-based approach (24). The Safe Delivery Incentive Programme (SDIP), associated with the revised 2006–2017 National Safe Motherhood and Newborn Health Long-Term Plan, provided a conditional cash transfer to mothers attending delivery services and a cash incentive for each skilled delivery performed in the community or a facility. Although this Programme was not explicitly designed using a human rights-based approach, it did incorporate equity, access and availability concerns.

A 2008 evaluation of SDIP revealed that the proportion of eligible women receiving the cash incentive had increased from 34% in the first year to 59% in the third year. The evaluation also revealed that women who had benefited from the Programme were 24% more likely to use government health facilities, 5% less likely to deliver at home and 13% more likely to have a skilled birth attendant at delivery in the future (25).

In 2009, there was a major change, when SDIP was replaced by the Aama Surakshya Karyakram, which is explicitly human rights-based. It provides free delivery services throughout the country, along with cash incentives for mothers and providers (26), in order to “ensure the right of people for free health service utilisation as guided by the Constitution of Nepal” (27). Annex 2, Table A2.3, summarizes some of the human rights-based elements of the Aama Surakshya Karyakram, and indicates some of the outcomes.

Early small-scale evaluations have suggested that the shortcomings of the SDIP are being redressed (28). In one study, awareness of the cash incentive and free delivery services was found to be 100% and 94%, respectively, thanks to a mass media campaign and motivation of health care providers to inform mothers of their entitlements (26). Improved fund allocation also means that 80% of women receive their cash incentive immediately following delivery. Although out-of-pocket expenses are incurred by 40% of women, most of these are not catastrophic expenses. There is also evidence of a shift away from home delivery, most notably among marginalized groups: a 19% increase in

institutional deliveries was reported in the first 18 months of the programme (26).

### Comprehensive abortion care services: National Safe Abortion Programme

In 2000, a study by UNICEF and the Government of Nepal attributed 20% of maternal deaths occurring in hospitals to unsafe abortion (29). Another prelegalization study suggested that over half of all hospital-based maternal admissions were abortion-related (30). Prison surveys conducted at the same time revealed that more than one in five women in prison had been convicted for illegal abortion (31).

Human rights considerations contributed to the decriminalization of abortion in 2002, as well as the implementation of comprehensive abortion care services. The National Safe Abortion Programme, which has its roots in the rights-influenced National Abortion Policy (2002) and the National Safe Motherhood and Newborn Care Long-Term Plan (2006–2017), is coordinated by a government committee, working in close partnership with advocacy groups, service providers and development partners.

Annex 2, Table A2.4, summarizes some of the human rights-based elements of the National Safe Abortion Programme, and indicates some of the outcomes. In 2004, the first Comprehensive Abortion Care Service was opened in Kathmandu Maternity Hospital. Since then, services have become available in all of Nepal's 75 districts, with more than 500 providers, public and private, now certified to provide comprehensive abortion care. Access to comprehensive abortion care has also increased, with approximately 100 000 safe abortions now being carried out each year (22). By comparison, only 719 safe abortions were carried out in the six months after the first services opened (32). A behaviour change communication intervention and mass media strategy have also increased public awareness of the legal provision of abortion (33). The creation of a curriculum, training programme and clear protocols, and government regulation of provider accreditation, have all served to ensure a satisfactory quality of service. A 2008 study showed a postabortion complication rate of 2%, which is in line with international standards; however, there was significant heterogeneity in service quality, with some providers having complication rates of up to 5.6% (34).

The decriminalization of abortion has had an undoubted

– though hard to quantify – impact on Nepal's MMR. Nevertheless, access to lawful abortion under the National Safe Abortion Programme has been limited by various considerations, including out-of-pocket expenses. In 2009, a landmark case, *Dhikta vs Government of Nepal* (35), described how Lakshmi Dhikta had been obliged to continue her fifth pregnancy because the cost of abortion at her local government hospital was prohibitive. The Supreme Court ordered the Government to fulfil its duty, as outlined in the Safe Abortion Law, to guarantee broad access to safe and legal abortion services and ensure their financial accessibility (35). The Court did not introduce or extend lawful abortion in Nepal; it held that the Government had to take steps to ensure that the abortion provisions enacted by Parliament were effective. In spite of progress since this pivotal case, there are still cost and transport barriers to access for remote and marginalized communities (32). Subsidizing services for the poor could reduce these inequities over time.

Human rights concerns have been raised about the potential for an increase in the number of sex-selective abortions with the advent of legal abortion in Nepal. Effective monitoring and auditing are required to ensure that this does not become an unintended consequence of the legalization of safe abortion services.

### Community-based integrated management of childhood illness – “Bal Bachau” Child Survival Project

The “Bal Bachau” Child Survival Project (2004–2007) used an explicitly human rights-based approach to target marginalized communities and improve child health in four western districts of Nepal. Included in the key cross-cutting strategies were a “focus on gender and child rights issues” and a “focus on disadvantaged groups and women empowerment” (36). Annex 2, Table A2.5, summarizes some of the human rights-based elements of the Project, and indicates some of the outcomes. For example, in one project district there was an increase in the rates of exclusive breastfeeding for 6 months from 50% to 88%; and uptake of iron and folic acid supplementation by women increased from 26% and 6%, to 85% and 60%, respectively. The Project demonstrated the value of community mobilization and participatory methods in increasing uptake of services, creating engagement between communities and health service providers, and promoting behaviour change to improve child health (36).

While further research is needed, it appears that the influence of the explicitly human rights-shaped “Bal Bachau” Project has been far-reaching (37). In 1999, for example, the Government modified its child health programmes to be in line with the WHO/UNICEF guidelines for Integrated Management of Childhood Illness (IMCI). When presenting the IMCI Strategy in 1999, WHO observed: “The Convention on the Rights of the Child ... provide[s] a valuable framework for the development of strategies to deal with issues affecting child health. ... IMCI strategies address directly the requirements of Article 24 [on the right to health] for countries to take action to reduce mortality and provide essential health care for children” (38). The Government's approach was further developed to create Nepal's Community-Based Integrated Management of Childhood Illness (CB-IMCI) Programme, drawing on the lessons learned from the “Bal Bachau” Project. CB-IMCI was scaled-up to be a national programme (39). In Nepal's second periodic report to the UN Committee on the Rights of the Child in 2004, it was declared that “the IMCI strategies for Nepal are in line with article 24 of the Convention”, i.e. the provision relating to the right to health (37).

Nepal's National Neonatal Health Strategy (2004) observes: “We are a signatory to the Convention on the Rights of the Child. Every vulnerable Nepali newborn has the greatest right to be taken care of and therefore we have to immediately invest resources to improve their health and survival.” Drawing from the CB-IMCI (and thus the “Bal Bachau” Project), the Neonatal Health Strategy generated the Community-Based Newborn Care Package, which was pilot-tested in ten districts and is currently being scaled-up in a further 15 districts (40). The female community health volunteers have a crucial role to play in the Package's implementation. While the Package has the hallmarks of a human rights-shaped initiative, further research is needed on the explicit role of human rights in relation to the Package, as well as its impact on neonatal health.

## 2A.5 Conclusion

Overall, there is evidence that human rights have contributed positively to women's and children's health interventions in Nepal, and that the human rights-shaped interventions contributed to significant health improvements for women and children.

**► Key messages**

- The Women’s Right to Life and Health Programme adopted an explicit human rights-based approach that led to improvements in emergency obstetric care, including increased accessibility.
- The Equity and Access Programme adopted an explicit human rights-based approach and saw notable results, including increased uptake of antenatal care visits and an institutional delivery rate twice the national rate.
- The explicitly human rights-based Aama Surakshya Karyakram Programme (to increase skilled birth attendance) redressed some of its predecessor’s shortcomings; there was a 19% increase in institutional deliveries in the first 18 months of the Programme.
- The National Safe Abortion Programme, rooted in human rights-influenced initiatives, has led to increased availability and accessibility of comprehensive abortion care.
- The “Bal Bachau” Child Survival Project, which used an explicit human rights-based approach, contributed to an increase in availability, accessibility and utilization of child survival services.
- Overall, there is evidence that human rights have contributed positively to women’s and children’s health interventions, and that the human rights-shaped interventions contributed to significant health improvements for women and children.

Secretary-General Ban Ki-moon and Dilma Rousseff, President of Brazil at the UN Conference on Sustainable Development, Rio+20, Brazil.



UN Photo/Eskinder Debebe

## Chapter 2B.

### Sexual, reproductive and maternal health in Brazil

*Gabriela Barros De Luca, Genevieve Sander, Sandra Valongueiro, Elcylene Leocádio, Jose Martinez, Islene Araujo de Carvalho, Paul Hunt*

In the past 25 years, Brazil has made rapid progress in terms of socioeconomic development, medical care and the health of the population. In 1985, after 21 years of military dictatorship, the country returned to democracy. Today, Brazil has the world's sixth-largest economy, a population approaching 200 million, and a growing influence on global affairs. Ranked 84th on the 2011 Human Development Index (1), it is on track to meet MDG4 on child mortality, and is one of the top-performing countries in reducing under-five mortality (from 58 per 1000 live births in 1990 to 22 per 1000 in 2007) (2, 3). As this report outlines, the country is making significant progress on sexual, reproductive and maternal health. However, while Brazil's MMR is declining, it is not on track to reach the MDG5 target (3). Despite notable overall progress, 16 million Brazilians live in extreme poverty, and wide socioeconomic and regional inequalities remain (4).

#### 2B.1 Research methods

A review was undertaken of the laws, policies and programmes relating to women's health, together with consultations with expert informants in Brazil. Laws,

policies and programmes explicitly shaped by human rights were examined, and relevant data from the past 30 years were analysed alongside relevant evaluations, to look for evidence of impact on sexual, reproductive and maternal health outcomes in Brazil.

#### 2B.2 The Brazilian context

##### Sexual, reproductive and maternal health

Since the 1980s, there have been notable improvements in sexual, reproductive and maternal health indicators. Fertility levels, for example, plunged from 4.4 children per woman in 1980 to 2.3 in 2000 and 1.8 in 2006, one of the fastest rates of decline ever recorded (5-7). The proportion of women in stable relationships who were using modern contraceptive methods increased from 57% in 1986 to 78.5% in 2006-07 (5, 8); while between 1981 and 2006-07, antenatal care coverage increased from 74.7% to 98.7% (5) and institutional deliveries increased from 79.6% to 98.4% (9). Inequalities in skilled birth attendance, antenatal care and contraceptive use between wealth quintiles narrowed significantly between 1996 and 2006-07 (10). Recent estimates

based on modelling suggest that maternal mortality is also in decline, as discussed below (9).

## Human rights

The 1988 Constitution is a landmark on Brazil's road to democracy and the realization of human rights (11). The Constitution recognizes civil, political, economic, social and cultural rights, and provides that all these human rights are enforceable in the courts. Social rights include "health ... and the protection of motherhood" (12). The Constitution elaborates on the right to health and provides special guarantees for family planning (Box 2B.1). The courts frequently hear and decide cases on some of these health-related provisions. While somewhat controversial (13), right-to-health judicial decisions have required the Government to take measures, such as the provision of equal access to pharmaceutical and medical services for all, including people living with HIV (11). In addition to the judiciary, other mechanisms for the promotion and protection of human rights include the Office of the Public Defender (14) and the National Secretariat for Human Rights (15). In 1985, the National Council for Women's Rights was established to ensure women's participation in political, economic and cultural affairs (16). Brazil has a dynamic civil society, including a vibrant women's rights movement.

Brazil has ratified several key international human rights treaties with a bearing on women's health rights. The CEDAW Committee has recently commended the expansion of health services in Brazil and the measures to reduce maternal mortality (17). In 2011, however, it found Brazil was in breach of its human rights obligations

### Box 2B.1. The Brazilian Constitution (1988)

Article 196: Health is a right of all and a duty of the State and shall be guaranteed by means of social and economic policies aimed at reducing the risk of illness and other hazards, and at the universal and equal access to actions and services for its promotion, protection and recovery.

Article 226 (7): Based on the principles of human dignity and responsible parenthood, family planning is a free choice of the couple, it being within the competence of the State to provide educational and scientific resources for the exercise of this right, any coercion by official or private agencies being forbidden.

following the death of Alyne da Silva Pimentel from pregnancy-related complications (18); the Government accepted the Committee's recommendations and has since announced remedial measures (19).

The 1990 law establishing Brazil's public health system – the Unified Health System (SUS) – confirmed that "[h]ealth is a fundamental right of the human person, and the State must guarantee the conditions necessary for its full exercise" (20). Tax-based, community-based and participatory, the SUS is universal, i.e. it provides free, comprehensive health care to all citizens, regardless of employment status or social security contributions. Within the SUS, the Family Health Programme (PSF) is the main strategy for delivering primary health care, and aims to serve people in the most hard-to-reach areas, including those living in poverty (21-23). The PSF is associated with a reduction in overall mortality, especially in the poorest regions (9, 23, 24). The successful implementation of women's health policies and programmes relies heavily on the SUS and health-related initiatives, such as PSF. *Bolsa Familia*, a national cash transfer programme, "has helped to reduce inequality and extreme poverty" (25) which, given the relationship between inequality, extreme poverty and ill-health, may prove to be highly relevant to women's health (26). Since coming to office in 2011, President Dilma Rousseff has made a major commitment to improve women's health, including allocating approximately US\$ 4.6 billion to maternal health services (27, 28).

### ► Key messages

- Since the 1980s, there have been notable improvements in sexual, reproductive and maternal health indicators in Brazil.
- The Constitution (1988) is a landmark on Brazil's road to democracy and the realization of human rights; the right to health, and special guarantees for family planning, are enforceable in the courts.
- Brazil's public health system is universal, tax-based, community-based and participatory; women's health initiatives rely heavily on this system and related schemes, such as the Family Health Programme.

### 2B.3 The influence of a human rights-based approach on laws, policies and programmes on sexual, reproductive and maternal health

The ratification of CEDAW in 1984, and the adoption

of the democratic Constitution in 1988, laid the human rights foundations for Brazil's policies and programmes on women's health. Table 2B.1, lists the key government interventions on sexual, reproductive and maternal health since 1984 that were explicitly shaped by human rights.

**Table 2B.1.**

Rights focus of Brazil's national laws, policies, strategies, plans and guidelines relevant to sexual, reproductive and maternal health

|   | Laws  | Year | Rights focus |
|---|---|------|--------------|
| 1   | Brazil's Democratic Constitution of 1988  | 1988 | Explicit     |
| 2   | Law no. 8.080 creating the "Sistema Único de Saúde" (SUS)   | 1990 | Explicit     |
| 3   | Law no. 9.263 on family planning  | 1996 | Explicit     |
| 4   | Law no. 11.108 on the right to a companion during labour  | 2005 | Explicit     |
| 5   | Law no. 11.634 on the right of pregnant women to know to which hospital they will be admitted for institutional delivery      | 2007 | Explicit     |
| Policies and programmes                         |   | Year | Rights focus |
| 6   | Programme for Comprehensive Assistance to Women's Health  | 1984 | Explicit     |
| 7   | Adolescent Health Programme   | 1989 | Implicit     |
| 8   | Programme on Humanized Assistance to Pregnancy and Childbirth   | 2000 | Explicit     |
| 9   | National Policy for Comprehensive Assistance to Women's Health  | 2004 | Explicit     |
| 10  | National Sexual and Reproductive Rights Policy  | 2005 | Explicit     |
| 11  | I National Programme for Women's Policies   | 2005 | Explicit     |
| 12  | National Family Planning Policy   | 2007 | Implicit     |
| 13  | National Policy on Obstetric and Neonatal Care  | 2005 | Explicit     |
| 14  | II National Programme for Women's Policies  | 2008 | Explicit     |
| Strategies and plans                            |   | Year | Rights focus |
| 15  | Safe Motherhood Project   | 1995 | Explicit     |
| 16  | National Pact to Reduce Maternal Mortality (until 2015)   | 2004 | Explicit     |
| 17  | Pact for Health (or "Pact for the SUS")   | 2006 | Explicit     |
| 18  | National Pact to Combat Violence Against Women  | 2007 | Explicit     |
| 19  | Plan to Combat the Feminization of the Epidemic of AIDS and other STDs  | 2007 | Explicit     |
| 20  | Campaign for Natural Birth and Against Unnecessary Caesareans   | 2008 | Implicit     |
| Ministerial decrees from the Ministry of Health |   | Year | Rights focus |
| 21  | Creation of National Committee on Maternal Mortality (no. 773)  | 1994 | Implicit     |
| 22  | Compulsory notification of maternal deaths (no. 256)  | 1997 | Implicit     |
| 23  | Procedures and resources for high-risk pregnancies (nos. 3016, 3482, 3477)  | 1998 | Implicit     |
| 24  | Procedures to reduce number of caesarean sections (no. 2816)  | 1998 | Implicit     |
| 25  | Creation of natural birth centres (no. 985)   | 1999 | Implicit     |
| 26  | Creation of Child and Maternal Mortality Surveillance System (no. 1399)   | 1999 | Implicit     |
| National guidelines                             |   | Year | Rights focus |
| 27  | Technical manual on assistance to family planning   | 1988 | Explicit     |
| 28  | Manual on maternal mortality committees   | 1994 | Implicit     |
| 29  | Technical guidelines on the prevention and treatment of injuries resulting from sexual violence against women and adolescents | 1999 | Implicit     |
| 30  | Technical manual on antenatal care  | 2000 | Explicit     |
| 31  | Technical manual on high-risk pregnancies   | 2000 | Implicit     |
| 32  | Maternal emergencies: guide for diagnosis and practice in relation to high-risk pregnancies and obstetric emergencies         | 2000 | Explicit     |
| 33  | Operational norm for health care services   | 2001 | Implicit     |
| 34  | Guidelines on the humanization of antenatal care and childbirth   | 2002 | Explicit     |
| 35  | Technical norm on abortion  | 2005 | Explicit     |
| 36  | Emergency contraception: guide for health professionals   | 2005 | Explicit     |
| 37  | National guidelines for attention to assisted reproduction  | 2006 | Implicit     |
| 38  | Manual on sexual and reproductive rights for people with disabilities   | 2009 | Explicit     |

This section outlines the human rights influence on four of these interventions.

### **Programme for Comprehensive Assistance to Women's Health (PAISM) (1984)**

Launched in 1984, PAISM anticipated the democratic Constitution (1988), the SUS (1990), the Programme of Action of the International Conference on Population and Development (Cairo, 1994), and the Platform of Action of the Fourth World Conference on Women (Beijing, 1995). Affirming sexual and reproductive rights, it reflected Brazil's dynamic women's movement (29-32). Eighteen years later, the Government reported: "The importance of PAISM by introducing the language of women's human rights is unquestionable. It pervaded the legislative process, consolidated important rights for women's health in the 1988 Constitution, and has enabled the organization, discussion and development of new rights based on their original conception" (32).

The Programme emphasized that "control of one's fertility [is] a fundamental right of the person" and recognized that all individuals should have access to contraceptive information and services. In addition to improving access to contraception, the Programme aimed to reduce the number of unsafe abortions, increase coverage of antenatal care, improve institutional and home deliveries, reduce the number of unnecessary caesarean sections, and reduce the incidence of sexually transmitted diseases. The Programme focused on training health professionals to ensure that women received the information they needed to control their health and fertility (30). Annex 3, Table A3.1, summarizes some of the Programme's key human rights elements.

PAISM was implemented through, and influenced, various laws, strategies and other interventions, a selection of which are outlined in the following paragraphs.

### **The SUS and access to contraceptives**

After 1990, contraceptives were distributed free of charge through the SUS (33). Their distribution was interrupted in 1997 when the federal Government decentralized this responsibility to states and municipalities, few of which chose to continue the distribution. In 2000, the federal Government again took over responsibility for contraceptive distribution (33). Emergency contraception became available through the SUS in 1998 (31).

### **Family planning law (1996)**

In 1996, a new law elaborated on the right to family planning, making it mandatory for the SUS to provide access to contraceptive information and services (34). The law confirmed that "family planning is a right of every citizen" and defined family planning as "a set of actions aimed at controlling fertility that ensures equal rights for women, men or couples with regard to starting, limiting or expanding their families" (34). It required full and informed consent for surgical sterilization, an especially sensitive issue because, in the late 1970s, many women were sterilized as a method of population control, and some were misled into believing that sterilization was the only option available to them (35, 36). While much of the family planning law is commendable, it requires consent from both spouses for surgical sterilization, restricting individuals' freedom to exercise control over their own bodies.

### **Technical guidelines on the prevention and treatment of injuries resulting from sexual violence against women and adolescents (1999)**

These guidelines emphasize that "the Brazilian State, through the Ministry of Health, has made a commitment to the human rights of women and to guarantee the full exercise of their physical and mental health, by devising public health policies that respond to their real needs" (37). The guidelines affirm, for example, that health professionals must provide women who have been raped with comprehensive information on how to access legal abortion (32).

### **Eight Steps for Safe Motherhood (1995)**

The Eight Steps aimed to improve the quality of maternal care in hospitals; for example, they encompassed the "guarantee that women receive information about reproductive rights and women's rights" and improved training of health professionals (38, 39).

### **Maternal mortality committees (MMCs)**

The move to establish MMCs arose from PAISM and the Pan-American Regional Action Plan for the Reduction of Maternal Mortality (1990) (40, 41). MMCs were mandated to: investigate maternal deaths with a view to supporting the collection of epidemiological data in the country; analyse the causes of maternal deaths; generate discussions in hospitals about the clinical aspects of maternal deaths; and train health professionals in preventing maternal deaths. The first MMCs were established in 1987 and by 1996 existed in all 27 states. In 1994, the Government established the

National Maternal Mortality Commission to oversee all MMCs. The Commission included public health experts, clinicians, and civil society, including representatives of the women's movement (40). When reforming the Commission in 2003, the Ministry of Health emphasized that "the rates of maternal mortality in Brazil constitute a violation of the human rights of women and a grave public health issue" and urged "the adoption of concrete measures to reduce such rates" (42).

An assessment in 2001 revealed that only 14 MMCs were active. Poor states lacked the resources to ensure the effective functioning of the Committee, leading to under-reporting in the regions where maternal mortality was estimated to be the highest (43, 44). From a human rights perspective, MMCs should be empowered to hold duty bearers (e.g. hospital directors) accountable in appropriate cases (44). Pernambuco's MMC has collaborated with the Public Prosecutor, but this is exceptional (45).

### **Programme on Humanized Assistance to Pregnancy and Childbirth (PHPN) (2000)**

This Programme was a response to several health concerns, including the overmedicalization of childbirth, with unnecessary caesarean sections, and the fact that women in labour were being turned away from multiple hospitals before being admitted to give birth (9, 46, 47). In a survey conducted in Rio de Janeiro between 1999 and 2001, one-third of women in labour were turned away by one or more hospitals before being admitted (48).

The Programme recognized the "right to dignified and quality care during pregnancy, birth and the postnatal period; the right to adequate antenatal care in line with the principles defined by the PHPN; the woman's right to know the hospital where she will be assisted in her delivery; and the right to have 'humanized' and safe maternal health care according to the terms of the PHPN" (49, 50). Also, the Programme established a "right to the presence of a companion", i.e. the right of a pregnant woman to be accompanied by a person of her choice during delivery. The "right to know" and the "right to the presence of a companion" were later enshrined in law (51, 52). The Programme also had an equity focus.

Driven by these human rights considerations, the Programme aimed to strengthen the care continuum,

especially antenatal, delivery and postnatal care (49). In 2000, the Government allocated approximately US\$280 million to finance the scheme (49, 50, 53). Resources were invested in, for example, up-to-date technical manuals on antenatal care, high-risk pregnancies and maternal emergencies, and in equipping medical facilities to conduct antenatal examinations (49). The Programme provided financial incentives to women who registered for integrated maternal health care (54).

Annex 3, Table A3.2, summarizes some of the Programme's key human rights elements. The Programme had some significant results. For example, an early assessment demonstrated an increase of 20% in the number of antenatal consultations between 2000 and 2002 (46). A 2004 evaluation showed that the average number of consultations rose from 2 or 3 in 2000 to 4 in 2004. Only 17% of women who began antenatal care completed the recommended minimum of six consultations, suggesting that there were problems with the quality of care or with access, despite the financial incentives (55).

### **National Policy for Comprehensive Assistance to Women's Health (PNAISM) (2004)**

Drafted with the active participation of civil society, this Policy built on and strengthened the ground-breaking PAISM of 1984. It confirmed that "the commitments here reflect the guarantee of women's human rights and the goal to reduce maternal mortality" and aimed "to make sexual and reproductive rights concrete". The Policy emphasized "the character of health care as being a right" and promoted the "advancement of women's health by guaranteeing their access to rights that are legal obligations of the State" (56). The Policy also emphasized the importance of specific measures for rural women, women with disabilities, black women, indigenous women, women in prisons and women of different sexual orientation (57). Recognizing that unsafe abortions were one of the main causes of maternal mortality, the Policy aimed to eliminate discriminatory practices by health service providers in relation to abortion (56). Annex 3, Table A3.3, summarizes some of the Programme's key human rights elements.

### **National Pact to Reduce Maternal Mortality (2004)**

This Pact, one of the most significant initiatives arising from PNAISM, aimed to mobilize all 27 states to achieve the goals for reducing maternal mortality by 2007 (58).



Emphasizing that “the high rates of maternal and neonatal mortality in Brazil are a violation of the human rights of women and children”, the Pact’s guiding principles include “respect for human rights of women and children”, “the inclusion of gender, race and ethnicity considerations in all strategies and measures”, and “the consideration of social inequalities in decision-making processes” (59). The Pact reaffirms that “women and men have the right to decide freely and consciously about family planning”, that they “have the right to lead a sexual life that is positive, healthy and safe” and that “these prerogatives, called sexual and reproductive rights, are the object of commitments assumed by Brazil and are guaranteed in the Federal Constitution” (59). The Pact aimed, for example, to provide culturally appropriate health services for indigenous women and women of African descent, to expand the Family Health Programme for family planning and maternity-related care in community health units, and to train medical professionals to assist in home deliveries (60, 61).

The Government allocated approximately US\$10 million in special funds to 78 municipalities selected on the basis of poor health indicators, including maternal mortality (62). A Commission was set up, composed of government and civil society representatives, to monitor and evaluate the implementation of the Pact. Specialized training was provided for midwives and community *doulas* (assistants who provide physical and emotional support) in the country’s five “indigenous districts” (60). The Government prepared and disseminated a manual for policy-makers and practitioners entitled *Equity perspective on the National Pact to Reduce Maternal and Neonatal Mortality: attention to Black women’s health* (61).

### National Sexual and Reproductive Rights Policy (PNDSR) (2005)

This Policy included reaffirmations of human rights, such as “the Brazilian Government abides by the respect and guarantee of human rights, among which are sexual and reproductive rights, for the formulation and implementation of policies in relation to family planning and to any other matter related to population and development” (62). Its aims included: expanding the supply of reversible contraceptive methods; improving access to surgical sterilization; and introducing assisted human reproduction to the SUS. The Policy emphasized the importance of including the prevention of HIV/AIDS

and other sexually transmitted diseases as an essential component of all family planning strategies (62).

Different elements of the PNDSR were implemented through various initiatives, such as the National Guidelines for Attention to Assisted Reproduction (2005) (63), the Health in Schools Programme (2007) and the National Family Planning Policy (2007). The Health in Schools Programme promoted sexual and reproductive health education in the public school system (64), while the Government recognized “young persons’ right and need to lead a sexual life that is positive, healthy and safe” (65). The National Family Planning Policy expanded existing contraceptive programmes and introduced additional elements, such as a new vasectomy procedure which was made available through the SUS. During the first six months of its availability, there was an increase of 69% in the number of vasectomies performed in the public health system (66).

Annex 3, Table A3.4, summarizes some of the key human rights elements of the PNDSR.

#### ► Key messages

- Human rights have explicitly shaped laws, policies, programmes and other interventions related to sexual, reproductive and maternal health in Brazil.
- The free distribution of contraceptives, capacity-building of health professionals and the integration of antenatal, delivery and postnatal services are among the key interventions.

## 2B.4 The evidence of impact of a human rights-based approach on sexual, reproductive and maternal health

This section considers the evidence of the impact of the human rights-shaped PAISM, PHPN, PNAISM, and PNDSR, and initiatives deriving from them.

### Sexual, reproductive and maternal health

Since 1980, fertility levels in Brazil, i.e. the mean number of children born to each woman, have dropped from 4.4 (1980), to 2.9 (1991) and 1.8 (2006) (5-7).

**Table 2B.2.**

Sexual, reproductive and maternal health indicators from national surveys (9)

|   | 1981 (67) | 1986 (8) | 1996 (68) | 2006–07 (5) |
|---|-----------|----------|-----------|-------------|
| Any contraceptive use in women living with their partner    | ...       | 65.8     | 76.7      | 80.6        |
| Modern contraceptive use in women living with their partner | ...       | 57.0     | 72.0      | 78.5        |
| Any antenatal care  | 74.7      | 74.0     | 85.7      | 98.7        |
| Antenatal care (six or more visits)                         | 40.5      | ...      | 75.9      | 80.9        |
| Started antenatal care during first trimester of pregnancy  | ...       | ...      | 66.0      | 83.6        |
| Received tetanus toxoid vaccine during pregnancy            | ...       | ...      | 58.5      | 76.9        |
| Institutional delivery                                      | 79.6      | 80.5     | 91.5      | 98.4        |

Table 2B.2 shows the significant improvements in other sexual, reproductive and maternal health indicators since 1981. For example, women in stable relationships using modern contraceptive methods increased from 57% (1986) to 78.5% (2006–07) (5, 8); antenatal care coverage increased from 74.7% (1981) to 98.7% (2006–07) (5); and institutional deliveries increased from 79.6% (1981) to 98.4% (2006–07) (9). These improvements reflect Brazil's human rights obligation to enhance access to health goods, services and facilities.

A recent study demonstrated that inequalities between wealth quintiles narrowed significantly between 1996 and 2006–07 (Table 2B.3). In 1996, for example, contraceptive use for the poorest quintile was 55.8% and for the richest quintile, 76.8%. By 2006–07, this gap had disappeared: contraceptives were used by 82.7% in the poorest quintile and 81.6% in the wealthiest. In 1996, skilled birth attendance in the poorest quintile was 72.6% and in the richest quintile, 99.2%. By 2006–07, this gap had almost closed to 96.8% (poorest quintile)

and 99.5% (richest quintile). The narrowing of these gaps reflects increased equity, equality and non-discrimination, and may be associated with interventions outside the health sector, such as *Bolsa Familia*, the national cash transfer programme, which is contributing to greater social equality (see section 2B.2).

The available data show that the proportion of caesarean deliveries in Brazil has always been above the WHO recommended level of 15% (69). Moreover, the percentage increased from 36.4% in 1996 to 43.8% in 2006–07 (5, 10, 68, 70, 71), confirming that PHPN (2000), and other government initiatives to reduce the proportion of caesarean deliveries, have not yet succeeded (9, 72).

Overall, however, the notable improvements in contraceptive use, number of antenatal consultations, institutional deliveries and other outcomes (Table 2B.2), including the narrowing of inequalities between wealth quintiles (Table 2B.3), suggest that the Government's

**Table 2B.3.**

Time trends in selected indicators by wealth quintile (10)

| Indicator and year of survey (5, 69) |         | Wealth quintile <sup>a</sup> |      |      |      |      |
|--------------------------------------|---------|------------------------------|------|------|------|------|
|                                      |         | 1                            | 2    | 3    | 4    | 5    |
| Skilled birth attendance             | 1996    | 72.6                         | 89.8 | 96.8 | 98.2 | 99.2 |
|                                      | 2006–07 | 96.8                         | 98.1 | 99.5 | 99.2 | 99.5 |
| Antenatal care (4 or more visits)    | 1996    | 52.5                         | 79.1 | 89.6 | 94.7 | 97.2 |
|                                      | 2006–07 | 92.7                         | 94.5 | 96.8 | 98.5 | 99.4 |
| Prevalence of contraceptive use      | 1996    | 55.8                         | 68.9 | 73.6 | 73.8 | 76.8 |
|                                      | 2006–07 | 82.7                         | 86.0 | 81.6 | 83.7 | 81.6 |

<sup>a</sup> Quintile 1 was the poorest; quintile 5 the richest.

human rights-shaped policies, programmes and other interventions have contributed to improvements in sexual, reproductive and maternal health care services (10).

### Maternal mortality

A study published in *Lancet* in 2011 analysed maternal mortality levels and trends in Brazil (9). It reported that maternal mortality estimates were affected by under-registration of deaths – especially in rural areas and small towns, where mortality ratios tended to be highest – and by under-reporting of maternal causes in registered deaths. A reproductive age mortality survey in all state capitals in 2002 had estimated an MMR of 54.3 per 100 000 population, ranging from 42 per 100 000 in the south to 73 per 100 000 in the northeast (9). This survey showed that many maternal deaths had been attributed to other causes and thus overlooked by the vital registration system. As already discussed, several initiatives in recent years, such as the strengthening of MMCs, have helped improve the reporting of maternal deaths.

The *Lancet* study also noted that, according to government statistics, the MMR had been stable since 1996, at around 50 deaths per 100 000 live births. Several alternative MMR estimates have given widely discrepant results (9). Two new estimates became available in 2010. One predicted an MMR of 55 per

100 000 live births for 2008, with an annual reduction of 3.9% (9). Using a different model, a UN study estimated a ratio of 58 maternal deaths per 100 000 live births for 2008, with an annual reduction of 4.0% (9).

The *Lancet* study concluded that, while the official MMR had been stable for the previous 15 years, estimates based on modelling suggested that ratios were declining. However, Brazil's MMR remains high in comparison with neighbouring countries, such as Chile, Argentina and Uruguay (10). In Brazil, abortion is lawful in very limited circumstances and, despite the introduction of PAISM in 1984 and related initiatives, unsafe abortion remains the fourth leading cause of maternal death in Brazil. These deaths are unevenly spread in the population (9, 10). The Alyne da Silva Pimentel case, decided by the CEDAW Committee in 2011, confirmed that Brazil continues to face systemic challenges in relation to maternal mortality (see section 2B.2).

### 2B.5 Conclusion

There is evidence that human rights have explicitly shaped government interventions related to women's sexual, reproductive and maternal health in Brazil, and that these human rights-shaped interventions have contributed to considerable health improvements for women.

#### ► Key messages

- There has been a notable improvement in contraceptive use, number of antenatal consultations, institutional deliveries and other outcomes, including the narrowing of inequalities between wealth quintiles; the MMR is declining.
- There is evidence that human rights have explicitly shaped government interventions related to women's sexual, reproductive and maternal health in Brazil, and that these human rights-shaped interventions have contributed to considerable health improvements for women.

*In 2009 in Malawi, a health worker takes a blood sample from an infant's foot at a hospital in Blantyre, Southern Region. The infant's mother is HIV-positive and participated in a programme to prevent mother-to-child transmission of the disease while she was pregnant and after she gave birth.*



## Chapter 2C.

### Children's health in Malawi

*Chisale Mhango, Levi Mvula, Genevieve Sander, Joo-Young Lee, Paul Hunt*

Development in Malawi has been hindered by intervals of poor governance, economic instability, widespread poverty, a high prevalence of HIV/AIDS and other diseases, and natural disasters, including both floods and droughts. Today it is considered one of the poorest countries in the world, ranking 171 of the 187 countries in the 2011 Human Development Index (1). This has serious implications for children, who make up 51% of the population (2). However, in recent years, Malawi has demonstrated an impressive commitment to improving children's health. Moreover, despite enormous challenges, it has made considerable progress: most notably, there has been a steady decline in the under-five mortality rate, from 234 per 1000 live births in 1992 to 112 per 1000 in 2010. In 2009, the UN Committee on the Rights of the Child commended Malawi for reducing infant and child mortality (3), and it is widely recognized that Malawi is on track to achieve MDG 4 (4). While these and other gains have been influenced by many factors, this section considers the possible impact of Malawi's increasingly human rights-shaped laws, policies, strategies and interventions on children's health.

#### 2C.1 Research methods

A review was conducted of the most significant laws, policies, strategies and programmes related to children's health in Malawi, and key informants in the country were consulted. The policies, strategies and programmes that were explicitly shaped by human rights were reviewed, and relevant data spanning roughly 15 years were analysed, together with relevant and accessible programme evaluations, in order to determine whether or not a human rights-based approach had had an impact on children's health in Malawi. Despite persistent attempts, it proved impossible to locate some government documents on specific projects and programmes, raising questions about access to information.

#### 2C.2 The Malawian context

##### Child health

There have been considerable improvements in child health indicators in the past decade. The under-five mortality rate was nearly halved between 2000 and

2010, with an average annual rate of decline of 6.9% (5). Between 2004 and 2009–10, the annual incidence of acute respiratory infections in children decreased from 19% to 6.8%, and that of diarrhoea from 22.3% to 17.5%. Over the same period, the percentage of health facilities providing a minimum package of services for prevention of mother-to-child transmission of HIV soared from 7% to 100% (6–8). There has also been a significant increase in immunization coverage, with 81.8% of children aged 12–23 months living in rural areas receiving all basic vaccinations in 2010, compared with 70.7% in 2004 (6, 7). Some of these issues, including their equitable dimensions, are discussed later in this section.

### Human rights

Malawi gained independence in 1964. Until the early 1990s, Dr Kamuzu Banda was life President, the Constitution did not guarantee human rights and violations were widespread. Malawi ratified its first international human rights treaty in 1987.

The adoption of a democratic Constitution in 1995 was a watershed. This Constitution contains a Bill of Rights, including civil and political rights, some economic, social and cultural rights, and the right to development (see Box 2C.1) (9). The Constitution includes a non-justiciable provision on health (Box 2C.1), but does not

encompass a justiciable right to the highest attainable standard of health. This is one reason why Malawi's judges have not been called on to make any determinations on children's health rights. In addition to the judiciary, the Constitution establishes other independent human rights oversight bodies, including the Malawi Human Rights Commission (MHRC) and the Office of Ombudsman. Since the 1990s, Malawi has ratified several international human rights treaties with a bearing on children's health. The MHRC has established a Child Rights Unit to evaluate implementation of the Convention on the Rights of the Child, including children's health (10). Since 2000, a children's parliament (reconfigured as a youth parliament in 2012) has met once a year to discuss important issues, including children's health.

Despite major advances since the mid-1990s, there have recently been deepening concerns about human rights and governance, as a result of which some donor partners suspended aid. This affected the availability of medicines and led to deep budget cuts for oversight bodies. In 2012, Mrs Joyce Banda became President, following the death of President Bingu wa Mutharika. She repealed many of the regressive laws sanctioned by her predecessor, and most bilateral donors subsequently lifted their suspension of aid. As President, Joyce Banda has prioritized safe motherhood in her Government's agenda (11).

#### Box 2C.1. The Constitution of Malawi (1995)

##### *Fundamental right*

**Article 30:** “[A]ll persons and peoples have a right to development and therefore to the enjoyment of economic, social, cultural and political development and women, children and the disabled in particular shall be given special consideration in the application of this right.”

##### *Principle of national policy\**

**Section 13(c), Health:** Obliges the State to “provide adequate health care, commensurate with the health needs to Malawian society and international standards of health care”.

*\*While fundamental rights are directly enforceable by courts, principles of national policy are intended to direct state action and may not form the sole basis for any claim in court.*

#### ► Key messages

- In recent years, Malawi has demonstrated an impressive commitment to improving children's health; while there have been significant improvements in child health indicators in the last decade, the challenges remain considerable.
- Malawi's adoption of a democratic Constitution (1995) marked a watershed in its progress towards good governance and the promotion and protection of human rights.

### 2C.3 The influence of an human rights-based approach on laws, policies, strategies and interventions related to children's health

The democratic election in 1994, and the adoption of the new Constitution in 1995, created an enabling environment for the realization of human rights. Since then, Malawi has experienced a policy shift towards pro-poor development, with an emphasis on health and human rights, more decision-making at the district and community levels, and a corresponding re-allocation of

human and financial resources. An increasingly human rights-based approach to children's health has emerged (see Table 2C.1) (12).

This section outlines some of the policies and strategies that reflect this emerging human rights-based approach. The main focus is on selected aspects of Malawi's policy on Integrated Management of Childhood Illness. Because this initiative has to be seen in the context of Malawi's overarching development strategies, the section begins by introducing the Malawi Poverty Reduction Strategy

**Table 2C.1.**

Rights focus of Malawi's national laws, policies, strategies, plans and guidelines relevant to children's health

| National laws                 |   | Year | Rights focus |
|-------------------------------|---|------|--------------|
| 1                             | Constitution of the Republic of Malawi  | 1995 | Explicit     |
| 2                             | Child Care, Protection and Justice Bill   | 2010 | Implicit     |
| National policies             |   | Year | Rights focus |
| 3                             | National Youth Policy   | 1992 | Explicit     |
| 4                             | National Population Policy  | 1994 | Unknown      |
| 5                             | Integrated Management of Childhood Illness Policy   | 2000 | Explicit     |
| 6                             | National Policy on Early Childhood Development  | 2003 | Explicit     |
| 7                             | Infant and Young Child Nutrition Policy   | 2003 | Explicit     |
| 8                             | Orphans and Other Vulnerable Children (OVC) Policy  | 2003 | Explicit     |
| 9                             | HIV/AIDS Policy (2003-2008)   | 2003 | Explicit     |
| 10                            | Policy on Equality in Access to Antiretroviral Therapy (ART) in Malawi  | 2005 | Implicit     |
| 11                            | Integrated Management of Childhood Illness Approach, Policy of Accelerated Child Survival and Development in Malawi | 2006 | Explicit     |
| National strategies and plans |   | Year | Rights focus |
| 12                            | Malawi Fourth National Health Plan (1999-2004)  | 1999 | Implicit     |
| 13                            | Integrated Management of Childhood Illness Strategy   | 2000 | Unknown      |
| 14                            | Malawi Poverty Reduction Strategy Papers (2002-2006)  | 2002 | Explicit     |
| 15                            | Malawi Essential Health Package (EHP) Plan of Action (2002/2003)  | 2002 | Implicit     |
| 16                            | SWAp Implementation Plan (2003-2006)  | 2003 | Implicit     |
| 17                            | National Plan of Action on Children (2003-2013)   | 2003 | Unknown      |
| 18                            | Joint Programme of Work (POW) for the Health Sector-Wide Approach (SWAp) (2004-2010)                                | 2004 | Implicit     |
| 19                            | Programme and National Plan of Action on Women, Girls and HIV/AIDS (2005-2010)                                      | 2004 | Unknown      |
| 20                            | National Plan of Action for Orphans & Other Vulnerable Children   | 2005 | Explicit     |
| 21                            | Malawi Growth and Development Strategy (2006-2011)  | 2006 | Explicit     |
| 22                            | Health Sector Strategic Plan (2006-2011)  | 2006 | Explicit     |
| 23                            | National Five Year Strategic Plan for Accelerated Child Survival and Development (2007-2012)                        | 2007 | Explicit     |
| 24                            | National HIV Prevention Strategy (2009-2013)  | 2008 | Explicit     |
| 25                            | National Strategic Plan for Early Childhood Development (2009-2014)   | 2009 | Explicit     |
| 26                            | Health Sector Strategic Plan (2011-2016)  | 2011 | Implicit     |
| National guidelines           |   | Year | Rights focus |
| 27                            | Guidelines for Paediatric HIV testing and counselling (HTC)   | 2007 | Explicit     |

Paper (PRSP) and the more recent Malawi Growth and Development Strategy (MGDS) (see Figure 2C.1).

### Malawi Poverty Reduction Strategy Paper, 2002–06

The PRSP recognized that the “respect and exercising of human rights are fundamental to poverty reduction” (13). Representing a consensus about how Malawi could achieve the MDGs through empowerment of the poor, the PRSP emphasized the importance of participation and placed particular emphasis on health. It acknowledged that “human rights are intended to protect the poor from mistreatment by more powerful individuals and organizations such as Government, and guarantee access of the poor to basic services” (13). The PRSP declared that the overall objective of the health sector was to improve the health status of Malawians, with a focus on the most vulnerable, including children, by enhancing equitable access to good quality health services.

### Malawi Growth and Development Strategy, 2006–11

Succeeding the PRSP, the MGDS incorporated lessons learned from the implementation of its predecessor and

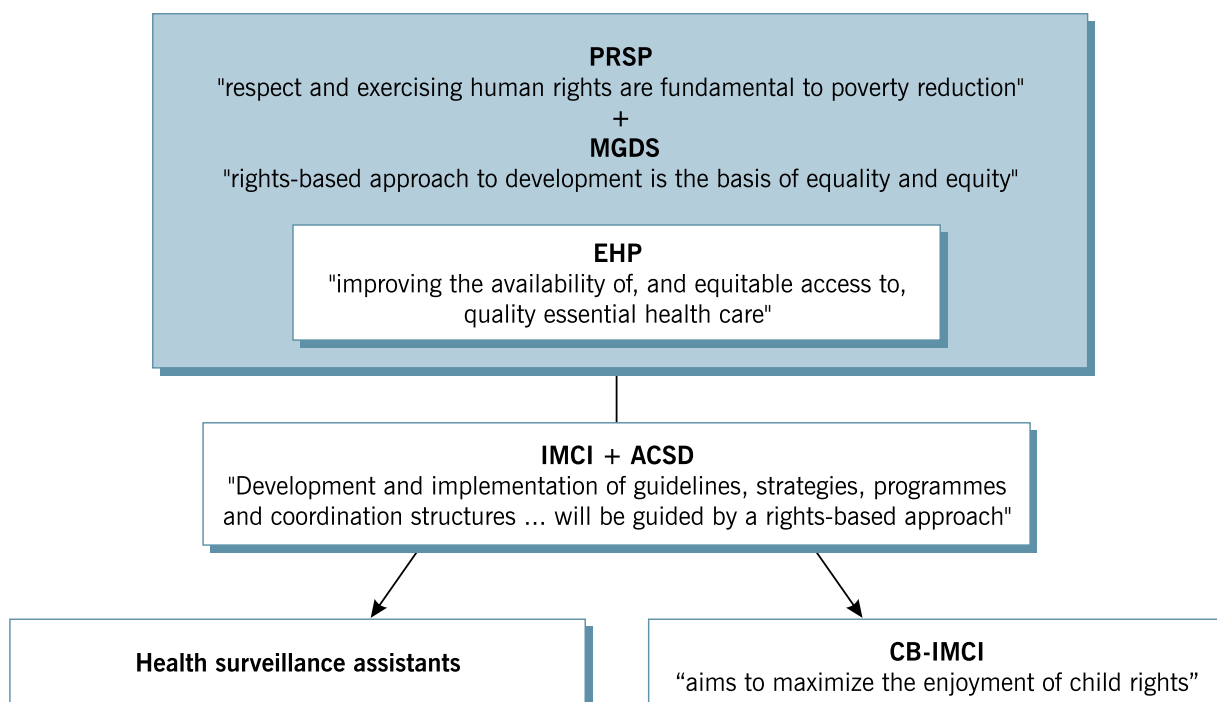
deepened the commitment to a human rights-based approach. It affirmed that a “rights based approach to development is the basis of equality and equity, both in the distribution of development gains and in the level of participation in the development process” (14). It covered six thematic areas, with child rights issues being included in the implementation strategies of each area (9). The MGDS placed a high priority on health as a strategy for social development. Among nine priorities, the Government identified child health as one of the most important. Key strategies for reducing child mortality and morbidity were identified, such as improving the availability and quality of health services and facilities, and increasing retention of qualified health workers (14).

### Essential Health Package (EHP)

The EHP was a feature of the PRSP and was further elaborated in the MGDS. It addressed the major causes of morbidity and mortality, with a particular focus on medical conditions and service gaps that disproportionately affected the rural poor (13). The EHP comprised 11 essential health services, including vaccinations, family planning and nutrition. Its main objectives included key elements of a human rights-based approach, such as improving the availability of, and equitable access to, quality essential health care.

Figure 2C.1.

Human rights and development: Malawi’s IMCI approach



It had an equity focus and aimed to provide free access to a minimum standard of health care for everyone. The EHP was first implemented in 2004, when a health sector-wide approach (SWAp) was established, generating the allocation of financial and human resources.

### **The IMCI policy and the accelerated child survival and development (ACSD) strategy**

EHP's child survival and development interventions were accelerated by two major policy initiatives: the Integrated Management of Childhood Illness Approach Policy for Accelerated Child Survival and Development in Malawi (IMCI policy, adopted in 2006) (15), and the Strategic Plan for Accelerated Child Survival and Development (ACSD strategy, 2007–11) (16).

As mentioned in section 2A, the IMCI approach was first developed by WHO and UNICEF in the early 1990s to address the disproportionate share of the disease burden falling on children under 5 years. According to the WHO Regional Office for Africa, IMCI was instituted to “give effect to the articles of the United Nations Convention on the Rights of the Child that deal with the right to health and health care” (17). It promotes a holistic approach to children's health, and an important component is the improvement of household and community child care practices, with an emphasis on child survival, growth, and development (16). This component is often referred to as community-based IMCI (CB-IMCI).

Between 1999 and 2006, the Government of Malawi pilot-tested implementation of the WHO/UNICEF IMCI approach. However, at that time, there was no adequate national policy to guide implementation. To address this gap (and accelerate EHP's child survival and development interventions), the Government launched its IMCI policy in 2006. The ACSD strategy was designed to scale up this policy from 2007.

Malawi's IMCI policy and the ACSD strategy aimed to reduce child morbidity and mortality and enhance child development by increasing access, coverage, and utilization of promotive, preventive and basic essential services for maternal, neonatal and child health (15, 16). An explicit human rights-based approach to programming is a guiding principle of both schemes:

Development and implementation of guidelines,

strategies, programmes and coordination structures designed for the purposes of achieving the objectives...will be guided by a rights-based approach. The promotion, protection and safe guarding of the rights of children will be used as the basis and criteria for assessing the feasibility of interventions and policy options during implementation of this Strategic Plan. This will also enable capacity building of communities (16).

Key elements of a human rights-based approach are repeatedly identified in the implementation strategies of the two schemes, including availability, accessibility, acceptability, quality, non-discrimination, equality, equity, participation, and accountability. Annex 4, Table A4.1, summarizes some of the key human rights elements of Malawi's IMCI policy.

The policy proposes 15 high-impact preventive and curative interventions, including immunization, breastfeeding, malaria prevention, oral rehydration for diarrhoea, treatment of severe malnutrition, prevention of mother-to-child transmission of HIV, and antiretroviral drugs for children and women living with HIV and AIDS (15). These interventions are predominantly implemented at the community level as part of Malawi's EHP. Implementation takes many forms, but among the most important are the scaling-up of the deployment of health surveillance assistants (HSAs) and the community-based IMCI approach (15).

#### **Health surveillance assistants**

The Government of Malawi trains community-based health workers, or health surveillance assistants, to provide first-line treatment for some childhood illnesses and, when necessary, to refer sick children to higher levels of care. While HSAs have operated as salaried members of Malawi's health workforce for decades, since the mid-2000s the Government has scaled up their deployment in hard-to-reach areas. In 2008, a grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria enabled the Government to double the size of the HSA workforce to 10 000 (18). Today, their responsibilities include the promotion of environmental health through home visits and inspection of sanitation facilities, collection of vital data and maintenance of the village register, disease outbreak response, and outreach campaigns (18). HSAs are also involved in routine delivery of various health programmes, including vaccinations, malaria prevention and care of HIV-infected people (19).



While carers of children have reported that they are satisfied with the HSA services (19), evaluations of the quality of care indicate that there is room for improvement (20). A 2009 assessment of the quality of care given by HSAs showed that 63% of children with confirmed fever, cough with fast breathing or diarrhoea were treated correctly (18). When inappropriate treatment was given, this was found to be partly a result of inadequate drug stocks (18).

### **Community-based IMCI**

With a focus on children aged 0–3 years, the community dialogue tool is a key methodology for implementation of CB-ICMI (17). A study by the Government of Malawi, UNICEF and DFID observed that the tool aimed “to maximize the enjoyment of child rights” (21). The tool underlines the importance of iterative, transformative processes based on dialogue between health workers and community members. Successful implementation often requires changes in the roles of health workers and community members. Through dialogue, community health workers become more accountable for their services and more receptive to input from the community. In turn, community members may

increasingly value, and access, the services provided.

CB-IMCI is also implemented through the care group methodology, which involves bringing health information and support services to villages through networks of community volunteers (22). Typically, around 10–15 women meet in a care group every couple of weeks to discuss effective health-promoting practices with a trained health educator. The practices might include caring for children with diarrhoea, preventing malaria by using insecticide-treated bednets, and cooking nutritious meals using local produce (22). Each woman is responsible for sharing this knowledge with 10–15 of her neighbours. In this way, care groups reinforce health-promoting practices and become a source of support.

In conclusion, the HSAs and CB-IMCI, as part of the IMCI policy, can contribute to the operationalization of a human rights-based approach. For example, the dialogue tool can enhance community participation and accountability for child care, and the care groups can empower women and help them keep their children, families and communities healthy (17, 21).

#### **► Key messages**

- Malawi’s development strategies provide a key policy context for its child health initiatives.
- Both the development strategies (e.g. the Malawi Growth and Development Strategy) and key child health interventions (e.g. IMCI policy and community dialogue tool) are explicitly shaped by human rights.

## 2C.4 Evidence of impact of a human rights-based approach on children's health

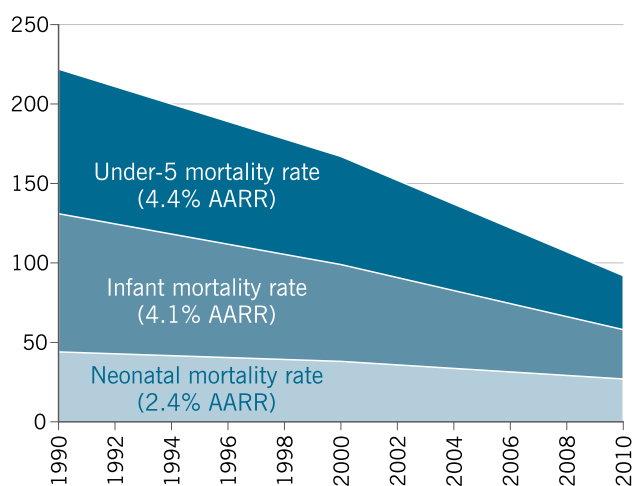
This section considers the evidence of impact of the human rights-shaped interventions described above on health-related outcomes for children.

### Progress towards MDG4

A recent study has shown that progress towards MDG4 in Malawi accelerated considerably between 2000 and 2010 (22). It is now widely acknowledged that Malawi is one of the few low-income countries in sub-Saharan Africa that is on track to achieve MDG4 by 2015 (4). A steady decline in early childhood mortality rates has been recorded (Figure 2C.2). While Malawi's neonatal mortality rate fell more slowly (3.5% per year) than under-5 mortality, it has still fallen faster than the regional average (22).

**Figure 2C.2.**

Trends in child mortality and average annual rates of reduction (AARR), 1990-2010 (rates are deaths per 1000 live births) (5)



**Table 2C.2.**

Percentage of children aged 12–23 months who had received specific vaccines at any time (6, 7)

|      | BCG  | DPT/Pentavalent |      |      | Poliovirus |      |      |      | Measles | No vaccinations |
|------|------|-----------------|------|------|------------|------|------|------|---------|-----------------|
|      |      | 1               | 2    | 3    | 0          | 1    | 2    | 3    |         |                 |
| 2004 | 91.4 | 95.0            | 90.6 | 81.5 | 37.1       | 94.9 | 89.7 | 77.7 | 78.7    | 3.5             |
| 2010 | 97.2 | 97.3            | 96.0 | 93.0 | 74.1       | 96.6 | 94.5 | 85.6 | 93.0    | 1.5             |

### Vaccination coverage

Vaccination coverage in Malawi has improved in recent years, contributing to the reduction in child mortality and the overall improvement in children's health. Table 2C.2 presents data on vaccination coverage of children aged 12–23 months from the 2004 and 2010 Demographic and Health Surveys (DHS). Notably, the DHS data showed not only that the gap between coverage in urban and rural areas that existed in 2004 had been eliminated by 2010, but also that rural coverage in 2010 surpassed urban coverage. In 2004, 70.7% of children aged 12–23 months living in urban areas had received all basic vaccinations, compared with only 63.5% of those living in rural areas. In 2010, the proportions were 75.8% and 81.8%, respectively. While this increase in, and more equitable distribution of, coverage cannot be solely attributed to one intervention, it coincides with the implementation of Malawi's IMCI policy, which includes vaccinations against preventable diseases.

### Nutritional status

Although there is still room for considerable progress in children's nutritional status, data from the 2010 DHS showed some improvements since 2004. The percentage of stunted children had decreased from 53% to 47%, wasting had decreased from 6% to 4%, and the percentage of children who were underweight has also decreased from 17% to 13% (6). The number of children under five years who were malnourished remained higher in rural areas, but the gap between urban and rural malnutrition narrowed by nearly 50% between 2004 and 2010, suggesting more equitable access to nutritional health services. Launched in 2005, the Farm Input Subsidy Programme, which is related to the PRSP, played an important role in improving nutritional status in Malawi (23).

## Antiretroviral drugs

As already observed, an explicit human rights-based approach to programming constitutes one of the guiding principles of Malawi's IMCI policy and ACSD strategy. The IMCI policy includes not only immunization and the treatment of severe malnutrition, but also the prevention of mother-to-child transmission of HIV, and the provision of antiretroviral (ARV) drugs to children and women living with HIV and AIDS. In 2004, the Government made antiretroviral drugs free in public health facilities for all who needed them (24). The percentage of health facilities providing a minimum package of services for prevention of mother-to-child transmission (PMTCT) of HIV soared from 7% to 100% between 2004 and 2009–10 (6-8). Since 2011, all pregnant women are offered an HIV test on their first antenatal visit (with an opt-out), and women with HIV infection may begin lifelong treatment irrespective of their clinical condition. Coverage among pregnant women is high. Children born to mothers with HIV infection receive ARVs, as well as the necessary follow-up tests until 24 months of age. Those found to have HIV infection are offered ARVs free for life. Over 90% of discharged newborns known to have been exposed to HIV receive ARVs (25). Steady improvements were recorded in children's access to antiretroviral therapy (ART) in 2010–2011 (Table 2C.3).

## Other child health indicators and equity

Substantial improvements were recorded in several key child health indicators between 2004 and 2010. Table 2C.4 shows quantitative data and does not address the quality of services; nonetheless, it demonstrates that access to essential health services for children improved between 2004 and 2010.

**Table 2C.3.**

ART coverage among HIV-positive children aged 0–14 years (26)

| Date               | Coverage |
|--------------------|----------|
| End April 2010     | 25%      |
| End June 2010      | 27%      |
| End September 2010 | 28%      |
| End December 2010  | 29%      |
| End April 2011     | 30%      |
| End June 2011      | 32%      |

Data for the past 10–15 years reveal that Malawi has made considerable progress in the area of children's health, although it has to be acknowledged that baseline values were low. In addition to improvements in overall children's health, there have also been significant improvements in equity (e.g. see "Vaccination coverage") and accessibility of child health services. A recent analysis of coverage of maternal, newborn and child health interventions in 54 countries identified Malawi as one of the countries with the least inequity (27). In its most recent health sector budget analysis, the Malawi Health Equity Network reported that, while there is considerable room for improvement, the 2010-11 health sector budget attempted to target vulnerable groups, including women and children, and to ensure equitable distribution of deliverables, with a specific focus on the most disadvantaged parts of the country (28).

**Table 2C.4.**

Child health indicators, 2004 and 2010 (6-8)

| Indicator   | Baseline (2004) | 2009–10 |
|---|-----------------|---------|
| % of children under 5 with fever in the 2 weeks prior to survey                         | 37.1            | 34.5    |
| % of children under 5 who received antimalarial drugs                                   | 28.4            | 43.3    |
| % of children under 5 with access to antimalarials within 24 hours of onset of symptoms | 22.7            | 28.2    |
| % of children who sleep under insecticide-treated bednets                               | 14.8            | 55.4    |
| % of children under 5 with an acute respiratory infection (ARI) in the previous 2 weeks | 19              | 6.8     |
| % of children under 5 with an ARI taken to health facility for treatment                | 19.6            | 70.8    |
| % of children with diarrhoea in the previous 2 weeks                                    | 22.3            | 17.5    |
| % of children underweight   | 17              | 13      |
| % of health facilities providing a minimum package of PMTCT services                    | 7               | 100     |
| % of births attended by skilled health personnel  | 38              | 52      |
| % of children who are breastfed   | 98.3            | 98.6    |
| % of children between 0 and 3 months who are exclusively breastfed                      | 75.2            | 81.9    |
| % of children aged 6–59 months with any kind of anaemia                                 | 73              | 62.5    |

### Quality of life

Numbers alone cannot capture all human rights-related outcomes. During an evaluation of CB-IMCI, community members acknowledged that the process had improved individuals' quality of life (21). Not only were fewer children becoming sick or dying because families and community members were more able to provide quality care, but the community also felt empowered. This sense of empowerment and increased capacity helped community members fulfil their human rights responsibilities, and claim their entitlements from health providers (21). Women reported that gender-based violence had declined and that men were increasingly taking a greater role in child care. Also, the quality of family relations improved, households and villages were cleaner, and sanitation facilities safer. In short, the evaluation suggested that the human rights-shaped

CB-IMCI not only had a positive impact on children's health, but also transformed relationships between health providers and community members, empowered the community, and improved individuals' quality of life.

This evaluation raises issues regarding the most appropriate research and evaluation methods to examine the impact of a human rights-based approach. These important methodological issues are discussed in Chapter 4.

### 2C.5 Conclusion

There is evidence that human rights have influenced children's health interventions in Malawi, and that these human rights-shaped interventions contributed positively to health improvements for children, as well as their families and communities.

#### ► Key messages

- Malawi has made significant progress in relation to health-related outcomes for children; it is on track to achieve MDG4.
- There is evidence that human rights have influenced children's health interventions in Malawi, and that these human rights-shaped interventions contributed positively to health improvements for children, as well as their families and communities.



*Participants in the Glocal Youth Parliament, a global parliament of urban youth in Rome, Italy.*



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## Chapter 2D.

### Women's and children's health in Italy

*Silvia Longhi, Walter Ricciardi, Mario Meriardi, Giuseppe Benagiano, Flavia Bustreo, Paul Hunt, Genevieve Sander*

Italy is one of the major industrialized democracies in the world, Europe's fourth-largest economy, and a member of the European Union. As in many other EU member states, the Government is currently implementing austerity measures in response to the difficult economic situation. Italy ranks 24th on the Human Development Index (1), and the majority of Italians enjoy a high standard of living, resulting in part from well established social and welfare policies. The health status of Italians has risen over the past 40 years: life expectancy at birth is now the second-highest in Europe (2); infant and neonatal mortality rates have steadily declined (3); and Italy's maternal mortality ratio was recently recognized as one of the lowest in the world (4). Considerable challenges remain, including wide disparities in health and access to services between the north and south of the country, as well as the prevalence of child poverty (5). Nevertheless, Italy has made impressive progress on women's and children's health, and this study considers the possible impact of its human rights-shaped laws, programmes, plans, and other interventions on these positive outcomes.

#### 2D.1 Research methods

A review of the laws, programmes, plans, and other interventions related to women's and children's health was conducted and key informants were consulted. Once the laws, policies and national plans explicitly shaped by human rights had been reviewed, programme evaluations and national data spanning a 30-year period were analysed to determine the impact of a human rights-based approach on women's and children's health outcomes in Italy.

#### 2D.2 The Italian context

##### Women's and children's health

There have been considerable improvements in women's and children's health in Italy since the 1970s. Infant and neonatal mortality rates declined steadily, although with high variability among regions, to reach 3.5 and 2.4 per 1000 live births, respectively, at national level in 2009 (3). Vaccination coverage has improved, which has led to health gains, such as the elimination of diphtheria and tetanus among children (6).

The maternal mortality ratio is also very low at 4 per 100 000 live births; in a recent study, Italy was found to have the lowest maternal mortality of 181 countries evaluated (4). Voluntary pregnancy terminations have decreased by 54.7% since 1982 (7), in association with an increase in the use of modern contraception. Cancer has emerged as one of the most serious health concerns for women, with breast cancer now the most common cause of death among women (8). The past decade has seen an increase throughout the country in the availability of, and equitable access to, screening services for early diagnosis, together with an associated decrease in mortality rates (9).

### Human rights

The 1948 Constitution enshrines economic, social and cultural rights alongside civil and political rights. Health is explicitly safeguarded as a fundamental right, and mothers, children and the young are afforded special protection (Box 2D.1) (10). Moreover, the courts have decided some right-to-health cases, e.g. in 1971 the Constitutional Court decided that the Penal Code's provisions prohibiting publicity on contraception were unconstitutional (11).

While Italy does not yet have an independent national human rights institution, the Government recently established the National Ombudsperson for Childhood and Adolescence, an independent authority that is mandated, for example, to monitor implementation of children's right to health care services (12). Since 1994, the National Office against Racial Discrimination has sought to eliminate racial and ethnic discrimination against, in particular, minority groups, such as the Roma and Sinti. While positive measures have been taken, the UN Committee on the Elimination of Racial Discrimination has expressed concern about the poor living conditions of some Roma and Sinti in Italy (13).

An active member of the UN Human Rights Council since 2007, Italy has ratified the key international human rights treaties with a bearing on women's and children's health.

#### Box 2D.1. The Italian Constitution (1948)

Article 31: ...The Republic protects mothers, children and the young by adopting necessary provisions.

Article 32: The Republic safeguards health as a fundamental right of the individual and as a collective interest, and guarantees free medical care to the indigent. No one may be obliged to undergo any health treatment except under the provision of law.

#### ► Key messages

- Most Italians enjoy a high standard of living and quality of life.
- Article 32 of the Constitution recognizes the right to health as a fundamental human right, and mothers and children are afforded special protection.
- While challenges remain, including the disparities between north and south and the prevalence of child poverty, impressive improvements in women's and children's health have been documented in recent decades.

### 2D.3 The influence of a human rights-based approach on laws, policies and programmes on women's and children's health

In Italy, current approaches to women's and children's health have their roots in the last years of the nineteenth century, when Parliament recognized the health risks posed by the new industrial sector and passed labour legislation to protect women and children. Today, interventions for women's and children's health

are part of the country's highly developed national health service (*Servizio Sanitario Nazionale* or SSN). In 2009, Italy spent over €100 billion on the SSN (14). This section describes how human rights have influenced the *Servizio Sanitario Nazionale* and – through the SSN and related initiatives – women's and children's health interventions. Table 2D.1 lists the key government interventions on women's and children's health since 1948 that were implicitly or explicitly shaped by human rights.

**Table 2D.1.**

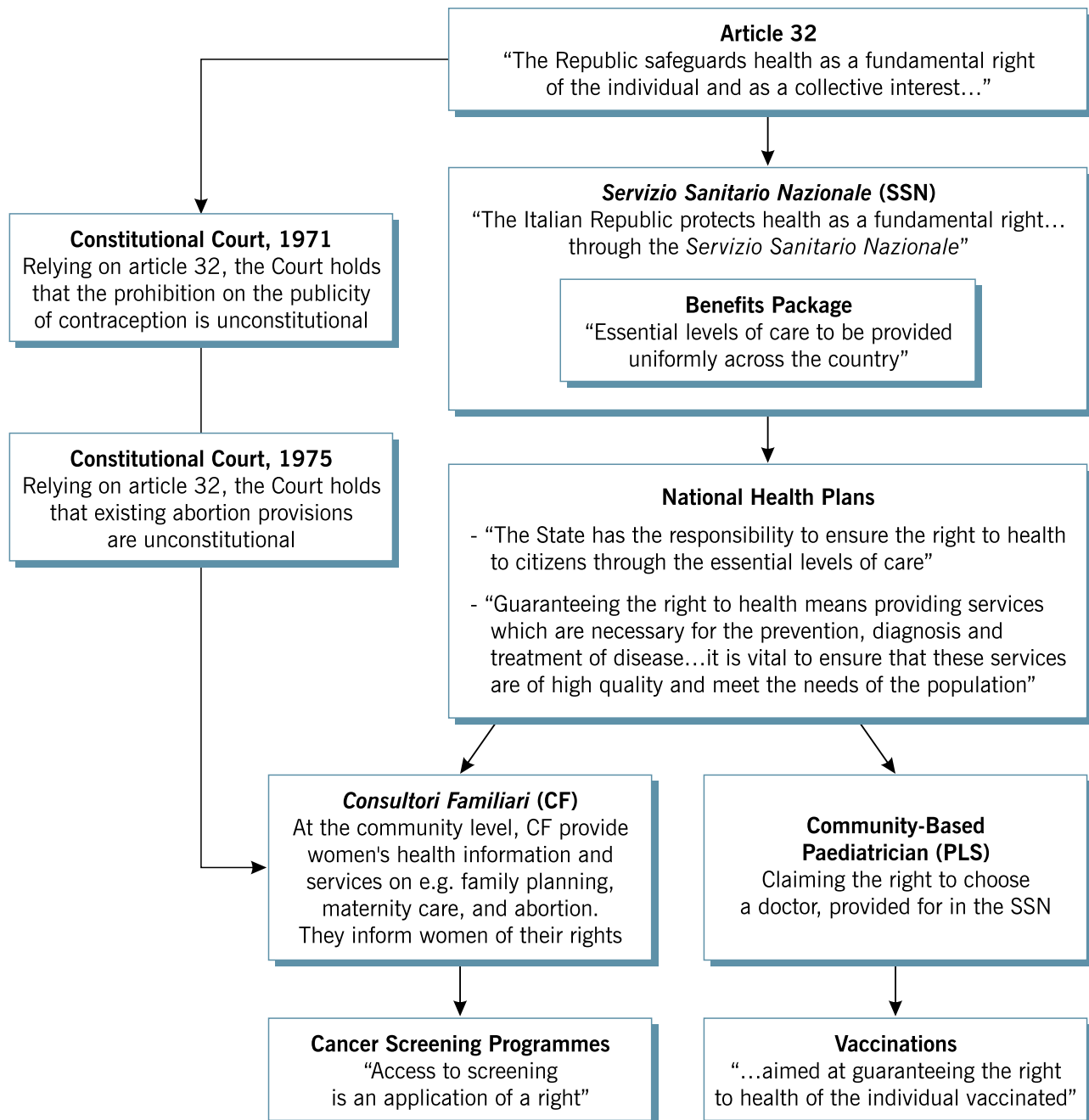
Key government interventions relating to women's and children's health with a human rights focus

| National laws                 |  | Year | Rights focus |
|-------------------------------|--|------|--------------|
| 1                             | Constitution of the Italian Republic   | 1948 | Explicit     |
| 2                             | Physical and economic protection of working mothers – Law 860/1950   | 1950 | Explicit     |
| 3                             | Protection of working mothers – Law 1204/1971  | 1971 | Explicit     |
| 4                             | Family law – Law 151/1975  | 1975 | Explicit     |
| 5                             | Norms for social protection of maternity and voluntary interruption of pregnancy – Law 194/1978  | 1978 | Explicit     |
| 6                             | Health care reform – Law 833/1978  | 1978 | Explicit     |
| 7                             | Health care reform – Law decree 502/1992   | 1992 | Explicit     |
| 8                             | Regulations for the protection of rights and opportunities for children and adolescents – Law 285/1997   | 1997 | Explicit     |
| 9                             | Health care reform – Law decree 229/1999   | 1999 | Explicit     |
| 10                            | Definition of essential levels of care – Prime ministerial decree  | 2000 | Explicit     |
| 11                            | Legislation on the protection of maternity and paternity – Legislative decree 151/2001   | 2001 | Explicit     |
| National strategies and plans |  | Year | Rights Focus |
| 12                            | National Health Plan 1994-1996   | 1994 | Explicit     |
| 13                            | National Vaccination Plan 1999-2000  | 1999 | Explicit     |
| 14                            | Progetto obiettivo materno infantile (Project to improve maternal and child health) – Ministerial decree   | 2000 | Explicit     |
| 15                            | National Health Plan 2003-2005   | 2003 | Explicit     |
| 16                            | National Plan for the Elimination of Measles and Congenital Rubella 2003-2007  | 2003 | Explicit     |
| 17                            | National Vaccination Plan 2005-2007  | 2005 | Explicit     |
| 18                            | National Health Plan 2006-2008   | 2006 | Explicit     |
| 19                            | National Plan for the Elimination of Measles and Congenital Rubella 2010-2015  | 2010 | Implicit     |
| 20                            | Project to improve the quality, safety, and appropriateness of treatments in childbirth and for the reduction of caesarean sections – State-Regional agreement | 2011 | Implicit     |
| 21                            | National Health Plan 2011-2013   | 2011 | Explicit     |
| 22                            | National Vaccination Plan 2010-2012  | 2010 | Explicit     |
| National guidelines           |  | Year | Rights Focus |
| 23                            | Diagnosis and therapy of ovarian cancer – Ministry of Health and National Health Institute   | 2004 | Implicit     |
| 24                            | Recommendations for setting up breast, cervical and colorectal screening – Ministry of Health  | 2006 | Explicit     |
| 25                            | Recommendations for the prevention of maternal mortality and severe diseases related to delivery or pregnancy – No. 6, Ministry of Health                      | 2008 | Implicit     |
| 26                            | Breastfeeding – Ministry of Health   | 2008 | Explicit     |
| 27                            | Caesarean section – Ministry of Health and National Health Institute   | 2010 | Explicit     |
| 28                            | Physiological pregnancy – Ministry of Health and National Institute  | 2011 | Implicit     |



Figure 2D.1.

From constitution to community: illustrative pathways



A large national health service is necessarily very complex. Figure 2D.1 outlines a pathway from Italy's right-to-health constitutional provision to community-level initiatives for cancer screening and vaccinations, as examples of services for women's and children's health.

### The Servizio Sanitario Nazionale

In 1978, Italy not only ratified the International Covenant on Economic, Social and Cultural Rights, which includes a provision on the right to health, but also passed a

law establishing its national health service. This law begins: “The Italian Republic protects health as a fundamental right of the individual and the community through the *Servizio Sanitario Nazionale*” (15). Other provisions in the law also adopt explicit human rights language; for example, one article assigns local responsibility for “the protection of reproductive rights”.

The SSN introduced universal coverage for Italian citizens and established human dignity, health needs

and solidarity as guiding principles for the health service. Consistent with human rights, it aimed to guarantee equal access to uniform levels of care, irrespective of income or geographical location, and to provide public democratic control over the management of the new system.

While reforms were introduced in 1992 and 1993, they also begin by affirming: “The protection of the right to health as a fundamental individual right and in the interest of society as a whole is guaranteed with respect to human dignity and freedom through the *Servizio Sanitario Nazionale*” (16). These reforms introduced managerial principles into the SSN and began concerted efforts to devolve health care powers to the regions. In 1999, further reforms began with an explicit recognition of the constitutional “protection of health as a fundamental individual right” and aimed to deepen the regional devolution process (17).

Today, Italy's health care system is a regionally based national health service, which provides universal coverage free of charge at the point of service. The national level is responsible for ensuring the general objectives and fundamental principles of the system. Regional governments, through regional health departments, are responsible for ensuring the delivery of a benefits package through a network of population-based health management organizations (*azienda sanitaria locale* or local health enterprises) and public and private accredited hospitals.

### The benefits package

The legislative reforms of 1992–93 introduced the important idea of “essential levels of care to be provided uniformly across the country” (16). The legislation confirmed that this benefits package was to be provided by the SSN free or at a minimal charge. Later, the catalogue of SSN benefits was defined in terms of a positive list (of services that the SSN is required to provide uniformly in all regions) and a negative list (of excluded categories of services). Every region must provide all the services in the positive list, but each is free to provide additional services, as long as they are financed from the region's revenues.

The *Servizio Sanitario Nazionale* and the benefits package are explicitly based on health as a fundamental right. In a recent report to Parliament, the Minister of Health referred to “the right of access to SSN practices and services” (18). Effectively, individuals are entitled

to the SSN's benefits package or essential levels of care.

### National Health Plans

Parliament approves framework legislation and additional details are provided by National Health Plans, which identify health priority areas. For example, the second National Health Plan (1998–2000) prescribed that the SSN should be organized in accordance with human dignity, equal rights, right to health care, equity, and solidarity with the most vulnerable (19), and laid out guidelines defining the benefits package introduced by the reforms of 1992–93. The third Plan (2003–05) emphasized that the right to health “is a priority” and “it is mandatory to ensure that the essential levels of care are available to the population”. The fourth Plan (2006–08) underlined that “the State has the responsibility to ensure the right to health to citizens through the essential levels of care”, i.e. the SSN benefits package. The fifth Plan (2011–13) emphasized: “Guaranteeing the right to health means providing services that are necessary for the prevention, diagnosis and treatment of disease ... it is vital to ensure that these services are of high quality and meet the needs of the population.”

In short, the right to health is integral to SSN, essential levels of care and recent National Health Plans.

Within the SSN, specific initiatives and interventions also explicitly recognize human rights, as briefly illustrated by the examples below. These examples are just part of a complex system of health care for women and children that includes community care and access to hospital services. There is a right to deliver in hospital, as well as maternity care for the mother and newborn. However, the following discussion focuses on a few specific examples of care for women and children at the community-level.

### Women's health

From the 1950s onwards, the growing presence of women in the labour market fuelled demands for gender equality and improved occupational protection. This led to a statutory “right to paid leave for antenatal check-ups”, “a right to paid maternity leave” equal to 80% of salary, and other safeguards for the health of working women (20). Human rights not only helped to improve safeguards in the workplace, they also contributed to making health facilities and services available to all women, as illustrated by *Consultori Familiari*.

### **Consultori Familiari (Family Counselling Centres)**

*Consultori Familiari* are a vital vehicle for the delivery of women's health information, facilities and services. Based in communities, they provide many of the entitlements designated for women by the SSN, essential levels of care, and National Health Plans, including medical care, psychological help and social support. They provide information and services on, for example, family planning, maternity care, breastfeeding, abortion and cancer prevention, and make referrals when necessary. Additionally, *Consultori Familiari* provide some paediatric services, especially postnatal care. The staff includes health professionals, social workers and educators. With limited exceptions, their services are free to all at the point of delivery.

The origin of *Consultori Familiari* includes Constitutional Court decisions on health rights. Until the 1970s, the Italian Penal Code (1930) prohibited publicity on contraception, as well as abortions, except when the life of the pregnant woman was threatened. In 1971, the Constitutional Court ruled that the provisions of the Code relating to contraception were unconstitutional and in 1975 it held that the abortion provisions were inconsistent with the Constitution. These judicial decisions were explicitly based on a number of considerations, including the right-to-health provision of the Constitution. The 1971 decision on contraception contributed to a law that established *Consultori Familiari* (405/1975). The 1975 decision led to a law that significantly increased access to abortion (194/1978), in relation to which *Consultori Familiari* were assigned some statutory responsibilities. In short, human rights contributed to the formation of *Consultori Familiari* in 1975, as well as the definition of their institutional responsibilities.

While *Consultori Familiari* are intended to improve access to health information and services for all women, difficulties remain; for example, *Consultori Familiari* are not yet evenly distributed throughout the country (21).

Since 1975, the influence of human rights on *Consultori Familiari* has been experienced not only indirectly via SSN, essential levels of care and National Health Plans, but also more directly. One provision, for example, requires *Consultori Familiari* to “take care of a pregnant woman ... [by] informing her of her rights in accordance with national and regional legislation”. Some regional regulations on *Consultori Familiari* robustly affirm human rights, including a “person's right to free and responsible choice in sexuality and

reproduction” (Emilia-Romagna region) (22). Further, some governmental measures have explicitly recognized women's particular health concerns, such as cancer prevention, as human rights issues.

### **Cancer screening**

Since 2001, the Government has adopted a series of measures to promote the widespread and uniform adoption of national policies and guiding principles on cancer screening. Because of its importance, secondary cancer prevention, such as Papanicolaou (Pap) tests and mammography screening, is included in the essential levels of care provided by the SSN. In 2006, Ministry of Health guidelines for health professionals responsible for breast, cervical and colorectal screening confirmed that “access to screening is an application of a right” (23).

Following the European Union's recommendation on cancer screening in 2003, several national plans, supported by significant resources (24), have aimed to improve screening coverage (25). With the objective of national coverage, Pap tests and mammography screening are offered free of charge to women in the target population. In accordance with the recommendation of 2003, the Pap test is offered every three years to women aged 25–64 years, and mammography screening every two years to women aged 50–69 years. Local health enterprises organize the screening programmes and reach out to target populations.

Established in 2002, the National Centre for Screening Monitoring (*Osservatorio Nazionale Screening*) monitors screening nationwide (26). Data are collected using a standardized method, including structured questionnaires. Investigations facilitate comparisons between regions and the identification of programme strengths and weaknesses. An annual report assesses implementation of the screening programmes.

Annex 5, Table A5.1 summarizes some key human rights elements of the screening programmes.

## **Children's health**

### **Community-based paediatricians**

Since the foundation of Italy's SSN, paediatric primary care has been available free of charge through community-based paediatricians (PLS), who provide care for children from birth to 14 years. The PLS work independently in their private offices, acting as SSN

primary care providers at the community level. Unlike in many other health systems, the PLS are a first point of contact, without the need for referral (27).

The law establishing the SSN includes the right to choose a doctor, subject to some limitations, such as restrictions on the number of patients that may be registered with a family physician. Parents are required to identify a paediatrician for their children aged 0 to 6 years. The PLS are responsible for prevention, diagnosis, care, treatment, rehabilitation and health education. They also have responsibilities towards parents, such as providing information and support. Vaccinations are among their responsibilities.

Health care costs, including those associated with the PLS, are covered by general taxation, facilitating equitable access to good quality care for all children, consistent with Italy's human rights obligations.

### **Vaccination programmes**

In Italy, the reduction or elimination of the burden of vaccine-preventable diseases is a health priority (28, 29). In recent years, the Government has put in place national prevention plans for infectious diseases, such as poliomyelitis, diphtheria and rubella.

According to the National Prevention Plan for 1999–2000, vaccination is “an intervention aimed at guaranteeing

the right to health of the individual vaccinated”. The Plan for 2005–07 referred to “the right to protection from vaccine-preventable diseases”. The current Plan (2012–14) emphasizes the “right to vaccination”.

Since immunization programmes are essential interventions for the prevention of infectious disease and protection of children, vaccinations are included in the package of essential levels of care provided by the SSN.

As well as emphasizing the “right to vaccination”, the current National Prevention Plan defines objectives, identifies risk groups and sets the standards (e.g. for quality and safety) of vaccination coverage and the activities to be undertaken. Local health enterprises and the Ministry of Health are responsible for implementing the Plan. Vaccinations are provided through a network of local centres established throughout the region.

To evaluate the efficacy of the immunization programmes, national and sentinel surveillance systems collect data and provide information on the incidence of infectious diseases and vaccination coverage (30). The national surveillance system is administered by the National Institute of Health, in collaboration with the Ministry of Health.

Annex 5, Table A5.2, summarizes some key human rights elements of the immunization programmes.

### **► Key messages**

- Human rights have explicitly shaped Italy's overarching *Servizio Sanitario Nazionale*, package of essential levels of care, and National Health Plans. Individuals are entitled to the SSN package of essential levels of care.
- At the community level, the human rights-shaped *Consultori Familiari* deliver women's health information and services, such as family planning, maternity care and cervical cancer screening.
- Community-based paediatricians, who provide primary health care services for children, are instrumental in Italy's immunization programmes, which are explicitly informed by human rights.
- *Consultori Familiari* and community-based paediatricians are part of a complex system of health care for women and children that is shaped and reinforced by human rights.

## 2D.4 Evidence of impact of a human rights-based approach on women's and children's health

This section considers some of the recent health gains for women and children that are associated with Italy's human rights-shaped policies and programmes, with particular attention to the interventions described in the previous section.

### Women's health

Women's health status in Italy has significantly improved in recent decades. Female life expectancy at birth is now the second-highest in Europe, having increased from 72 to 84.6 years between 1960 and 2009 (2). Italy's MMR is currently 4 per 100 000 live births, one of the lowest in the world (4). A good system of antenatal, intrapartum and postpartum care is available. Antenatal examinations and hospital visits, as well as hospital deliveries, are free of charge. All deliveries are attended by health professionals (31).

According to a survey in 2005, the average number of antenatal visits, in the public and private sectors, was 7; 86% of women were informed of antenatal diagnosis techniques; 21.5% had between one and three ultrasound examinations; 49.6% had between four and six ultrasound examinations (three is the

target recommended by national protocols); and a high percentage of women (81.4%) breastfed their babies (32).

The rate of caesarean section increased from 21.2% in 1990 to 38.4% in 2009; this is the highest in Europe and is a cause for concern (33, 34). The rate of caesarean sections is higher in the south of the country (35).

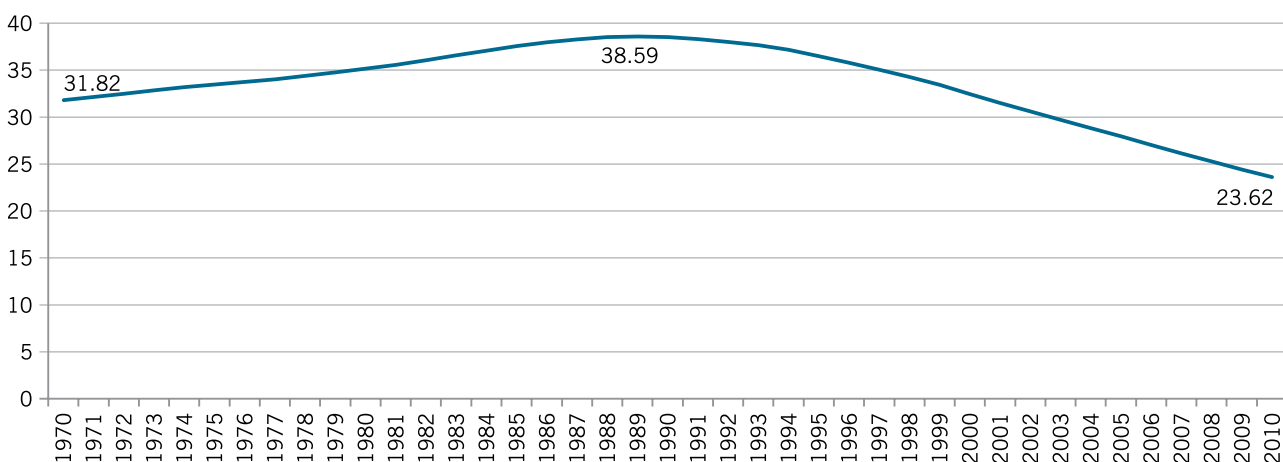
### Screening programmes

Breast cancer is the most common cancer among women in Italy, accounting for 42% of all cases. Breast cancer mortality decreased between 1989 and 2010, from 38.59 per 100 000 to 23.62 per 100 000 (see Figure 2D.2) (7). This can be explained by a combination of factors, including improved screening and advances in treatment. One study showed that the introduction of breast cancer screening programmes in Italy was associated with a 25% reduction in the probability of dying from breast cancer among invited women, and a 45% reduction in the probability of dying from breast cancer among screened women (8).

In the past, screening programmes were unevenly distributed, resulting in marked social and geographical inequalities. In this respect, there has been significant

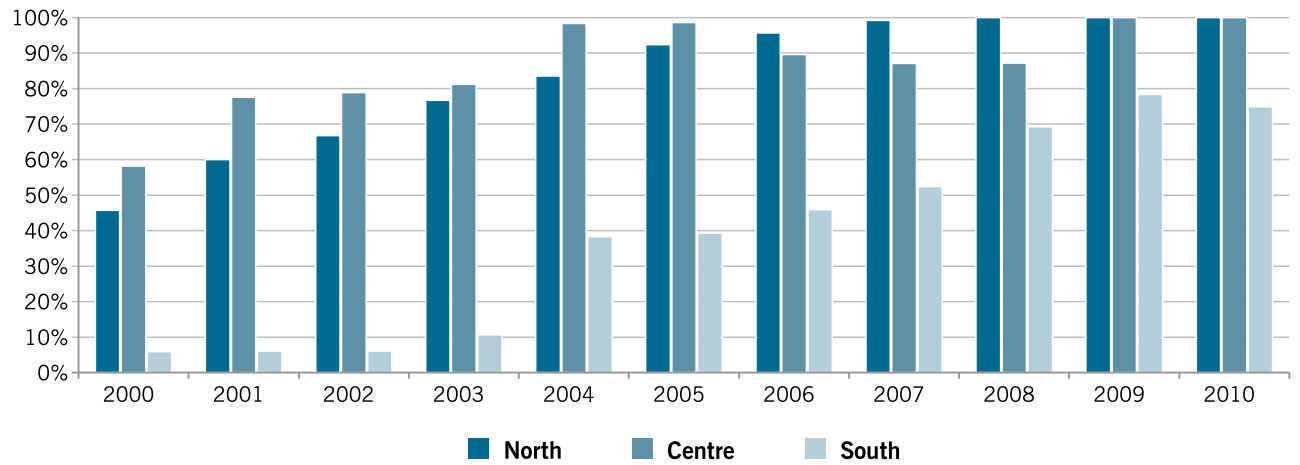
**Figure 2D.2.**

Standard mortality rate for breast cancer, per 100 000 women aged 0–84 years, 1970–2010 (7)



**Figure 2D.3.**

Breast cancer screening coverage, 2000–10 (26)



progress. As Figure 2D.3 shows, breast cancer screening programmes expanded between 2000 and 2010, contributing to more equitable access to early diagnosis and reducing the gap between the north and the south of the country. During that period, the overall situation improved markedly, with more women being invited for screening, and an increasing response rate. However, the percentage of women screened is still higher in the north (26). The response-rate to the invitation is a key indicator of a programme's efficacy in detecting cancer. In 2010, 2 496 000 women were invited for mammography and 55.6% (1 382 000) accepted. As a result, over 6000 cases of breast cancer were detected, accounting for 31% of all breast cancers in

Italian women aged 50–69 (32). Also in 2010, 3 450 000 women were invited for cervical screening and 39.8% (1 375 000) accepted. As a result, over 4500 cervical carcinomas were detected (26).

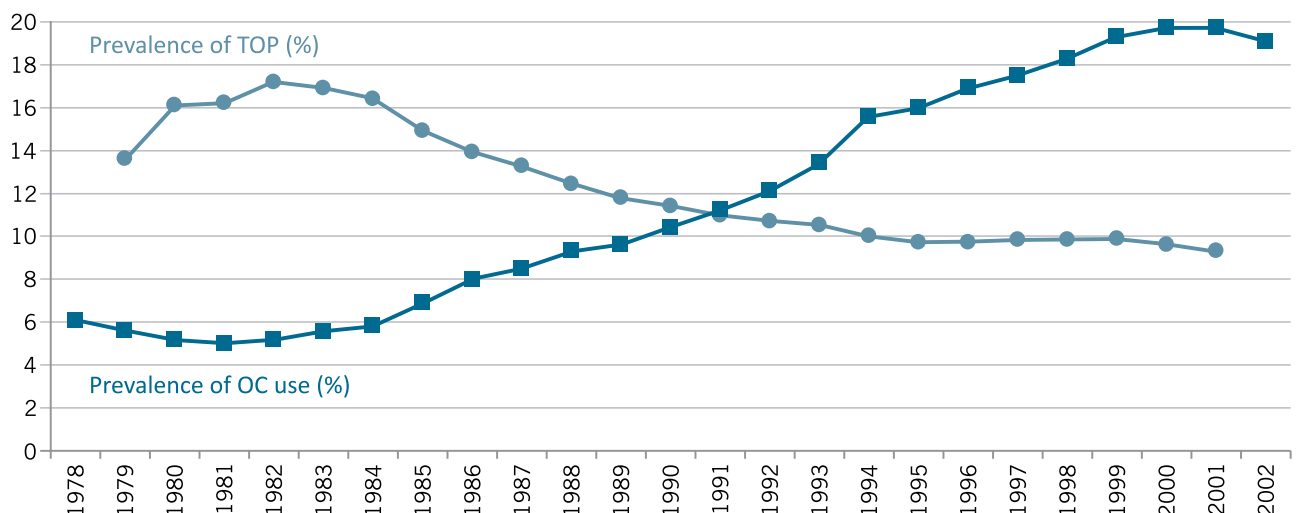
In 2011, the CEDAW Committee applauded the results achieved by Italy's breast cancer screening programmes, but voiced concern at the persisting disparity in access between the north and south of the country (36).

#### Abortion and contraception

Following the abortion law reform of 1978, the number of illegal abortions decreased significantly. Before 1978, it was estimated that there were between 220 000 and

**Figure 2D.4.**

Rates of voluntary termination of pregnancy (TOP) and use of oral contraceptives (OC) among women of reproductive age in Italy, 1978–2002 (40)



500 000 illegal abortions per year (37); in 2005, there were an estimated 15 000 (38). Since 1978, there has been a substantial decrease in the number of hospital admissions for “miscarriage”, a word often used to refer to morbidity associated with illegal abortion (39).

The rate of legal abortions increased immediately after 1978 and peaked in 1982. One study reported that the number of voluntary pregnancy terminations fell by 35% between 1980 and 2000 (40). A more recent study confirmed that, from its peak in 1982, the number of legal abortions had decreased by 54.7% by 2011 (7). Italy now has one of the lowest abortion rates among the high-income countries (41), although it is reported that most of the reduction in the rate occurred among educated, employed and married women (7).

Crucially, the number of voluntary pregnancy terminations fell as the use of oral contraception increased (Figure 2D.4). Data from national surveys in 1979, 1996 and 2006 suggest that the prevalence of contraceptive use by women of reproductive age remained stable at 20%, but that the choice of method changed significantly, with over half of couples abandoning traditional methods (coitus interruptus) for more reliable modern methods (42). Between 1985 and 2000, the use of oral contraception increased by 12% (Figure 2D.4). However, the use of modern contraceptive methods remains lower in Italy than in other European countries (43).

The activities of *Consultori Familiari* in counselling, educating, informing and supporting women in exercising their reproductive choices and rights are related to the fall in the number of illegal abortions, as well as associated morbidity, the increased use of modern contraception, and the decline in the number of legal abortions after 1982.

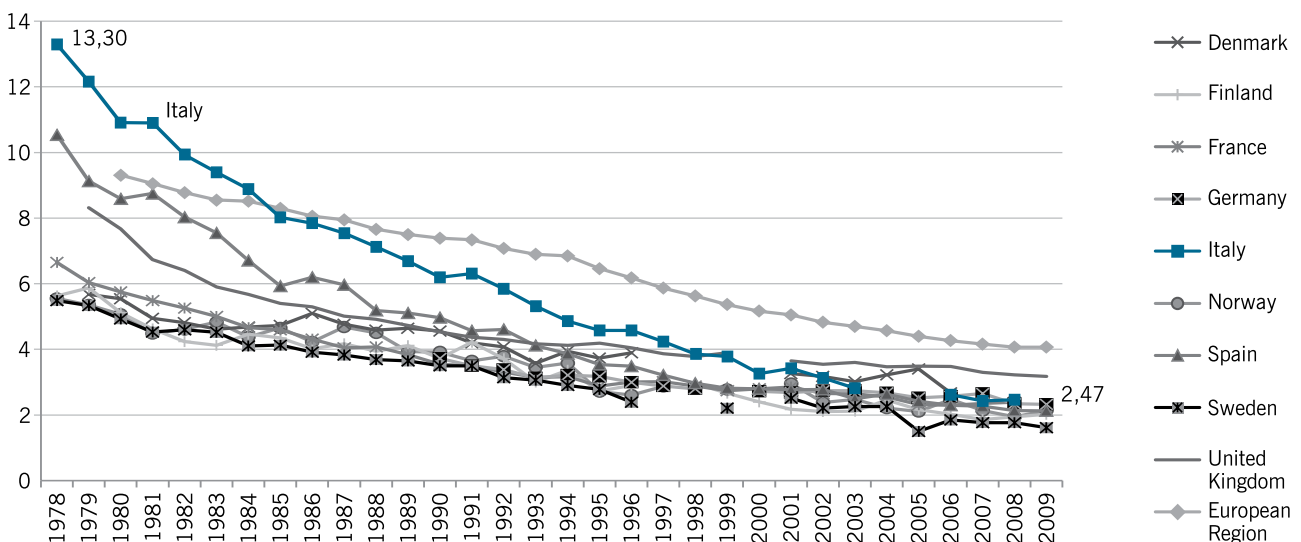
**Children’s health**

Recent years have witnessed considerable improvements in children’s health. Most significant have been the sharp declines in infant and neonatal mortality, from 16.79 and 13.30 per 1000 live births to 3.51 and 2.47 per 1000, respectively, between 1978 and 2009 (see Figure 2D.5). Still, higher mortality rates have been recorded in the south of the country (35). The percentages of preterm deliveries and low-birth-weight babies have been drastically reduced; in 2009, 1% of newborns were below 1.5 kg, while 6.1% were between 1.5 and 2.5 kg (31).

**Vaccination programmes**

Italy has made impressive progress in the control and prevention of infectious diseases. Poliomyelitis was eradicated in Italy in 1982, long before the official European eradication in June 2002. The last case of diphtheria in a child occurred in 1991 and the last case of neonatal tetanus in 1982 (6). Since 1991, hepatitis B incidence has decreased by almost 80% in the population and, between 2000 and 2009, in the age

**Figure 2D.5.** Neonatal mortality rates in various European countries, 1978–2009 (3)



group 0-14 years, the incidence of measles declined by 73.42% and that of rubella by 97.8%. Coverage of the mandatory vaccinations is 96%, above the 95% target set by the National Vaccination Plan, in accordance with WHO guidelines. Coverage of the measles, mumps and rubella vaccine is 89.9%, requiring further efforts to meet the target of 95% (35). However, measles, mumps and rubella coverage is not uniform across the country; for example, in Bolzano, coverage is 70.8%, while in Sardinia it is 95.5% (40).

## 2D.5 Conclusion

Overall, there is evidence that human rights have contributed positively to women's and children's health interventions in Italy, and that the human rights-shaped interventions have contributed to important health improvements for women and children.

### ► Key messages

- Laws, plans and initiatives explicitly shaped by a human rights-based approach have contributed to improving and strengthening the system of health protection for women and children.
- Significant improvements in key women and child health indicators can be observed, including assistance during pregnancy, cancer screening, neonatal and infant mortality, and vaccination coverage. Also, as the use of modern contraception has increased, the number of abortions has declined.





A girl child writes a sanitation message on the blackboard in her classroom at a UNICEF supported primary school in Malawi.



## Chapter 2E.

### Conclusions

The operationalization of human rights depends on the context, so these country experiences cannot provide a blueprint for others to follow. However, they do provide instructive illustrations of how some governments have applied human rights to women's and children's health, with evidence of a beneficial impact.

The first research question was: has a human rights-based approach shaped the laws, policies and programmes related to women's and children's health? The evidence from all four countries suggests that it has. In Nepal, human rights appear to have influenced policies (e.g. the National Safe Motherhood and Newborn Health – Long Term Plan), as well as the design of implementing programmes (e.g. the Women's Right to Life and Health Programme and the "Bal Bachau" Child Survival Project). In Brazil, a human rights influence is more evident in policies (e.g. the Programme for Comprehensive Assistance to Women's Health and the National Sexual and Reproductive Rights Policy) than in implementation programmes. In Malawi, the human rights influence is more evenly balanced between policies (e.g. the IMCI policy) and implementation programmes (e.g. the community dialogue tool). In Italy, human rights are evident from the overarching laws and policies (e.g. those establishing the *Servizio Sanitario Nazionale*), to

community-level initiatives (e.g. *Consultori Familiari*). In all four countries, human rights appear to have shaped laws, policies and programmes related to women's and children's health to one degree or another.

The second research question was: what is the evidence that the explicitly human rights-shaped interventions have contributed to improvements in women's and children's health? In relation to the themes selected for this study, Nepal, Brazil, Malawi and Italy have made significant progress in recent years. Several factors have contributed to this progress, including the development of political will, proactive measures to reduce health disparities, and increased investment. Also, it is highly plausible that human rights-shaped policies, programmes and other interventions contributed positively to equitable health and health-related improvements for women and children, such as increased access to emergency obstetric care (Nepal), increased access to modern contraception (Brazil), reductions in early childhood mortality (Malawi), and increased cancer screening and vaccination coverage (Italy).

In Nepal, it is plausible to attribute some improvements in women's and children's health to specific human rights-shaped implementation programmes. This is not

possible for Brazil, Malawi and Italy without more research and evaluation. For this reason, the discussion of the five case studies in Nepal combines (a) the influence of human rights on the programmes, and (b) the evidence of the impact of the programmes. These two issues are discussed separately in relation to Brazil, Malawi and Italy, with a few exceptions. For the same reason, the tables for Nepal, showing the elements of a human rights-based approach in relation to specific implementation programmes, include outcomes, while the equivalent tables for Brazil, Malawi and Italy do not (see Annexes 2, 3, 4 and 5). This signals important issues, addressed in Chapter 4, related to the challenge of attributing health outcomes to specific human rights-shaped interventions.

The experiences of Nepal, Brazil, Malawi and Italy suggest that human rights commitments help to establish a favourable environment for improvements in women's and children's health. Conversely, it appears that a human rights-based approach to women's and children's health is facilitated by an enabling environment with a number of features, including international human rights commitments and constitutional recognition of health rights, reinforced by judicial and non-judicial human rights oversight bodies, under the watchful eye of the country's civil society. Support and guidance from development partners and international agencies have also been notable. In Malawi, international human rights commitments seem to have been more influential than constitutional provisions. Chapter 4 discusses in more detail some of the key features of an environment conducive to a human rights-based approach for women's and children's health.

The four reports of country experiences are primarily based on reviews of existing material. It is striking how little research and evaluation there has been on the impact of a human rights-based approach to women's and children's health in the countries. With few exceptions, this study had to draw on existing quantitative data collected for other purposes. However, these data do not capture many of the distinctive elements of a human rights-based approach. One of the few exceptional evaluations, conducted for the Government of Malawi, UNICEF and DFID, used a mixture of quantitative and qualitative methods; it found that Malawi's human rights-shaped CB-IMCI enriched the community in ways that would have eluded exclusively quantitative assessment (1). This underscores the urgent need for more research and

evaluation on a human rights-based approach to women's and children's health, as well as fresh thinking on the appropriate methods to be used. Both points are addressed in Chapter 4.

While Nepal, Brazil, Malawi and Italy provide examples of human rights-based approaches that may yield numerous lessons for other countries committed to improving women's and children's health, the approaches are not comprehensive and remain work-in-progress. Each of the four countries faces major challenges in the areas of women's and children's health and human rights. Neonatal mortality in Nepal and Malawi is very high, at 33 and 31 per 1000 live births, respectively (2, 3). In Brazil, caesarean births account for almost half of all deliveries (4). In Italy, wide disparities in health and access to services between the north and south of the country persist. The more consistent application of a human rights-based approach would assist Nepal, Brazil, Malawi and Italy to address these and other pressing issues. Nonetheless, the governments deserve great credit for their leadership in taking human rights beyond the law books and beginning to apply them to women's and children's health policies and programmes.

**► Key messages**

- In Nepal, Brazil, Malawi and Italy, human rights appear to have shaped, to one degree or another, laws, policies and programmes related to women's and children's health.
- It is highly plausible that human rights-shaped policies, programmes and other interventions contributed positively to equitable health and health-related improvements for women and children, such as increased access to emergency obstetric care (Nepal), increased access to modern contraception (Brazil), reductions in early childhood mortality (Malawi), and increased cancer screening and vaccination coverage (Italy).
- Although this report does not attribute improvements in women's and children's health exclusively to the use of a human rights-based approach, there are plausible levels of evidence that human rights contributed positively to women's and children's health gains in the four countries.
- It appears that a human rights-based approach to women's and children's health is facilitated by an enabling environment with a number of features (which are discussed in Chapter 4).
- It is striking how little research and evaluation there has been on the impact of a human rights-based approach to women's and children's health; this study mainly had to draw on existing quantitative data collected for other purposes. However, such data do not capture many of the distinctive elements of a human rights-based approach.
- Although major challenges remain in the areas of women's and children's health and human rights in Nepal, Brazil, Malawi and Italy, the governments deserve great credit for their leadership in taking human rights beyond the law books and beginning to apply them to women's and children's health policies and programmes.



*Members of Participation and Practice of Rights (Belfast, N. Ireland) campaign and work on mental health issues.*



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## Chapter 3

### Participation and human rights: impact on women's and children's health. What does the literature tell us?\*

*Laura Ferguson, Emma Halliday*

This chapter reports on findings from a review of a specific subset of the academic literature on participation, human rights, women's health and children's health. The review sought to illustrate the impact of one principle of a human rights-based approach – participation – on women's and children's health, while retaining a focus on other human rights principles.

Participation was chosen as the entry point for deepening understanding of the impact of a human rights-based approach because it is “a crucial part of the common ground shared by health and human rights” (1). To increase the plausibility of attribution of impact of participation on health outcomes, the review focused on women's participation in community-level health services and activities.

Although previous reviews have found evidence that the participation of communities can result in beneficial health and social outcomes (Box 3.1), less attention

#### Box 3.1.

#### Findings from previous reviews related to participation in women's and children's health

- A systematic review showed that community-based intervention packages led to significant reductions in maternal morbidity, stillbirths and perinatal mortality, but did not reduce maternal mortality. Referrals to a health facility for pregnancy-related complications also increased by 40% and early breastfeeding rates improved by 94% (2).
- Reviews of community participation in the context of maternal health and HIV prevention (3) and in rural health systems (4) observed positive health outcomes associated with participation, but noted that the evidence was limited to a small number of high-quality studies.
- A review of empowerment strategies (5) found these to be promising in producing both empowerment and health impacts. The authors observed participation to be central to empowerment, but underscored that it is insufficient on its own to achieve empowerment, and that attention also needs to be paid to the capacity of community organizations and individuals for decision-making and advocacy.

\* This review was jointly conducted by the authors, with advisory support from the Universities of Southern California, Lancaster, and Essex, members of the Steering Group (see Acknowledgements) and representatives of WHO.

has been paid to the analysis of participation in the context of other human rights principles.

Using participation as its focus, the review exemplified a rigorous methodology that frames its analysis through the “lens” of a human rights-based approach. This methodology could be replicated for assessment of evidence of impact in relation to (a) the other principles of a human rights-based approach, such as accessibility, quality and accountability, and (b) a wide range of women’s and children’s health issues. When their findings are grouped together, multiple reviews of this nature could provide a more holistic understanding of the overall impact of a human rights-based approach than is currently available from the peer-reviewed literature.

### 3.1. Purpose and methods of the review

The overarching review question was:

“What evidence is there that the participation of women in the design, implementation, management and/or evaluation of their community health services/systems leads to greater access to, and use of, acceptable and

quality reproductive, maternal and child health services, and/or improved outcomes?”

In addition to this overarching question, the review process identified more specific questions that it sought to answer.

- To what extent is attention given to human rights and HRBA principles in existing evidence on participation and health/health-related outcomes in the subset of literature reviewed?
- Does participation affect outcomes equally across the population (e.g. in different socioeconomic or ethnic groups)?
- What are some of the contextual factors (e.g. legal and policy factors, who initiates participation, processes of participation) that influence the success (or not) of participation in relation to the outcomes assessed?
- What lessons can be learnt about how participation is approached for future policies and programmes, including those implementing a human rights-based approach?

The review process and methodology are outlined in Box 3.2.

#### Box 3.2. Literature review process

Early searches of the literature for evidence of impact of a human rights-based approach (i.e. all its component parts looked at together) on women’s and children’s health yielded poor findings. For example, a search in Medline for “human rights” as a MESH term or keyword, in combination with other relevant search terms (“sexual or reproductive or maternal” and “outcome or evaluation or assessment”) produced 325 hits. However, a review of one-third of these results found that none were relevant: many were about ethics or were commentaries, and very few included any data. This exploratory project had a limited timeframe and it was not feasible comprehensively to review evidence of impact of all the separate principles of a human rights-based approach to women’s and children’s health. The decision was made to narrow the focus of the literature review to one key principle – participation – looked at in the context of other human rights principles.

As described in Annex 6 (section A6.1), there were two main phases to the subsequent literature review. The first phase involved mapping the extent and nature of published research. The findings from this mapping exercise were used to refine the questions for the second phase, which was a detailed review of relevant literature

to systematically address the review questions. Searches were conducted of seven multidisciplinary online databases for research published between 2000 and 2012, by combining the concepts: “participation or empowerment” and “sexual or reproductive or maternal” and “community or primary” and “outcome or evaluation or assessment”. After excluding duplicate records and articles that were immediately irrelevant, 5842 publications were considered for the review on the basis of predetermined inclusion and exclusion criteria. Relevant records ( $n=247$ ) were included in an initial mapping exercise of key trends in published research, which was used to refine the focus and agree on the feasibility of specific questions to be addressed.

Records were sampled to include those making reference to human rights and recognized elements of a human rights-based approach. A total of 23 records were identified for inclusion in the second phase of the review, which involved detailed analysis of the full text. Further information on the individual studies is available in Annex 6. As the primary criterion for inclusion in the second phase of this review was mention of human rights or of an HRBA principle, we tracked the patterns of exclusion in comparison with the broader body of literature on participation in the initial mapping exercise. The results of this are also presented in Annex 6 (section A6.2).

## Definitions of participation

For the purposes of this review, participation was defined as the active involvement of individuals, communities or community-based organizations in the design, implementation, management or evaluation of their community health services or systems. Educating or informing individuals or groups or consulting them to gain support for actions already decided by governments or organizations was not considered participation (1).

Participation in women's and children's health ranges from communities coming together to plan strategies to address local priorities (e.g. perinatal health or HIV), to delivery of community-based responses for maternal and newborn health (e.g. lay health workers) to social movements advocating for national policy change in respect of women's and reproductive rights.

While this chapter does not explicitly deal with political or

### Box 3.3.

#### Examples of studies reporting on participation and health outcomes

##### **A systematic review reporting on intrapartum-related mortality (11)**

A systematic review by Lee et al. of strategies to link families and facilities for care at birth found that community mobilization strategies can increase rates of institutional births and significantly reduce perinatal and early neonatal mortality. Meta-analysis of study results showed a doubling of skilled birth attendance and a 36% reduction in early neonatal mortality.

Studies meeting the review's inclusion criteria were mainly from south Asia with a few from Latin America or Africa. Community mobilization strategies included women's groups, village health committees, community health workers, lady health workers, traditional birth attendants, community mobilizers and peer education.

The reviewers found that programmes demonstrating a reduction in mortality had high levels of active community participation, contextualized newborn problems in the local customs and culture, involved a broad range of key community stakeholders, and included home visitation and peer counselling. Programmes with passive community involvement, with a low frequency of contact with participants, or that provided education without addressing problems generally failed to demonstrate effectiveness.

##### **A cluster-RCT that assessed birth outcomes including neonatal mortality and maternal death (9)**

Manandhar et al. carried out a cluster-randomized controlled trial of 42 pair-matched geopolitical clusters in Makwanpur district, Nepal. The trial aimed to assess if a community-based participatory intervention could improve birth outcomes, including decreasing neonatal and maternal mortality.

In each intervention cluster, a female facilitator convened nine women's group meetings every month. Using an action-learning cycle, facilitators helped the groups to identify perinatal problems and formulate strategies to address them. Birth outcomes were monitored in a cohort of 28 931 women, of whom 8% were members of the women's group.

The intervention seemed to bring about changes in home-care practices and health-care seeking for both neonatal and maternal morbidity. This was also reflected in the mortality rates reported. The neonatal mortality rate in intervention clusters was 26.2 per 1000 live births while in control clusters it was 36.9 per 1000 (adjusted odds ratio 0.70 (95% confidence interval 0.53–0.94)). The maternal mortality ratio in intervention clusters was 69 per 100 000 live births while in control clusters it was 341 per 100 000 (adjusted odds ratio 0.22 (95% confidence interval 0.05– 0.90)).

##### **An RCT reporting neonatal mortality outcomes (8)**

The Ekjut cluster-randomized controlled trial assessed the impact of a participatory learning and action cycle with women's groups to improve maternal and newborn health outcomes. Rath et al. reported on process evaluation data from the trial, exploring the context and implementation of the learning and action cycle. The trial involved 244 women's groups in 18 intervention clusters covering an estimated population of 114 141. Intervention areas were typically rural, largely tribal, and with limited access to health services and poor newborn health outcomes.

Local, literate, married women were recruited as the facilitators of the women's groups and developed materials for training community members. Group members disseminated stories about pregnancy and delivery during community meetings, which enabled women and the wider community to discuss cause and effect linkages, as well as some of the more distal causes of health problems.

The trial showed a 45% reduction in neonatal mortality over the last two years of the study, largely mediated by improvements in safe delivery practices for home deliveries. The authors suggested that, since over 37% of home deliveries in the intervention clusters were conducted by family members, it is possible that group members or their relatives managed deliveries using information and skills from the meetings. There was also a 57% reduction in moderate maternal depression reported in the third year of the study.



civic participation, it is suggested that any discussion of participation cannot be separated from political issues. Participation in health decisions is “intertwined with notions of democracy” (6) and participation is invariably a discussion of “power and control” between more powerful and less powerful elements of communities (7).

### 3.2. Findings

A total of 5842 publications were considered for the review, 247 were included in the initial mapping exercise and 23 were included in the second phase, which involved detailed analysis of the full text. In the 23 records, the most frequently featured forms of participation were women’s groups, general community mobilization, and social movements. The most commonly reported outcomes were: uptake of services ( $n=8$ ; 35%), empowerment ( $n=8$ ; 35%), social capital/community engagement ( $n=8$ ; 35%), neonatal mortality rate ( $n=6$ ; 26%), and legal and policy outcomes ( $n=4$ ; 17%).

The findings from the literature review are presented in relation to: (1) impact on health and health-related outcomes; (2) attention to human rights and HRBA principles; and (3) factors influencing participation.

#### Trends in health and health-related outcomes

The review found evidence of an association between women’s participation and improved health and health-related outcomes. Thirty percent of the studies reported on mortality rates, with most observing significant improvements. With regard to children, this included reductions in: neonatal mortality (8-13); perinatal mortality (9-11, 13); intrapartum-related mortality (10, 11); stillbirth rates (12); and infant and under-5 mortality (12-14). Two studies reported decreases in maternal mortality (9, 14) and one study found an increase in female life expectancy (14). Most of the studies took place in Asia, and often targeted rural, remote, resource-poor areas (see Box 3.3 for examples). The publications reporting on mortality rates included various study designs, such as randomized trials and systematic reviews of randomized controlled trials (RCTs), observational, quasi-experimental and other intervention studies.

Results from studies reporting on health-related outcomes, including service uptake and contraceptive use or health and social behaviour, were mixed but on the whole positive.

Little additional information (either positive or negative) was reported in studies on other types of health outcome for women or children.

The few available studies reporting on social capital or empowerment were positive.

#### ► Key message

- There was evidence of an association between women’s participation and improved health and health-related outcomes.

#### Attention to human rights and HRBA principles

The sections below look at human rights and each of the HRBA principles in turn, with attention to whether these are referred to in the process or outcomes of studies and interventions.

##### Human rights

Most of the articles that mentioned human rights were based on campaigning or advocacy activities, but two were about women’s groups more broadly, one was a systematic review and one was about training of traditional birth attendants (TBAs).

Seven articles considered rights as a framework within which their work took place or a rationale for their work, rather than explicitly aiming to improve human rights (or measure an improvement). Health as a human right was mentioned in four articles, citing Alma-Ata or primary health care as the basis for this, while two articles mentioned the influence of the International Conference on Population and Development (1994) on their work (14, 15).

None of the studies that explicitly mentioned human rights reported on health outcomes other than national-level statistics; any changes in these were difficult to attribute to intervention activities.

Given states’ obligation to ensure the consonance of national legal and policy frameworks with their international human rights commitments, attention to these national frameworks is also warranted. Eight publications noted the need to pay attention to the legal and policy context within which the study or

project took place. In some cases, authors reported that the planned activities could not be carried out since they fell outside local policies (16, 17), while in other cases legal and policy commitments were used to justify or support participation and other project activities (e.g. where gender equity was included in policies) (13, 18-20).

Participation to influence policy and policy processes was predominantly by women's or social movements or NGOs. It generally occurred at national level, but was community-initiated. One study highlighted the influence of the donor movement in pressing for more attention to rights (14).

Five publications considered laws and policies as outcomes, focusing primarily on community advocacy efforts to influence their content, including in relation to abortion, gender-based violence and access to antiretroviral therapy. Most of these studies also included attention to other HRBA principles in their efforts to influence laws and policies, e.g. advocating for equality (21), joint attention to availability, accessibility, acceptability and quality (18, 19), improved accessibility and quality of care (21), and increased attention to accountability (14, 21).

Three studies noted that they achieved positive changes in the content of laws and policies but had no impact on implementation (14, 18, 22).

Although many records covering national policy developments (18, 19, 21, 23) reported changes in health outcomes to describe the impact of national policies, it was not possible to attribute these impacts to participatory processes (other than in terms of the role that participation had played in policy formation or in influencing policy priorities).

#### ► Key messages

- None of the studies that explicitly mentioned human rights reported on health outcomes other than national-level statistics.
- Participation to influence policy and policy processes was predominantly by women's social movements or NGOs.

#### Equality and non-discrimination

Only one article considered equality in its implementation processes: Bleijenbergh & Roggeband (24) stressed that strong gender equality mechanisms were a prerequisite for the development of social care policies. They also noted that a high representation of women in national parliaments and a strong women's movement facilitated the development of such policies.

Marsiglia et al. (17) and UNFPA (21) were concerned with redressing gender inequalities, with the former also drawing attention to inequalities based on economic and immigration status.

Only one article explicitly discussed discrimination; it described a study that sought to decrease discrimination on the basis of gender, poverty, caste and being a sex worker, but did not report any related outcomes (25).

Despite the paucity of attention to equality and non-discrimination, equity was addressed in many of the articles, primarily in the context of ensuring adequate attention to vulnerable groups in either the participatory processes of a project or study or the disaggregation of outcomes to highlight any potential inequities (see Box 3.4).

#### Box 3.4. Attention to equity in studies

Attention to equity in study or project processes generally involved trying to ensure the participation of marginalized groups (including women who were pregnant, unmarried, of lower caste, poor, illiterate, or of ethnic minorities), which was often noted to be difficult to achieve.

Insufficient attention to participation of marginalized groups in implementation processes was reported as a barrier to success (13, 22).

Community mobilization strategies in rural, remote and resource-limited settings (mainly in south Asia) were recognized as promising approaches for addressing inequities in maternal and newborn survival and stillbirth rates (9-12).

Malhotra reported that ensuring the active involvement of disempowered groups – the poor, women and ethnic minorities – in participatory structures and processes reduced gender, wealth and rural/urban inequities in access to youth reproductive health services and health-related outcomes (26).

### ► Key message

- There was a lack of attention to equality and non-discrimination, but equity was assessed in many articles.

### Availability, accessibility, acceptability and quality together

The two studies that mentioned all these four elements focused on legal and policy outcomes (18, 19) and were advocating for attention to these issues in the context of providing reproductive and maternal health services.

National health statistics and accountability mechanisms were reported on as outcomes. Little could be discerned regarding changes in the quality of services but some major improvements in availability were noted. For example, within two years of passing a new abortion act in South Africa, which was explicitly shaped by human rights, availability of services had improved to the extent that the number of women with serious abortion-related morbidity had almost halved (9.5% in 1999 compared with 16.5% in 1994) and the vast majority (91%) had no signs of infection on admission. Maternal mortality from unsafe abortions also decreased (19).

### Availability

None of the publications reviewed considered availability (in isolation from accessibility, acceptability and quality), either in relation to the processes of implementing study or project activities or as an outcome of interest. One study sought to improve the coverage of antenatal care services but this was not framed as availability (18). Although some studies sought to increase the uptake of services, if any HRBA principle was mentioned in this connection, it was either accessibility or acceptability.

### Accessibility

Mechanisms associated with increasing accessibility included local community committees in India (16), women's groups in Nepal (27), and community mobilization strategies involving community health workers (CHWs) and TBAs in multiple settings (10, 11). One study examined the political participation of women and the role of a national women's organization in independently monitoring the national policy environment (21).

Eight studies explicitly sought to increase the accessibility of services. This was addressed in two main ways: first,

through the use of lay workers, such as CHWs and TBAs, who sought to make services more accessible in poor remote or rural areas and, secondly, through community involvement in planning health services.

Changes in health and social behaviour and services were reported by a number of the studies that reported on accessibility. Reductions in mortality rates were reported in three studies (10, 11, 27). UNFPA (21) reported improvements in national reproductive, maternal and sexual health indicators, but it was not feasible to attribute any change to participation.

### Acceptability

Mechanisms addressing acceptability included women's groups (8, 27) and lay cultural brokers in health services (17).

A process evaluation of a randomized controlled trial (8) highlighted the importance of ensuring the acceptability of all study activities, such as ensuring that all facilitators delivering an intervention have adequate knowledge of local languages and practices. The authors noted that acceptability can be improved by involving the local community in collective problem-solving and joint learning, and underscored this as a key factor in the success of their study.

All studies reported improved uptake of services as a result of the intervention. The trials of women's groups interventions (8, 27) reported significant mortality-related outcomes (e.g. significant reduction in neonatal mortality) and behaviour change and Rath (8) observed improvements in women's mental health.

### Quality

Studies referring explicitly to quality included capacity-building of TBAs (15), participation in World Bank health sector reform (28), and participation to improve perinatal care through service planning undertaken by women's or community groups (27, 29). None of the projects or studies reported on quality in relation to their own implementation process.

Eight studies mentioned the importance of quality as an outcome, although only four (15, 27-29) reported on quality indicators and the impact of their project. All four studies reported a positive impact. Quality was generally viewed in terms of improving the standard of services provided by individual lay workers (e.g. TBAs) or improving planning and development of local

services and care by using local knowledge through community mobilization.

Two studies (15, 29) reported changes in knowledge and behaviour related to maternal and reproductive care practices. Sirivong et al. (15) also showed increased uptake of the TBA service for antenatal care, physical examination, and attendance at birth.

The study of women's groups in Nepal (also mentioned under "Accessibility") reported significant reductions in mortality rates (9, 27).

#### ► Key message

- Improvements in the availability, accessibility, acceptability and quality of services were reported across different studies, but these principles were rarely considered together.

#### Empowerment

Studies that made reference to empowerment were mainly concerned with group participatory processes. Some studies focused more specifically on support for marginalized groups, such as disadvantaged young people (26) and empowerment of sex workers (25). Empowerment was also considered explicitly in relation to one-to-one support provided to Latin American women in the USA (17).

Five studies highlighted the importance of empowering participants for project success (11, 17, 22, 25, 30), while two drew attention to the lack of capacity to participate as a factor contributing to project failure (13, 14).

With the exception of articles addressing sex worker empowerment (25) and widowhood practices (30), where empowerment was reported on, it was generally conceptualized as an additional benefit to activities being studied rather than an end in itself.

#### ► Key message

- Although empowerment of participants was often considered as key to project success, it was generally conceptualized as an additional benefit to activities rather than as an end in itself.

#### Accountability

Two studies (22, 28) focused predominantly on the relationship between participation and accountability. In both studies, a range of participatory mechanisms was described, in the context of improvements to sexual and reproductive health services.

The absence of accountability was mentioned in a few studies (14, 21, 22) and the need for accountability mechanisms to be local, rather than only national, was highlighted (27). Cooper (19) observed that, while civil society played a significant role in effecting legislative and policy change in South Africa, it was less involved in implementation and monitoring of policy and thus in holding governments to account for policy implementation.

Policy change resulting from legal advocacy in Brazil reportedly led to improved accountability in relation to maternal mortality at municipal level, as regular audits were mandated (18). Similarly, local task forces were reported to improve accountability in Nigeria (30). In a report on World Bank health sector reforms, the authors argued that, while most projects addressed participation and accountability in some form, these were often initiated by governments and thus occurred within the "boundaries of priorities that are defined through non-participatory processes" (28).

In studies reporting directly on accountability, little additional outcome information was reported.

#### ► Key message

- Some studies reported a positive impact on accountability, but these studies included little additional outcome information.

#### Factors influencing participation

A thematic analysis was undertaken of factors reported as influencing the success of participation. This was considered in two ways: first, by examining the barriers and facilitators in participatory processes and, secondly, by looking at the influence of socioeconomic and political environments. The influence of some factors was different in different studies, i.e. they sometimes appeared to promote success while in other instances they seemed to impede it.

## Barriers

Some issues reported as impeding the success of participatory processes included:

- insufficient attention given to reaching the most disadvantaged and marginalized groups;
- more powerful or educated members of communities overshadowing the participation of those with less confidence;
- opposition among some sections of the community, including leaders and other women;
- a focus on professional or government priorities rather than those of the community;
- a lack of mechanisms or processes to support participation (e.g. capacity building) at national or local levels.

## Facilitators

Studies observed how attention to participatory processes could help the credibility and success of projects through, for example, strategies to increase the focus on marginalized communities or attention to local customs, culture and lay knowledge. Other issues observed as important were: ensuring transparency; supporting participation of wider communities beyond the core group of participants; building relationships with community leaders; gaining trust and respect from government and public service workers; and ensuring that communities participated at all stages of a programme.

## Socioeconomic and political environments

The progress made by policies related to women's and children's health generally, including the capacity of the wider health and social workforce, was substantially affected in countries with high HIV prevalence (13, 19). In some instances, a favourable political and economic climate led to greater pressure on states to respond to women's demands, realize political rights, and comply with international agreements. Such international agreements were cited as useful for national NGOs advocating for change. Historical legacies of participation, e.g. a thriving civil society or social movements, provided a basis for women's health groups and civil activism to exert influence. Conversely, where civil society was weak, difficulties in effecting change were noted (14).

### ► Key messages

- Reported barriers to successful participatory processes included inadequate attention to the constituencies represented and insufficient mechanisms to support participation.
- A favourable political environment and strong civil society can help promote participation.

## 3.3. Discussion

This review found that participation is associated with positive changes in health and health-related outcomes. This was particularly notable in studies reporting reductions in mortality rates and improved birth outcomes, where study designs included cluster randomized controlled trials and systematic reviews (see Box 3.3). There is promising, though more mixed, evidence (in terms of its nature and quality) in relation to other health-related outcomes. These tendencies broadly confirm those found in previous reviews of participation (2-4).

This section considers in turn each of the review questions that could be answered and draws attention to lessons for policies and programmes. Box 3.5 outlines some of the review's methodological limitations. Section 3.4 considers lessons for future research. The final review question ("What lessons can be learnt about how participation is approached for future policies and programmes, including those implementing a human rights-based approach?") is discussed throughout the sections below rather than being addressed separately.

### To what extent is attention given to human rights and HRBA principles within existing evidence on participation and health/health-related outcomes within the subset of literature reviewed?

No study reported systematic attention to all elements of a human rights-based approach to health. Twelve studies mentioned one or two human rights principles in addition to participation. Of the eleven studies that mentioned three or four additional principles, seven also explicitly mentioned human rights. While attention to participation, if well conceived, appears to positively

### Box 3.5. Limitations of this review

Insufficient evidence was found to answer two of the review questions identified during the initial mapping phase. Specifically, it was not feasible to compare studies where participation was framed either as a human right or as part of a human rights-based approach (however defined) with studies where human rights and human rights-based approaches were not mentioned. Many advocates and practitioners appeared to be strongly informed by human rights values, even if these were not explicitly framed as such, while some who mentioned human rights appeared to do so primarily rhetorically. There was also significant variation in the approaches to participation identified in the literature, so it was impossible to attribute differences plausibly to the presence or absence of any mention of attention to human rights.

This meant that it was impossible to tease out rigorously any differences in how participation was approached or how outcomes were affected when participation was framed as a human right or part of an HRBA and when it was not framed as such. This was one of the factors that led to the review's focus on the very specific subset of literature that referred to human rights or HRBA principles in the context of participation.

Three key limitations resulting from sampling records in this way are acknowledged.

1. This approach excluded the majority of literature on participation, where HRBA principles are not mentioned. Efforts were therefore made to place findings from the review

in the context of other major reviews of participation.

2. Assessment of the degree to which studies might take into account other principles important to human rights was based on the limited information available in study abstracts. When screening records for their inclusion, reviewers erred on the side of caution in determining which publications should be included, but a few relevant records may have been excluded.
3. There was some concern that, where records made reference to terminology familiar to a human rights framework, this framework might not have been considered by the original researchers or by those who planned and implemented the intervention. Every effort was made not to impose a rights-based framework on any research if it was not explicitly there.

There was insufficient time to contact authors for further details on their work, especially with regard to human rights and HRBA principles. It was also only feasible to look at literature published in electronic databases, which has implications for the nature of the evidence used in the review. First, local programme evaluations were largely absent unless they had been indexed in electronic databases. Secondly, as community-initiated projects are typically unreported in peer-reviewed literature, perspectives on how participation is viewed and valued by communities are missing, as has been noted in other reviews of participation (4).

affect outcomes, these publications highlight the importance of a range of HRBA principles that also have a positive impact. Taken together, the studies in this review highlight the benefits of attention to these principles alongside participation.

The abortion-related legislation in South Africa that was reported by Cooper et al. (19) to have led to improved women's health outcomes has been described as "in line with the Human Rights Approach" (31). In addition to attention to participation and the legal and policy environment, Cooper et al. also mentioned availability, accessibility, acceptability and quality, i.e. more HRBA components were discussed than in most of the other studies reviewed.

Women's groups, general community mobilization, and social movements appeared to be the forms of participation most likely to be employed where human rights or HRBA principles were considered. The most

explicit discussion of human rights tended to be in articles on the national policy context. However, where most reference to human rights was made this was not always reflected in the actual attention to human rights in the process and outcomes of the study or intervention. For example, some studies used human rights to contextualize their research into participation (e.g. making reference to appropriate international declarations), but then did not appear to use a human rights-based approach framework for the research or intervention.

Studies that considered availability, accessibility, acceptability and quality were more likely to comprise interventions such as women's groups or use of traditional birth attendants. These studies more frequently reported on health-related outcomes than studies that made reference to the less tangible principles, e.g. accountability or human rights in general, which could be argued to be less traditionally or directly associated with public health. Similar to this, a review

by Marston et al. that searched for publications on accountability and participation failed to find any articles reporting outcome information (3).

Studies that considered HRBA principles did so most often in the context of the desired outcomes of their work rather than the study or intervention implementation processes, e.g. studies that wanted to promote the acceptability of health services did not explicitly focus on the acceptability of their intervention processes. Conversely, most of the studies that mentioned human rights did so in the context of rights providing a framework within which their work occurred or a rationale for the work, e.g. government commitments to health-related rights highlight the need for the project to support realization of these commitments. Only one study had the inclusion of sexual and reproductive rights in national policies as a desired outcome (18). Five publications sought to influence the content of the national legal and policy environment in some way (14, 18, 19, 21, 23).

### **Does participation affect outcomes equally across the population (e.g. in different socioeconomic or ethnic groups)?**

Efforts to reach different population groups were not considered consistently across studies. While some studies reported evidence of the differential impact of reach or outcomes of interventions, this information was limited. Available evidence suggests that, unless strategies are in place to engage with the poorest and most marginalized, these sections of the population and their priorities will not be represented.

### **What are some of the contextual factors (e.g. legal and policy factors, who initiates participation, processes of participation) that influence the success (or not) of participation in relation to the outcomes assessed?**

Some studies noted the negative impact of a restrictive legal and policy environment on the work they could carry out; others highlighted the value of international agreements as advocacy tools for government action.

There was some suggestion that the impact of participation on project outcomes was related to the intensity of participation, i.e. projects involving more active community participation and a greater range of community stakeholders appeared to have a greater impact on outcomes (11). As suggested below, further

research is required to understand how and why participation works. Nevertheless, it seems critical that participation is included from the initial stages of a study or project, and that it is promoted throughout planning, implementation, monitoring and evaluation. Specific attention to marginalized populations is required to ensure that they participate and that appropriate attention is given to their issues or concerns, even though this may require additional time and resources.

Some publications gave details of who initiated participation in the context of studies and interventions. Some projects were the initiative of local communities, while others were instigated by governments or foreign donors. However, the degree to which this might affect sustainability and the communities' sense of ownership of project activities is not certain as this was often not documented. The impact of such factors on project outcomes was also not clear from the publications reviewed.

#### **► Key messages**

- Participation was associated with a positive impact on health and health-related outcomes.
- The studies in this review highlighted the benefits of attention to additional HRBA principles alongside participation.
- No study reported systematic attention to all elements of a human rights-based approach to health.
- Studies that considered availability, accessibility, acceptability and quality more frequently reported on health-related outcomes than studies that made reference to human rights or accountability.
- Unless strategies are in place to engage with the poorest and most marginalized, these sections of the population and their priorities will not be represented.
- The impact of participation on health and health-related outcomes may be related to the intensity of participation.

### 3.4. Suggestions for further research

This section gives some illustrative suggestions for further research arising from the review. Some of the suggestions relate generally to a human rights-based approach and women's and children's health, while others focus on participation. Because the range of issues that urgently need research is extensive, Chapter 5 outlines a process that will help governments and other stakeholders identify priorities and set a coherent and manageable agenda for strengthening research on, and evaluation of, the impact of an HRBA on women's and children's health. It is hoped that the following research suggestions will be considered in this agenda-setting process.

#### Urgent need for accessible evidence on the impact of a human rights-based approach, including participation, on women's and children's health

Although the initial intention had been to carry out a review of the literature documenting the impact of adopting a human rights-based approach on women's health and children's health, this was not possible. This may be because of a scarcity of available research or of ineffective indexing of literature in the databases searched. Both of these potential explanations require further investigation. It is important to ensure that this type of evidence is being generated and made accessible, so that the strengths, weaknesses and impacts of human rights-based approaches can be better understood.

Any intervention study that explicitly attempted to implement a comprehensive human rights-based approach to women's or children's health, and that included data on implementation processes and health (and other) outcomes, would constitute an invaluable contribution to current knowledge.

#### Consideration or non-consideration of a human rights-based approach

The inability to answer questions that sought to compare the outcomes associated with participation according to whether or not human rights (or HRBA principles) had been considered also highlights the scarcity of evidence of impact of a human rights-based approach in the literature.

Further research should focus on understanding the commonalities and differences between approaches to participation shaped, or theoretically not shaped, by a human rights-based approach. This would present a learning opportunity for advocates and practitioners working in different disciplines, whose approach to participation may be strongly informed by explicit or implicit rights values and who may share similar ideals.

#### Participation

This review suggests that few published studies have considered participation in the framework of a human rights-based approach. Few studies were identified that reported on women's health outcomes and no studies were found that reported outcomes relating to children's health and well-being. There is an urgent need for

*At a meeting of Mahila Swasthya Adhikar Manch (Women's Health Rights Forum), women line up to sign their names and add their fingerprints to a petition demanding local government officials improve access to local health care services in Gorakhpur District, Uttar Pradesh, India.*





rigorously designed research to assess the impact of participation, as an explicit component of a human rights-based approach, on women's and children's health outcomes. Such research could include, for example, evaluation of the impact on women's and children's health outcomes of: women's participation in health facilities committees; the use of lay health workers to provide supplementary sexual and reproductive health services; and the introduction of peer education into sexual and reproductive health services. The latter would seem particularly important, as the peer education studies identified in the mapping exercise were excluded from the second phase of the review since none of them mentioned human rights or any HRBA principles other than participation.

This literature review identified a scarcity of research on important HRBA processes, such as the role of participation in accountability processes, and the impact this has on health and health-related outcomes. This gap was also noted in a review of participation for maternal health and HIV prevention by Marston et al. (3), who identified no studies on accountability and participation reporting health outcomes even when accountability was explicitly searched for. This should be a priority area for research, particularly given the crucial role of participatory processes in increasing public accountability for health.

### Other challenges in evaluating participation

Attribution of outcomes to participation was challenging, particularly if interventions included multiple forms of participation. Studies showed different conceptual understandings of participation and gave varying levels of detail about participatory processes. While there is promising evidence of positive health outcomes arising from participation, this evidence is based on only a small number of studies.

Other reviews of participation have noted that such issues make it challenging to be able to reach strong conclusions about whether or not different types of community participation in different contexts affect health outcomes, or if some types of participation work better than others (3). In this regard, other review authors have called for better-designed studies to increase understanding of community participation, its participatory processes and its context-dependent nature (3, 4, 32).

This review identified no studies of cost-effectiveness.

Cost-effectiveness analysis is important in helping decision-makers to assess their programmes and can also help inform decisions about funding of interventions that make best use of available resources. This has also been acknowledged by other reviewers as a priority area for future research on participation generally (2, 10).

### What are the key human rights features of participation?

There is a lack of consensus regarding what constitutes meaningful participation or a failure to implement it, and what is meant by the human right to participate. A human rights-based approach to participation would probably require, at a minimum, special attention to marginalized populations, attention to priorities identified by local communities, and capacity-building for individuals, communities and professionals to ensure that participation can be active, informed and meaningful. Further attention is needed to the key human rights features of participation and how they can facilitate participatory processes.

### Geographical variation in mention of human rights

In comparison with the general literature on participation, a high proportion of the studies carried out in Asia made reference to human rights or HRBA principles, while a very low proportion of those carried out in Africa, Canada and the USA included mention of these issues. A similar geographical distribution was noted in a review of community-based intervention packages to reduce maternal and neonatal morbidity and mortality and improve neonatal outcomes (2).

These findings suggest that research is needed to: (i) develop a greater understanding of why attention to human rights or HRBA principles appears to be less prominent in studies of participatory interventions in Africa, Canada and the USA; and (ii) determine how participation, considered alongside other human rights elements, affects women's and children's health outcomes in these areas.

### Sample bias and the politics of human rights-related research in health

In the interests of feasibility, the review assessed a very specific subset of the literature on participation and health outcomes, i.e. publications that mentioned human

rights or HRBA principles. This undoubtedly constitutes a biased sample. But why is the sample biased? How do researchers decide: (i) whether or not to explicitly design their work as rights-based; and (ii) whether or not to write up their work in this way? Are (some) donors more or less likely to fund, and (some) academic journals more or less likely to publish, and (some) countries more or less likely to allow work that is explicitly rights-based? Understanding the source of these biases will help identify ways in which they might be overcome.

### **Much interest in equity, but a lack of attention to equality and non-discrimination**

The lack of attention to equality and non-discrimination in the context of substantial interest in equity highlights a potential linguistic divide between the fields of public health and human rights. Explicit study of how equality and non-discrimination can be used as a framework for addressing inequities in health would be useful for highlighting the potential contribution of a human rights-based approach.

#### **► Key messages**

- While there is promising evidence of improved health outcomes resulting from participation, the evidence is based on a small number of studies.
- There is a need for rigorously designed research to assess the nature and impact of a human rights-based approach, including participation, in different settings on women's and children's health outcomes.
- Intervention studies that explicitly consider participation within the framework of a human rights-based approach are urgently required.
- Studies assessing the cost-effectiveness of participation (and other elements of a human rights-based approach) are needed.
- Further attention needs to be given to identifying the key human rights features of participation and how they can facilitate participatory processes.
- The majority of studies reviewed were based in Asia; there is a lack of articles in the peer reviewed literature on participation that make reference to human rights or human rights-based approach principles, e.g. from Africa, Canada and the USA.
- An explicit study of how non-discrimination can be used as a framework for addressing inequities in health could usefully highlight the potential contribution of a human rights-based approach in this area.
- The scarcity of literature available for this review highlights the need to ensure that evidence is generated and made accessible so that the strengths, weaknesses and impact of human rights-based approaches can be better understood.



*Consisting of independent experts, the UN Committee on the Rights of the Child considers the periodic report of France, May 2009, Geneva.*



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## Chapter 4

### Emerging themes: the features of an enabling environment and the scarcity of research and evaluation

*Daniel Tarantola, Maya Unnithan, Linsey McGoey, Shyama Kuruvilla, Jennifer Franz-Vasdeki, Paul Hunt*

A number of themes emerge from the country experiences and review of the literature described in Chapters 2 and 3. The country experiences demonstrate that there is evidence that a human rights-based approach contributes to improvements in women's and children's health. The literature review, with its focus on women's participation in community health, confirms that attention to participation, if well conceived, appears to positively affect outcomes. Notably, it also concludes: "Taken together, the studies in this review highlight the benefits of attention to [HRBA] principles alongside participation."

This chapter considers two other emerging themes. First, the country experiences suggest that a human rights-based approach to women's and children's health is facilitated by an enabling environment with a range of features. Secondly, both the country experiences and the literature review confirm the scarcity of research and evaluation on the impact of a human rights-based approach on women's and children's health. This chapter explores one of the reasons for this scarcity and outlines a methodological response to the problem.

#### 4.1. An enabling environment for a human rights-based approach to women's and children's health

The experiences of Nepal, Brazil, Malawi and Italy suggest that a human rights-based approach to women's and children's health is supported by an enabling environment with a number of features. While their mix and sequencing are likely to vary from one country to another, the features described below may be instructive for other countries committed to implementing an HRBA to women's and children's health.

1. Nepal, Brazil, Malawi and Italy have ratified key international human rights treaties, including the Convention on the Rights of the Child (1) and the Convention on the Elimination of Discrimination against Women (2). They also take seriously other important global commitments, such as those arising from the Cairo Conference on Population and Development (3), the Beijing World Conference on Women (4) and the Millennium Declaration (5). Treaty ratification alone is unlikely to lead to a human rights-based approach; indeed, it was some years after Nepal ratified a

number of international human rights treaties that an explicit human rights-based approach to women's and children's health emerged (6). Nonetheless, it appears that commitments to international human rights and other global agreements may help to establish a positive environment for women's and children's health initiatives shaped by human rights.

2. Constitutional recognition of health-related rights helps to create the conditions for human rights-shaped laws, policies and other interventions on women's and children's health. As in Nepal, Brazil, Malawi and Italy, a policy may explicitly refer to constitutional provisions and human rights principles may be drawn on in the design of its content. Conscious of the Constitution, a government may recognize that individuals have a legal entitlement to a minimum package of services, as in Italy. In Brazil and Nepal, aspects of women's sexual and reproductive health are explicitly protected by the Constitution, and violations of health-related rights may be brought before the courts. Such cases have

led to judicial decisions supportive of a human rights-based approach, such as the case of *Prakash Mani Sharma & Others vs Government of Nepal*, which concerned the high incidence of uterine prolapse. Not only can courts help to support an HRBA, there is evidence that judicial decisions based on human rights have themselves had a beneficial impact on women's and children's health. Consider, for example, the South African Constitutional Court decision concerning access to nevirapine (Box 4.1).

3. In Nepal, Brazil, Malawi and Italy, the protection of human rights is supported by formal, non-judicial bodies, such as Nepal's National Human Rights Commission, Brazil's National Council for Women's Rights, the Malawi Human Rights Commission (which has a specialist Child Rights Unit), and Italy's recently established National Ombudsman for Childhood and Adolescence. It appears that such bodies may contribute positively to an environment supportive of a human rights-based approach to women's and children's health.

#### Box 4.1.

##### *Minister of Health and Others v Treatment Action Campaign (2002)*

In South Africa in the late 1990s, around 70 000 newborns each year were being infected with HIV as a result of mother-to-child-transmission. In 2000, the antiretroviral drug nevirapine, which had the potential to prevent nearly half of these infections, was offered to the South African Government free of charge for five years. The Government announced that it would introduce the drug only in certain pilot locations, and postponed setting these up for one year, thereby denying or delaying access to life-saving treatment for most mothers.

In response, the Treatment Action Campaign, a grassroots organization that advocates for increased access to treatment, care and support services for people living with HIV/AIDS, filed a law suit contending that the government was violating the constitutionally recognized right to access health care services. The South African Constitutional Court declared that the constitutional provisions relating to the right to health "require government to devise and implement within its available resources a comprehensive and coordinated programme to realize progressively the rights of pregnant women and their newborn children to have access to health services to combat mother-to-child-transmission of HIV". The Court ordered the Government "without delay" to permit doctors to prescribe nevirapine in state clinics and hospitals, and to take "reasonable measures" to expand testing and counselling programmes in the state sector to facilitate the use of nevirapine for PMTCT.

The judgement challenged the HIV/AIDS denialism that existed within the Government at that time. It also ensured that the ministry of health could no longer refuse to fulfil mothers' and children's rights to PMTCT services in the public sector. It is widely accepted that the judgement saved tens of thousands of lives.

*Source: Minister of Health and Others v Treatment Action Campaign and Others (No 1) (CCT9/02) (2002) ZACC 16; Berger J, Kpazynski A. The story of the TAC case: the potential and limits of socio-economic rights litigation in South Africa. In: Hurwitz DR et al., eds., Human rights advocacy stories, New York, Foundation Press, Thompson Reuters, 2009: 43-79.*



*Treatment Action Campaign chair Zackie Achmat and a colleague talk to their legal team at the Constitutional Court in Johannesburg.*

4. A human rights-based approach to women's and children's health is unlikely to be advanced by a single, isolated policy or programme. Brazil's human rights-shaped women's health initiatives depend on the country's universal public health system. Malawi's human rights-shaped IMCI policy is informed by the country's Growth and Development Strategy. The Women's Right to Life and Health Programme in Nepal partly derives from the country's National Safe Motherhood and Newborn Health – Long-Term Plan. Italy's human rights-shaped *Consultori Familiari* are grounded in the country's *Servizio Sanitario Nazionale*. Women's and children's health policies and programmes that are shaped by human rights are likely to be closely connected to broader health, developmental or other policy initiatives.
5. It is helpful if these broader policy initiatives explicitly support an HRBA. For example, NSMNH-LTP (Nepal), SUS (Brazil), MGDS (Malawi) and SSN (Italy) explicitly affirm a human rights-based approach. The experiences in these three countries suggest that human rights-shaped women's and children's health policies and programmes are more likely to flourish if the broader policy context is also explicitly supportive of human rights. In short, policy coherence is important.
6. The experiences in Brazil and Italy, and to a lesser degree those in Nepal and Malawi, suggest that a well informed, dynamic and diverse civil society can play a vital role in the application of a human rights-based approach to women's and children's health across the government's policy-making, implementation and review cycle. But this is not the limit of civil society's contribution to an HRBA to women's and children's health. In many countries, civil society organizations have explicitly used human rights in the design and implementation of their own health interventions, with compelling evidence of beneficial impact. An example is the Sonagachi Project in India (Box 4.2).
7. In Nepal, Brazil, Malawi and Italy, the human rights-shaped women's and children's health initiatives depended on high-level political leadership and support, which also extended to a human rights-based approach to women's and children's health. In a recent speech, for example, Eleanora Menicucci de

Oliveira, Brazil's Minister of Women's Policies, confirmed that human rights must guide health policies for women: "The right to access all components of the SUS, which guarantees universal coverage, equity and comprehensive care, is essential

#### Box 4.2. The Sonagachi Project, Kolkata

The Sonagachi STD/HIV Intervention Project (SHIP) started in 1992 as a public sector initiative undertaken by the All India Institute of Hygiene and Public Health, Kolkata, promoted by the WHO Global Programme on AIDS in collaboration with the Indian National AIDS Control Office. Since then, it has become an example of the "empowerment approach" to STD/HIV prevention, building a social movement of more than 60 000 sex workers in over 60 West Bengali communities.

From the beginning, human rights principles explicitly underpinned the Project, including respect for sex workers as people who have the same human rights, including workers' rights, as others. These principles "became enshrined in SHIP and permeated its everyday work", contributing to some of the Project's distinctive features, such as participation, egalitarianism, flexibility, responsiveness to community need, empowerment, community ownership, and equitable access to services and resources. One report concludes, "it is the interaction of these values that led to the particular success of the SHIP interventions".

Among the many indicators of success, the most compelling is the prevalence of HIV infection. While HIV prevalence among sex workers in most other Indian cities has reached more than 50%, in Sonagachi it remains below 10%. Levels of STI are also low. The Project has enabled sex workers to have more control over their bodies, as well as their living and working conditions.

Sources: Blankenship KM et al. Structural Interventions: concepts, challenges and opportunities for research. *Journal of Urban Health*, 2006, 83(1): 59-72; UNAIDS. *Female sex worker HIV prevention projects: lessons learnt from Papua New Guinea, India, and Bangladesh*. Geneva, 2000; Wallerstein N. *What is the effectiveness of empowerment to improve health?* Copenhagen, WHO Regional Office for Europe, 2006 (Health Evidence Network report; [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0010/74656/E88086.pdf](http://www.euro.who.int/__data/assets/pdf_file/0010/74656/E88086.pdf)); The Durbar Mahila Samanwaya Committee, Theory and Action for Health Research Team. *Meeting community needs for HIV prevention and more: intersectoral action for health in the Sonagachi red-light area of Kolkatta*. Geneva, WHO, 2007.

- these guarantees also guide the [PNAISM] ... it is crucial to extend this right to all women, who must be seen beyond their reproductive roles, enabling the development of health policies that improve the quality of life of different groups of women” (7).

8. Throughout this monograph, particular attention is given to the role of the executive branch of government. However, the experiences of Nepal, Brazil, Malawi and Italy underscore that the implementation of a human rights-based approach to women's and children's health depends on the active engagement of many stakeholders. The courts, national human rights institutions and civil society have already been mentioned, but there are others with responsibilities, such as legislatures, development partners, and international agencies and partnerships. Experience suggests that an enabling environment encourages the active engagement of a wide range of stakeholders in the application of an HRBA to women's and children's health across the policy-making, implementation and review cycle.

Some of the features of an enabling environment mentioned above correspond to key messages in Chapter 3, e.g. that a strong civil society can help promote participation. Governments can take measures towards creating an enabling environment supportive of a human rights-based approach to women's and children's health, for instance by endorsing global commitments, incorporating recognition of health rights in national laws, establishing non-judicial human rights oversight bodies, ensuring policy coherence and promoting effective coordination among multiple stakeholders. The implementation of a human rights-based approach depends on other measures, too, such as human rights training and human rights mainstreaming. As seen in Nepal, Brazil, Malawi and Italy, an HRBA is unlikely to be implemented comprehensively and simultaneously in all women's and children's health programmes; this is consistent with the obligation to progressively realize the right to health. Governments are more likely to begin by focusing on a few carefully chosen policies and programmes. It is beyond the scope of this monograph to set out how different stakeholders can implement an HRBA to women's and children's health policies and programmes. However, Annex 7 lists some useful resources on this crucial issue.

#### ► Key message

- A human rights-based approach to women's and children's health is supported by an enabling environment with a range of features, including ratification of key international human rights treaties, endorsement of other global commitments, constitutional recognition of health-related rights, non-judicial human rights oversight bodies, policy coherence, a dynamic civil society, political leadership and support for a human rights-based approach to women's and children's health, and the engagement and effective coordination of multiple stakeholders.

## 4.2. A scarcity of research on, and evaluation of, the impact of a human rights-based approach on women's and children's health

Another theme emerging from the country experiences and literature review is the scarcity of research on, and evaluation of, the impact of a human-rights based approach on women's and children's health.

There may be a number of reasons for this scarcity. For example, the relationship between health and human rights has only recently attracted sustained attention, and so far priority has not been given to impact evaluations but to other issues, such as the elaboration of health-related human rights standards. There are various interpretations of what constitutes a human rights-based approach, while some relevant concepts, such as progressive realization and maximum available resources, are not yet widely understood. These conceptual uncertainties may discourage researchers from undertaking impact evaluations. Donor interest is relatively limited and there is a lack of funding; for example, there is no wealthy industry to provide financial backing to demonstrate the effectiveness of human rights-shaped interventions.

Another reason for the scarcity of impact evaluations is that there is insufficient clarity and agreement about the methods and tools needed to carry out meaningful research and evaluation of the impact of a human rights-based approach on women's and children's health. This section provides a response to this methodological challenge.

### A response: multidisciplinary and multi-method approaches

A wide array of methods and tools are commonly used to monitor health policies, programmes, outcomes and impacts. Different policy-makers need different types of information of varying precision and complexity, for different purposes (6). The first step is to establish what it is that needs measuring, i.e. what is the policy or research question? Then the appropriate disciplines, methods and information needed to answer the question can be addressed. This section identifies some disciplines and methods that can help policy-makers evaluate laws, policies and programmes based on a human rights-based approach and the resulting impact on women's and children's health. (For working definitions of key terms, see Chapter 1.)

As the experiences of Nepal, Brazil, Malawi and Italy demonstrate, in assessing the impact of a human rights-based approach on women's and children's health it is necessary to be alert to (a) the historical, political, social, cultural and environmental context; (b) laws, policies and programmes; and (c) health-related outcomes and impacts, including health gains, individuals' well-being and community empowerment. For example, the evidence of the impact of Malawi's IMCI policy included indications of contributions to gains in children's health, transformed relationships between health providers and community members, and improvements in individuals' quality of life. What are the policy and research questions, disciplines and methods best suited to capture these contextual and public policy issues, as well as health-related outcomes and impacts?

#### Policy and research questions

In relation to an HRBA and women's and children's health, likely policy and research questions are numerous and may include the following:

- How do morbidity, mortality and disability affect different populations as disaggregated by, for example, age, sex and ethnicity?

- What are the biological, socio-economic, political and environmental determinants of women's and children's health in relation to the burden of morbidity, mortality and disability?
- What are the social, political and legislative structures, including decision-making processes on priority setting and financing, that influence health and human rights outcomes? What are the impacts on women's and children's health of judicial decisions based on human rights?
- What impact do explicitly human rights-shaped interventions have on health, well-being, health-related behaviour, access to services, quality of services, participation and accountability? Are the impacts different if the interventions are explicitly shaped by all, or only some, human rights principles?
- What role does a human rights-based approach play in relation to people's experiences of health, well-being, institutional power and legal processes, as well as their understandings of rights, and related concepts, that are established features of the indigenous culture?

#### A range of disciplines and methods

The above policy and research questions cannot be answered by any one discipline alone. Their scope means that several disciplines have a significant contribution to make, including epidemiology, clinical medicine, demography, social and behavioural sciences (e.g. sociology and anthropology), political science, law and economics.

While all disciplines use a mix of methods, a multidisciplinary approach underlines the critical importance of using a broad and diverse array of methods and tools. These encompass quantitative and qualitative methods, and include ethnographic analysis, a specific qualitative approach that captures the processes through which human rights are understood, made meaningful and applied by health policy-makers, providers and users (8, 9).

More specifically, the methods and tools needed for a multidisciplinary approach to evaluate the impact of an HRBA may include disease surveillance, in-depth case studies, randomized controlled trials, observational studies, evidence syntheses including systematic reviews, participant observation, cross-cultural and historical comparisons, interviews,



questionnaires, participatory research, focus groups, surveys, analysis of censuses and vital data, interpretation of laws (e.g. treaties and constitutions), analysis of policy documents and court decisions, and cost-benefit analyses.

In summary, no single discipline or method can address all policy and research questions related to the impact of a human rights-based approach on health: different disciplines and a broad and diverse array of methods and tools are needed. The scarcity of impact evaluations identified in Chapters 2 and 3 calls for multidisciplinary and multi-method approaches, which will generally entail quantitative and qualitative, including ethnographic, methods.

### **An example of a multidisciplinary, multi-method approach**

To illustrate the application of multidisciplinary and multi-method approaches to assessment of the impact of a human rights-based approach on women's and children's health, consider the Malawi country study (Chapter 2C).

The research questions were: has a human rights-based approach shaped the laws, policies and programmes related to children's health in Malawi? If so, what is the evidence that these explicitly human rights-shaped interventions contributed to improvements in children's health in Malawi?

To answer these two questions, a review of existing material was undertaken. The first question led to consideration of the evolving national political context and the role of institutions, such as the Malawi Human Rights Commission, together with an analysis of texts of, for example, treaties, laws, policies and programmes. The second question led to analysis of quantitative data, such as child health indicators, and qualitative data, e.g. as reported in an evaluation of a community-level health intervention.

The study then examined the relationship between the material and analysis generated by the two questions. It drew on analysis in a range of disciplines, including epidemiology, clinical medicine, anthropology, law and public policy. It also used existing quantitative and qualitative material collected using various methods, including disease surveillance, interviews of community members and interpretation of normative and programmatic texts. Thus, the review contains

elements of a multidisciplinary and multi-method approach in the range of material reviewed.

Crucially, the two research questions also invite primary research and evaluation using a multidisciplinary, multi-method and more comprehensive analysis than was possible in the study of Malawi. For example, an epidemiologist could collect data on child morbidity and mortality, through household surveys, to look for shifts in patterns following the implementation of a particular human rights-shaped policy. Colleagues from other disciplines, including clinical medicine and the social sciences, could then analyse the disease-related mechanisms and outcomes, and related health behaviours, using statistical methods that would allow tracking of outcomes and attribution of causality. Causality of impact from the policy could be gauged by a public policy specialist, with some human rights expertise, whose role it would be to clarify issues around timing, mechanisms and implementation of the particular policy, which would then inform the interpretation of associated health outcomes. This type of policy analysis could be done by examining the context, content, actors and processes involved in policy-making, and the related mechanisms by which the expected and unexpected effects of the human rights-shaped policy were achieved. Economists could contribute to the analysis by assessing the costs, and cost-efficiencies, associated with implementation of the human rights-shaped policy and estimate the economic implications (benefits and costs) of the human rights-related impacts on women's and children's health, for example through improved labour productivity. Ethnographic and participatory research methods, such as participant observation and focus groups, could reveal community-specific issues that may influence health outcomes, including community participation, economic, political and social empowerment, patterns of discrimination and inequity, and sociocultural norms and perceptions. Through the use of detailed case studies, social scientists, including ethnographers, could better understand impact, or lack of it, across groups and structures, and look for patterns in behaviour by engaging with the study population to develop holistic and grounded perspectives.

By deepening the evidence, such multidisciplinary and multi-method approaches would help policy-makers understand the multiple impacts of an HRBA on women's and children's health, formulate effective recommendations and take robust action. For

example, it would help them identify the most effective designs for human rights-based interventions, guide the allocation of scarce resources for maximum effect in reducing illness, saving lives, increasing empowerment and improving well-being, track if objectives are being achieved, ensure accountability in relation to pledges and commitments, and inform remedial action, including legislative, policy and programme changes.

Such a level of understanding and associated action is unlikely to arise from research and evaluation that are not based on multidisciplinary and multi-method approaches.

#### **Levels of evidence: how sure do we need to be?**

In addition to identifying what is to be measured and how, it is also necessary to establish what level of evidence is sufficient to inform decisions and actions.

The scale of evidence strength and attribution ranges from adequacy through plausibility to probability (described further below). Public health and social research have traditionally devoted more attention to both ends of the scale (adequacy and probability) than to the intermediate position (plausibility) (10). This is important because plausible levels of evidence have particular relevance for the assessment of the impact of a human rights-based approach on women's and children's health, as discussed in the following paragraphs.

As Habicht et al. put it: "Inferences about the *adequacy* of programme outcomes depend on the comparison of the performance or impact of the project *with previously established adequacy criteria*" (emphasis added) (10). For example, the criteria may be the distribution of 10 million packets of oral rehydration salts to children with diarrhoea and a 20% decline in reported diarrhoeal deaths in the programme area. If results are compared with such established criteria, adequacy assessments require no control groups. As such, adequacy evaluations are limited to describing whether or not the expected changes took place, and may not establish a causal link between the intervention and the expected changes. However, as Habicht et al. observe: "Despite their inability to causally link programme activities to observed changes, adequacy evaluations may provide all the reassurance necessary that the expected goals are being met and lead to continued support for the programme" (10).

*Plausibility* assessments provide a greater degree of confidence that the observed changes (i.e. outcomes and impacts) are due to the specific intervention being implemented. This level of evidence can be achieved by controlling for external (or "confounding") factors, for example, by using non-randomized control groups. Control groups may be historical (e.g. the same target population before and after the intervention), internal (e.g. a geographical area where the intervention is going to be implemented but has not yet been), or external (e.g. a geographical area outside where the intervention is being implemented). As Habicht et al. observe, the use of control groups results in much more plausible conclusions than if no controls are used. Plausibility encompasses a continuum, ranging from weak to strong (10).

*Probability* assessments use statistical methods, including the randomized selection of individuals who receive a specific intervention and control groups who do not. These methods are designed to isolate and measure the effects of confounding variables. However, probability assessments are often not feasible for public health programme evaluations, especially in relation to a human rights-based approach. There would be obvious ethical and legal difficulties if a randomized control trial were to deny individuals in the control group their human rights. Writing in 1999, Habicht et al. suggested that "there are many limitations to the use of the probabilistic approach in assessing large-scale programmes ... However, key individuals in donor or international agencies, as well as the evaluators themselves, may have been trained to regard probability assessments as the gold standard and fail to understand that this approach is seldom mandatory or even feasible for the routine evaluation of programme effectiveness" (10). The authors recognized, however, that sometimes probability assessments are essential, e.g. for testing the efficacy and safety of a new medicine.

In conclusion, when assessing the impact of a human rights-based approach on women's and children's health, there may be a role for the three levels of evidence: adequacy (e.g. no control groups), plausibility (e.g. non-randomized control groups) and probability (e.g. randomized control groups). Each may have a role to play in particular contexts. They may also be used in combination. In comparison with adequacy, plausibility provides a greater degree of confidence that the observed changes are due to the human rights-shaped

intervention. Also, plausibility will often be more feasible than probability. So, when assessing the impact of a human rights-based approach on women's and children's health, it will often be most compelling and feasible for evaluators to use the plausible level of evidence. This has various implications, some of which are briefly addressed in Chapter 5.

### 4.3. Conclusion

This chapter has considered two themes emerging from the country studies and literature review. First, it has

outlined some of the features of an enabling environment supportive of a human rights-based approach to women's and children's health. Secondly, it has highlighted the scarcity of research on, and evaluation of, the impact of an HRBA on women's and children's health. One reason for this scarcity is insufficient clarity and agreement about the methods and tools needed to carry out the necessary research and evaluation. In response to this methodological problem, evaluators are advised to adopt multidisciplinary and multi-method approaches that give particular attention to the plausible level of evidence.

#### ► Key messages

- There is a scarcity of research on, and evaluation of, the impact of a human rights-based approach on women's and children's health.
- There are a number of reasons for this scarcity, one of which is a lack of clarity and agreement about the methods and tools needed to carry out research and evaluation.
- Research on, and evaluation of, the impact of a human rights-based approach on women's and children's health requires multidisciplinary and multi-method approaches.
- Plausibility will often be the most compelling and feasible level of evidence for researchers and evaluators to use when assessing the impact of a human rights-based approach on women's and children's health, although adequacy and probability may also have a role.

*Pilar Mazzetti, Peruvian Minister of Health, launches a national mobilisation on health rights and responsibilities. Second National Health Conference, Lima, August 2004.*



*Courtesy of Care-Perú*

## Chapter 5

### **Towards the future: creating a platform for policy-makers and an agenda-setting process to strengthen research and evaluation**

*Daniel Tarantola, Maya Unnithan, Linsey McGoey, Shyama Kuruvilla, Jennifer Franz-Vasdeki, Paul Hunt*

Today, more attention than ever before is being devoted to the operationalization of a human rights-based approach to health. In addition, collaboration between the health and human rights communities is deepening. There is a growing appreciation that human rights can help health workers achieve their professional objectives, and that the health community has an indispensable contribution to make towards the realization of health-related human rights. While this progress is encouraging, much remains to be done by a wide range of stakeholders.

This chapter highlights two initiatives, related to the focus of this study, which would help to consolidate recent achievements and accelerate progress. It proposes an organizational initiative to advance implementation of a human rights-based approach to women's and children's health, as well as a process to strengthen research and evaluation on the impact of an HRBA on women's and children's health. These initiatives should be seen as contributions towards a multidimensional strategy for the

operationalization of a human rights-based approach to women's and children's health, and health more generally.

#### **5.1. A platform for policy-makers seeking to implement a human rights-based approach to women's and children's health**

While this report has highlighted experiences in Nepal, Brazil, Malawi and Italy, many other countries are endeavouring to operationalize a human rights-based approach to women's and children's health, and there is much to learn from their rich experiences.

Unfortunately, policy-makers sometimes find it difficult to locate documentation about these diverse country experiences – the successes, challenges and pitfalls – and this can hinder learning. Also, there are few cross-sectoral fora, where representatives of, for example, ministries of health, planning, justice, finance, women and children can discuss these issues. Policy-makers may benefit from improved opportunities to discuss these rapidly developing topics.

Accordingly, it is suggested that policy-makers would benefit from a platform that both facilitates the exchange of documentation about country experiences, and provides an opportunity for policy-makers to discuss ideas and provide advice, support and encouragement on the implementation of a human rights-based approach to women's and children's health.

Participants in such a platform might consider, for example: the main features of an enabling environment for a human rights-based approach; how different countries have put in place such an enabling environment; different institutional frameworks; good practices for the operationalization of a human rights-based approach; how to advance cross-sectoral and multidisciplinary dialogue and collaboration; the relationship between universal health coverage and a human rights-based approach to health; the best ways for the international community to help governments; how the UN human rights procedures (e.g. reporting to the Women's Rights Committee) can be used to advance women's and children's health; the meaning of a human rights-based approach; and the evidence of impact of a human rights-based approach on women's and children's health.

Four key features are suggested for such a platform.

- It would be directed mainly towards policy-makers working in the executive and legislative branches of government, who have primary responsibility for ensuring that laws, policies, programmes and other interventions advance the government's obligations in relation to women's and children's health. However, others would have important contributions to make, such as international agencies and initiatives, national human rights institutions, health professional associations and other civil society organizations, lawyers and private sector business organizations.
- It would be cross-sectoral and multidisciplinary, i.e. it would provide a supportive environment for those in health-related sectors, including those responsible for human rights, such as ministries of justice and foreign affairs. This is important for policy coherence between national ministries with shared responsibilities for health and human rights.
- The platform would engage with existing and projected multistakeholder networks that aim to share experiences on implementation (1), such as the knowledge hubs endorsed by the Manila Declaration

of the Asia-Pacific Leadership and Policy Dialogue for Women's and Children's Health (2), and the Research Consortium for Universal Health Coverage anticipated by the Beijing Statement from the Second Global Symposium on Health Systems Research (3).

- There would be some advantage in the platform giving particular attention to the specific challenges of women's and children's health, but it would also benefit from country experiences with human rights implementation in relation to a wide range of health issues, including HIV/AIDS. The platform might also learn from experiences of human rights implementation in other sectors, such as education, housing and food.

Finally, while a global platform is envisaged, there may be support for regional and national platforms along similar lines.

#### ► Key messages

- There is a need for a platform for policy-makers to exchange country experiences on implementation of a human rights-based approach to women's and children's health.
- Although mainly directed towards those working in the executive and legislative branches of government, such a platform would include a wide range of stakeholders.
- Cross-sectoral and multidisciplinary, the platform would engage with existing multistakeholder networks that share experiences on implementation.

## 5.2. An agenda-setting process to strengthen research and evaluation

An agenda-setting process is needed to strengthen research on, and evaluation of, the impact of a human rights-based approach on women's and children's health. An agenda will help stakeholders from different disciplines to collaborate, coordinate and make strategic choices about what to prioritize. Chapter 3 identified a number of research issues, some of which relate generally to a human rights-based approach and women's and children's health, while others address narrower topics, such as participation. Here, the main aim is not to identify more research suggestions, but to set out a process for identifying and agreeing a coherent and manageable agenda to strengthen research on, and evaluation of, the impact of a human rights-based approach on women's and children's health. Benefiting from analogous experiences and lessons learnt with respect to health research and evaluation, a 5-step approach to this agenda-setting process is outlined below (4-6).

### 1. Establish a baseline: conduct situational analyses of the health and human rights of women and children

Although not complete, there is already a considerable amount of relevant information on health and human rights, which can provide a baseline for future impact evaluations of an HRBA on women's and children's health. The health and human rights communities tend to use different information sources. The health community, for example, uses national surveys, Joint Assessments of National Health Strategies, and Countdown to 2015, while the human rights community uses reports submitted to independent UN human rights treaty-monitoring bodies (e.g. the Committee on the Rights of the Child), reports from national human rights institutions, and the publications of civil society organizations. Each group would benefit from the information and insights of the other. Health reports should integrate human rights considerations, e.g. the human rights focus on disadvantaged groups needs to be translated into disaggregated health data. And human rights reports can be deeply enriched by the extensive data set out in health surveys and other sources. Combining information sources will provide a more complete understanding of the health and human rights status of women and children, the reality in which they live, and the baseline for future impact evaluations.

### 2. Find out what research on, and evaluation of, the impact of a human rights-based approach on women's and children's health have already been carried out

The present study suggests that, within its parameters, there has been relatively little research or evaluation of the impact of an HRBA on women's and children's health. An agenda-setting process will need to look beyond this study's parameters. In relation to country experiences, for example, it may seek to identify: existing impact evaluations for both governmental and nongovernmental interventions; the health-related impact of judicial decisions based on human rights; and interventions both explicitly and implicitly shaped by human rights. In relation to literature reviews, an agenda-setting process will need to consider research on, and evaluation of, not only participation (as in Chapter 3), but also other elements of a human rights-based approach.

A review of the literature will be needed to evaluate existing knowledge (and gaps) on the impact of a human rights-based approach on women's and children's health. This will lead to the production of a comprehensive bibliography containing key sources. Existing databases will also need to be evaluated: for example, PubMed for access to the biomedical literature; World Bank, UNDP and other indicators for key development data at national, regional and global levels; legal databases, such as WestLaw, for material on laws, including judicial decisions and their impacts; and JSTOR, which encompasses the social sciences,.

It would be helpful to use bibliometrics to assess the impact of existing research, in order to evaluate the quality and transferability of contributions from different institutions and scientific disciplines and using different methods. Also, the identification of funding sources promoting research on, and evaluation of, the impact of a human rights-based approach on women's and children's health would be instructive.

### 3. Set priorities for new research on, and evaluation of, the impact of a human rights-based approach on women's and children's health

These priorities should be established through a participatory process, based on stakeholders' needs and priorities, with particular attention to

disadvantaged groups in low-, middle- and high-income countries. Once selected, the research and evaluation will require a multidisciplinary and multi-method approach as outlined in Chapter 4.

As priorities are discussed, it will often be helpful to keep in mind two distinct research questions. First, has an HRBA shaped a particular policy or other intervention relating to women's and children's health? Second, if so, what is the evidence that this particular human rights-shaped policy or other intervention has contributed to improvements relating to women's and children's health? While both these questions are important, the second question is critical if the aim is to improve women's and children's health, rather than improve a policy or other intervention.

These two questions can also be refined and applied in other contexts. For example, have human rights shaped a judicial decision? If so, what is the evidence that this human rights-shaped decision contributed to improvements relating to women's and children's health?

Numerous considerations will help to set the priorities for new impact evaluations. For example, there might be a wish to prioritize research on, and evaluation of, the impact of an HRBA in relation to: a specific population group (e.g. those living in poverty); access to particular facilities or services (e.g. contraception, oral rehydration therapy or antibiotics for pneumonia); one or more elements of an HRBA (e.g. quality, participation or accountability); or different stages of the policy cycle (e.g. national plans, budgets or accountability).

#### 4. Establish a research and evaluation network

The exciting challenges for research and evaluation highlighted in this study cannot be adequately addressed by ad hoc isolated projects, in different disciplines, scattered across disparate institutions. As noted by Pang et al. (4), there is a need for a multidisciplinary network of policy-makers, practitioners and scholars interested in research on, and evaluation of, the impact of a human rights-based approach on women's and children's health (Box 5.1).

A research and evaluation network on a human rights-based approach and women's and children's health might, for example:

- encourage and support such research and evaluation;
- improve collaboration and mentoring within and across disciplines;
- bring together researchers and evaluators from the health and human rights communities;
- help to build capacities for multi-method, multidisciplinary research and evaluation;
- address methodological challenges. For example, as suggested in Chapter 4, evaluators may wish to give particular attention to a plausible level of evidence; but how should plausibility be established? Should, for instance, research and evaluation include a consultative mechanism for stakeholders to determine collectively the plausibility of findings?
- encourage the mainstreaming of human rights into health-related research and evaluation;
- provide advice and support on the financing of research and evaluation;
- provide opportunities to discuss the findings and implications of relevant research and evaluation;
- set up a database or registration system for research on, and evaluation of, a human rights-based approach and women's and children's health, e.g. along the lines of the WHO International Clinical Trials Registry Platform (<http://www.who.int/ictrp/en/>).

##### Box 5.1

“Health research is too often a fragmented, competitive, highly specialized, sectoral activity where researchers within scientific disciplines often work in isolation from other disciplines. There is often little effective communication and consultation between these producers of research and the end-users (i.e. the decision- and policy-makers, health professionals, consumers, and the public). Arguably, there is a need for a rational framework that values both the production and use of research, and a platform for effective communication and interaction between all the players and stakeholders from a more integrated and coordinated, systems perspective.”

Source: Pang T et al. (4).

Such a research and evaluation network could be either a new discrete arrangement or located within an existing appropriate framework. In any event, progress in this field will be severely constrained without some sort of supportive network along these lines.

There should be close links between this network and the platform for policy-makers seeking to implement an HRBA to women's and children's health. Each can inform and reinforce the work of the other; for example, questions raised by policy-makers can help to shape the research agenda.

## 5. Ensure effective dissemination of action-oriented findings

In order to ensure that the results of research on, and evaluation of, evidence of impact of a human rights-based approach on women's and children's health are accessible to multiple stakeholders, they should be disseminated through clear, simple, action-oriented and tailored messages, adapted to the audience. Findings can be disseminated through a number of channels, including education, media and research networks (7). Knowledge-brokers are intermediaries between those doing the research and potential beneficiaries and interested parties (e.g. policy-makers). They "translate" research, promote use of the findings and strengthen linkages between the academic research system and the policy environment, civil society, patients, and the general public (8-10).

### ► Key messages

- An agenda-setting process is needed to strengthen research on, and evaluation of, the impact of a human rights-based approach on women's and children's health. The process might include five steps:
  - Conduct situational analyses of the health and human rights of women and children, to establish a baseline.
  - Find out what research and evaluation of the impact of a human rights-based approach on women's and children's health have already been carried out.
  - Set priorities for new research on, and evaluation of, the impact of a human rights-based approach on women's and children's health.
  - Establish a multidisciplinary network of policy-makers, practitioners and scholars interested in research on, and evaluation of, the impact of a human rights-based approach on women's and children's health.
  - Disseminate the findings of research on, and evaluation of, evidence of impact of a human rights-based approach on women's and children's health, so that the knowledge and evidence become well known and are used to advance the health and human rights of women and children.





Doctor in pediatric ward talking to patients at Samangan Provincial Hospital, Afghanistan.



WHO / Christopher Black

## Chapter 6

### Conclusions

Human rights are enshrined in the Charter of the United Nations, the Constitution of WHO, the Universal Declaration of Human Rights, the Declaration of Alma-Ata, legally binding international human rights treaties, constitutions and other national laws, and many other important instruments. Countries and the global community have put in place institutions, policies, programmes and numerous other measures to ensure that these human rights are respected and implemented. While strongly affirming the commanding moral, political and legal authority of human rights, this monograph addresses a challenging question: what is the evidence that human rights have helped to improve the health of women and children?

#### Helping governments improve health and comply with their human rights obligations

The country experiences of Nepal, Brazil, Malawi and Italy (Chapter 2) demonstrate a plausible level of evidence that a human rights-based approach has contributed to health gains for women and children. These experiences show that the constitutional and international right to health can be translated into improved health services and health status through laws,

policies and programmes that are explicitly shaped by health rights principles, such as accessibility, participation, quality and accountability. Explicitly influenced by human rights, Nepal's Aama Surakshya Karyakram programme has helped, for instance, to increase access to safe delivery services. Malawi's human rights-shaped community-based IMCI has both deepened community participation in children's health issues and contributed to fewer children dying. In Italy, the constitutional right to health has shaped, and been implemented through, the *Servizio Sanitario Nazionale*, which includes community-based paediatricians who are responsible for good quality paediatric care. Brazil's human rights-influenced policies have contributed to the establishment of maternal mortality committees, which have improved accountability for maternal deaths. The Commission on Information and Accountability for Women's and Children's Health has recently reiterated the critical importance of independent accountability in the struggle to save the lives, and improve the health, of women and children (1).

None of these four countries claims to have comprehensively implemented all dimensions of the right to health. Each continues to face considerable

health and human rights challenges. Nonetheless, they have begun to translate the constitutional and international right to health into operational practice – and with evidence of beneficial impact.

With its focus on one key principle of a human rights-based approach, the literature review (Chapter 3) confirms that attention to women's participation at the community level, if well conceived, appears to positively affect outcomes. Further, it concludes that “the studies in this review highlight the benefits of attention to [HRBA] principles alongside participation”, and identifies a number of pressing research priorities.

In summary, applying human rights to women's and children's health policies, programmes and other interventions not only helps governments comply with their binding national and international obligations but also contributes to improving the health of women and children.

### Accelerating operationalization

The key human rights challenge is to ensure that national and international human rights standards are operationalized and made “real” for individuals, communities and populations. The operationalization of an HRBA to women's and children's health, and indeed health in general, requires a multidimensional strategy, the contours and contents of which fall beyond the scope of this monograph. Nonetheless, this study has identified some elements of such a strategy and contributes to operationalization in a number of ways.

### Establishing an enabling environment

The report notes that a human rights-based approach to women's and children's health is supported by an enabling environment with a range of features, such as high-level political leadership and advocacy for an HRBA (Chapter 4). Steps that governments can take towards such a positive environment include ratifying key international human rights treaties, endorsing other global commitments, recognizing the right to health in the constitution, establishing non-judicial human rights oversight bodies, and ensuring policy coherence and effective coordination among multiple stakeholders. These measures will often be enhanced by appropriate human rights training and mainstreaming.

### Multidisciplinary and multi-method approaches to research and evaluation

The study found few human rights-shaped women's and children's health policies and other interventions that were accompanied by research or evaluation that was well equipped to capture many of the human rights dimensions of the interventions. The observed scarcity of evidence may therefore be attributable, not to lack of impact, but to a scarcity of appropriately designed research and evaluation. There are a number of reasons for the scarcity of appropriately designed research and evaluation, including a diversity of understanding about what constitutes a human rights-based approach and a lack of funding. The report gives particular attention to one reason: the lack of clarity and agreement about the methods and tools needed to carry out the research and evaluation. In response to this methodological problem, the study suggests that research on, and evaluation of, the impact of an HRBA on women's and children's health requires multidisciplinary and multi-method approaches. On the question of attribution, it concludes that plausibility is often the most compelling and feasible level of evidence for evaluators to use, although adequacy and probability may also have a role (Chapter 4).

When governments and other stakeholders design human rights-shaped policies and programmes for women's and children's health, they should include research and evaluation that is well equipped to capture the human rights dimensions of the interventions. Funding for appropriately designed impact evaluation should be built into the policies and programmes from the outset.

As an initial assessment, this study has given attention only to selected aspects of women's and children's health. As research and evaluation of human rights-shaped women's and children's health interventions become deeper and more widespread, it is important that they together encompass a holistic understanding of health, the continuum of care and all aspects of women's and children's health.

### A multidisciplinary network for research and evaluation

An agenda-setting process is needed to strengthen research on, and evaluation of, the impact of a human rights-based approach on women's and children's health. A five-step process is suggested, one step of

which is to establish a multidisciplinary network of policy-makers, practitioners and scholars interested in research on, and evaluation of, the impact of a human rights-based approach on women's and children's health. The network could help, for example, to strengthen multidisciplinary and multi-method research and evaluation capacities, bring together evaluators from the health and human rights communities, and provide advice and support on the financing of research and evaluation. There is an important role for WHO in helping to establish such a multidisciplinary network.

### **A place for policy-makers to exchange country experiences**

There is also a need for a suitable arrangement whereby policy-makers can exchange country experiences on implementation of an HRBA to women's and children's health. While this study gives particular attention to the experiences of Nepal, Brazil, Malawi and Italy, other countries are endeavouring to operationalize a human rights-based approach to women's and children's health and there is much to learn from their experiences. Chapter 5 describes one way of facilitating supportive exchanges of experiences and ideas – a global platform for policy-makers – but there are other possibilities. While mainly directed towards those working in the executive and legislative branches of government, a platform or other arrangement should include a wide range of stakeholders. Cross-sectoral and multidisciplinary, it should engage with existing multi-stakeholder networks that share experiences on implementation. There is an important role for WHO, in close collaboration with OHCHR and other stakeholders, in helping to establish a suitable arrangement whereby policy-makers can exchange experiences and ideas on implementation of an HRBA to women's and children's health, and in cooperating with others who wish to establish equivalent regional or national arrangements.

A place for policy-makers to exchange country experiences on the implementation of a human rights-based approach will also contribute to discussions on universal health coverage in relation to the post-2015 agenda. Universal health coverage is a practical expression of the concern for health equity and the right to health. Universal access to quality care and a human rights-based approach to health are mutually reinforcing (2).

Research commissioned by the World Bank's Nordic Trust Fund recently concluded that human rights are "a positive instrument for people and their governments" (3). This report illustrates this finding by demonstrating the positive contribution human rights have made to women's and children's health. It also identifies steps towards the implementation of a human rights-based approach to women's and children's health. Human rights-shaped women's and children's health interventions can help governments comply with their binding human rights obligations, health workers achieve their professional objectives, and individuals, communities and populations improve their health, life and well-being.

**► Key messages:**

- Applying human rights to women’s and children’s health policies, programmes and other interventions not only helps governments comply with their binding national and international obligations but also contributes to improving the health of women and children.
- The key human rights challenge is to ensure that national and international human rights standards are operationalized and made “real” for individuals, communities and populations. Operationalization requires a multidimensional strategy; this report contributes to such a strategy and to operationalization in a number of ways.
- A human rights-based approach to women’s and children’s health is supported by an enabling environment with a range of features; governments can take steps towards such a positive environment.
- The study found few human rights-shaped women’s and children’s health policies and other interventions that were accompanied by research and evaluation well equipped to capture many of the human rights dimensions of the interventions. The observed scarcity of evidence may therefore be attributable not to lack of impact but to a scarcity of appropriately designed research and evaluation. Funding for appropriately designed impact evaluation should be built into human rights-shaped interventions.
- As research on, and evaluation of, human rights-shaped women’s and children’s health interventions become deeper and more widespread, it is important that they together encompass a holistic understanding of health, the continuum of care and all aspects of women’s and children’s health.
- There is an important role for WHO in the creation of a multidisciplinary network of policy-makers, practitioners and scholars interested in research on, and evaluation of, the impact of a human rights-based approach on women’s and children’s health.
- There is a need for a place, such as a global platform, where policy-makers can exchange country experiences on implementation of a human rights-based approach to women’s and children’s health. There is an important role for WHO, in close collaboration with OHCHR and other stakeholders, in helping to establish such an arrangement and in cooperating with others who wish to establish equivalent regional and national arrangements.
- Human rights-shaped women’s and children’s health interventions can help governments comply with their binding human rights obligations, health workers achieve their professional objectives, and individuals, communities and populations improve their health, life and well-being.

# References

## 1. Introduction

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## Annex 1



### A HUMAN RIGHTS-BASED APPROACH TO HEALTH

#### Why a human rights-based approach?

A human rights-based approach (HRBA) aims to support better and more sustainable development outcomes by analyzing and addressing the inequalities, discriminatory practices (de jure and de facto) and unjust power relations which are often at the heart of development problems.

Under a human rights-based approach, development efforts are anchored in a system of rights and corresponding State obligations established by international law. Civil, cultural, economic, political and social rights provide a guiding framework for development plans, policies and processes. A HRBA also appreciates the importance of capacity development.

#### Policy commitments to mainstreaming human rights in development

*The UN Programme of Reform (1997)* sets out human rights as a cross-cutting issue in all UN activities and urges its mainstreaming across the UN system.

At the *2005 World Summit*, UN Member States unanimously resolved to integrate human rights into their national policies and gave explicit support for the integration of human rights within the UN system.

*The Accra Agenda for Action (2008)*, which aimed to accelerate and deepen implementation of the Paris Declaration on Aid Effectiveness, commits developing countries and donors to "ensure that their respective development policies and programmes are designed and implemented in ways consistent with their agreed international commitments on gender equality, human rights, disability and environmental sustainability."

#### A UN common understanding of a human rights-based approach

Human rights-based approaches have been advanced by a broad range of stakeholders. Recognizing the need for coherence of approaches in the context of UN inter-agency collaboration, the UN Common Understanding on a Human Rights-based Approach was agreed upon in 2003.

The UN common understanding has served as a reference point and guiding framework for many other partners, including governments, bilateral agencies and non-governmental organisations.



A human rights-based approach is one of the key programming principles guiding UN common country programmes, and has been integrated into the Guidelines for UN Country Teams on Preparing a Common Country Assessment (CCA) and United Nations Development Assistance Framework (UNDAF). Nevertheless, stakeholders are increasingly calling for sector and issue specific guidance on the practical application of a human rights-based approach.

#### Key elements of a HRBA to health

A human rights-based approach to health specifically aims at realizing the right to health and other health-related human rights. Health policy making and programming are to be guided by human rights standards and principles and aim at developing capacity of duty bearers to meet their obligations and empowering rights-holders to effectively claim their health rights.

Elimination of all forms of discrimination is at the core of a HRBA. Gender mainstreaming is a key

strategy to achieving gender equality and eliminating all forms of discrimination on the basis of sex.

**Policy commitments to promote health-related human rights**

*The WHO Eleventh General Programme of Work (2006-2015)* provides a global health agenda for WHO's Member States, its Secretariat and the international community. It highlights seven priority areas for the international community, including promoting universal coverage, gender equality, and health-related human rights.

The integration of a human rights-based approach is specifically addressed in Strategic Objective 7 of the **WHO Medium-Term Strategic Plan (MTSP) 2008-2013**.

The strategic agenda for WHO cooperation, as reflected in the **WHO Country Cooperation Strategy**, should incorporate the human rights-based approach to development and the commitment to gender equality adopted by the United Nations system (2008 CCS e-guide).

Building on the UN Common Understanding on a Human Rights-based Approach, the below sections identify core aspects of the HRBA elements: goal, process and outcome.

**GOAL**

**All programmes, policies and technical assistance should further the realization of human rights**

A HRBA emphasizes that the ultimate goal of all health policies, strategies and programmes is to further advance the realization of the right to health and other health-related human rights as laid down in national and international human rights legislation. Human rights standards provide guidance in defining the precise elements of a health objective.

If the right to health and other health-related human rights are to be fully realized, policies and plans need to systematically integrate and further these rights.

The right to health is recognized in several core international and regional human rights treaties and national constitutions. The International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and the Convention on the Rights of the Child (CRC) are some of the central human rights instruments for the protection of the right to health.

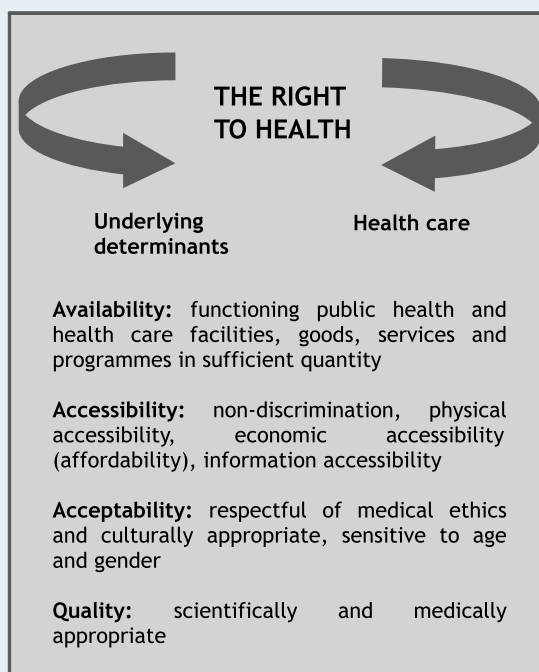
The Committee mandated to monitor the implementation of the ICESCR (Committee on

Economic, Social and Cultural Rights) has interpreted the content of the right to health in the General Comment No. 14, available at OHCHR's web site:

[http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358b0e2c1256915005090be?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/40d009901358b0e2c1256915005090be?Opendocument)

Among other essential points, General Comment No. 14 highlights that the right to health extends to both timely and appropriate health care and to the underlying determinants of health, such as safe and potable water, sanitation, food, housing, health related information and education, and gender equality. These points highlight the importance of inter-sectoral action to effectively realize the right to health.

Similarly, General Comment No. 14 explains that the four elements of availability, accessibility, acceptability and quality (AAAQ) are essential to the enjoyment of the right to health by all.



**PROCESS**

**Human rights standards and principles guide programming in all sectors**

A human rights-based approach gives importance not only to outcomes, but also to the processes. Human rights standards and principles - such as participation, equality and non-discrimination, and accountability - are to be integrated into all stages of the health programming process: assessment and analysis, priority setting, programme planning and design, implementation, and monitoring and evaluation.

**Participation and inclusion** means that people are entitled to active, free and meaningful participation in decisions that directly affect them,

such as the design, implementation and monitoring of health interventions. Participation increases ownership and helps ensure that policies and programmes are responsive to the needs of the people they are intended to benefit.

Information sharing is a critical component of participatory processes. Participation can only be meaningful if relevant information is available on time and in an accessible language and format, considering for example age, gender, ethnic, religious and cultural backgrounds. Effective participation also requires that the freedom of association is guaranteed.



**Equality and non-discrimination** requires States to address discrimination in laws, policies and practices, such as in the distribution and provision of resources and health services. Discrimination can be indirect, for example, policies and actions can lead to inequalities in access and in the enjoyment of rights, as a result of being gender-blind.

Functioning national health information systems and availability of disaggregated data are essential to be able to identify the most vulnerable groups and diverse needs. Commonly marginalized groups include: children and adolescents; women (across groups); persons with disabilities; indigenous peoples, ethnic, religious or linguistic minorities; internally displaced people and refugees; migrants, particularly undocumented; and persons living with HIV or AIDS.

General Comment No. 20 of the Committee on Economic, Social and Cultural Rights offers ample details about non-discrimination in relation to the right to health. General Comment No. 20 is available on OHCHR's web site: <http://www2.ohchr.org/english/bodies/cescr/comment20.htm>

**Accountability:** States must be transparent about their decision-making processes, actions, or omissions, and put redress mechanisms in place. There are many ways to address accountability such as:

- Ratification of treaties and incorporation of standards in domestic law;
- Judicial and quasi-judicial mechanisms, e.g. court rulings, constitutional reviews, national human rights commissions or ombudspersons;
- Administrative and policy mechanisms, e.g. reviews of health policies and strategies, audits, and human rights impact assessments;
- Political mechanisms, e.g. parliamentary processes, monitoring and advocacy by NGOs;
- Reporting on human rights treaties incorporating the right to health.

**Recommendations of international human rights bodies and mechanisms** should inform programming. The Universal Human Rights Index of UN documents provides easy access for all countries to human rights information from the UN system: <http://www.universalhumanrightsindex.org>

The index includes observations and recommendations of UN treaty monitoring bodies and the Special Procedures of the Human Rights Council.

#### OUTCOME

**Focus on capacity development of duty bearers to meet their obligations and of rights-holders to claim their rights**

A human rights-based approach focuses on capacity development, both of duty bearers to meet their obligations and of individuals to claim their rights. Capacities include skills, abilities, resources, responsibilities, authority and motivation.

**Duty bearers:** A HRBA aims to build the capacity of the State at all levels (local, regional/federal and national) to *respect*, *protect* and *fulfil* human rights. Important categories of duty-bearers in relation to health include policy makers, hospital managers, health professionals, inspectors and parliamentarians, among others.

#### Three types of State obligations:

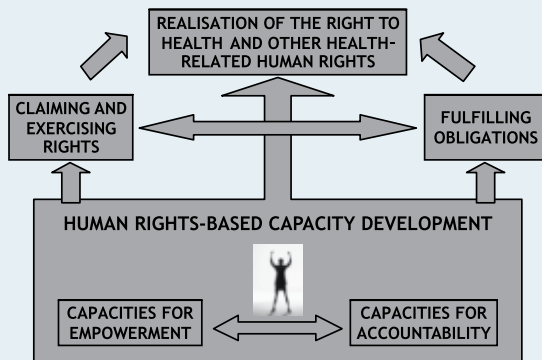
**Respect:** not to interfere directly or indirectly with the enjoyment of the right to health, e.g. refrain from limiting access to health-care services or marketing unsafe drugs.

**Protect:** prevent third parties from interfering with the right to health, e.g. ensure that private companies provide safe environmental conditions for their employees and surrounding communities

**Fulfil:** adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to fully realize the right to health.

**Rights-holders:** A human rights-based approach gives attention to ways of empowering individuals and communities, particularly marginalized groups, to understand and claim their rights.

In order to effectively claim their rights, rights-holders must be able to access information, organize and participate, advocate for policy change and obtain redress.

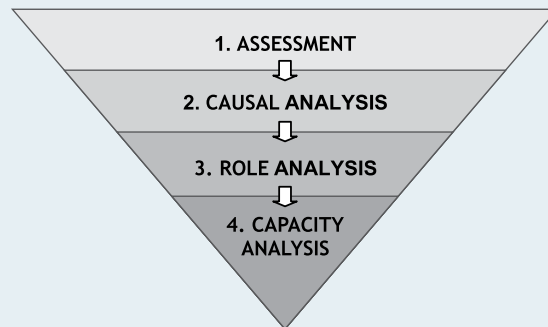


#### A HRBA situation analysis

The 2009 Guidelines for UN Country Teams on Preparing a Common Country Assessment (CCA) United Nations Development Assistance Framework (UNDAF) provide guidance on how to carry out a HRBA situation analysis. In relation to health, such an analysis responds to four main questions:

- 1. What is happening, where and who is more affected? (assessment)** For every health challenge, identify the inter-related human rights standards and the groups suffering from a greater denial of rights.
- 2. Why are these problems occurring? (causal analysis)** Identify the underlying and root causes of exclusion, discrimination and inequality.
- 3. Who has the obligation to do something about it? (role analysis)** Identify individual and institutional duty-bearers and their corresponding obligations.
- 4. What capacities are needed for those affected, and those with a duty, to take action? (capacity analysis)** Identify the skills, abilities, resources, responsibilities, authority and motivation needed by those affected to claim their rights and those obliged to fulfil the rights.

Once capacity development assets and needs have been identified, the central question is: **where and how can capacity development efforts produce the greatest results?**



The U.N. Secretary-General has reaffirmed the centrality of human rights in development (Policy Decision 2008/18) and requested the Office of the High Commissioner for Human Rights (OHCHR) and the United Nations Development Group (UNDG) to initiate an interagency process to strengthen system-wide coherence, collaboration and support for UN Resident Coordinators and UN Country Teams in mainstreaming human rights.

WHO and other UN agencies working in the area of health need to continue strengthening their capacity to integrate a human rights-based approach and advocate for health-related human rights.

#### Country example: CCA Iraq 2009

The CCA in Iraq addresses health as a human right and a range of essential services. It gives importance to equality, inclusion, participation and empowerment, noting that people often lack the information and awareness needed to make informed choices and claim their rights.

The CCA used a HRBA to guide the thematic analysis of key challenges. This helped focus attention on vulnerable groups and reveal the immediate, underlying and root causes of poor health. The analysis discussed the roles of various stakeholders and identified specific areas where capacity development is needed.

#### Selected resources

- OHCHR/WHO, The Right to Health, Factsheet No. 31, 2008
- OHCHR/WHO, Human Rights, Health and Poverty Reduction Strategies, 2008
- WHO, 25 Questions and Answers on Health and Human Rights, 2002
- OHCHR/Sida/WHO, Human Rights and Gender Equality in Health Sector Strategies - an analytical tool (forthcoming)
- UN Practitioners' Portal on HRBA Programming: [www.hrbaportal.org](http://www.hrbaportal.org)
- Also refer to the WHO Health and Human Rights web site: [www.who.int/hhr/en](http://www.who.int/hhr/en)



**World Health Organization**

Department of Ethics, Equity, Trade and Human Rights (ETH) Information, Evidence and Research (IER) [www.who.int/hhr](http://www.who.int/hhr)



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## Annex 2

## Nepal

Table A2.1.

Elements of a human rights-based approach in the Women's Right to Life and Health (emergency obstetric care) Programme\*

| Goal      | Reduce maternal mortality and morbidity through emergency obstetric care by creating services, developing community action and promoting good governance   |  |   |   |  |
|-----------|--|--|---|---|--|
| Processes | Participation  | Availability   | Accessibility   | Acceptability   | Quality  |
|           | - Adoption of a decentralized action programme<br>- Participatory workshops including service providers and users  | Development of emergency obstetric care in districts where it was previously not available | - Provision of emergency obstetric care ambulances<br>- Establishment of emergency delivery funds<br>- Awareness-building campaigns | - Gender- and equity-sensitive  | - Weekly "continuing medical education"<br>- Clear clinical protocols and standards<br>- Competency-based training<br>- Training sites created |
|           | Equality and non-discrimination  |  | - Targeted involvement of women from marginalized communities<br>- Gender- and equity-sensitive                                     |   |  |
|           | Accountability   |  | - Regular monitoring and evaluation with disaggregated measures   |   |  |
|           |  |  |   |   |  |
| Outcomes  | Duty bearers   |  |   | Rights holders  |  |
|           | <ul style="list-style-type: none"> <li>- Four Comprehensive and four Basic Emergency Obstetric Care Centres established</li> <li>- Met need for emergency obstetric care increased from 2.6% to 15.38%</li> <li>- Proportion of institutional deliveries increased from 3.8% to 8.3%; met need for delivery services increased from 1.9% to 16.9%</li> <li>- Deaths in childbirth decreased from 2.7% to 0.3%</li> <li>- Government support for scale-up of emergency obstetric care – with prioritization of emergency obstetric care in 15-year National Safe Motherhood Programme – Long Term Plan</li> </ul> |  |   | <ul style="list-style-type: none"> <li>- Community participation in twice yearly planning meetings</li> <li>- Collaboration between high and low caste women</li> </ul> |  |

\* The Women's Right to Life and Health (Emergency Obstetric Care) Programme does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.

Table A2.2.

Elements of a human rights-based approach in the Support to Safe Motherhood; Equity and Access Programme\*

| Goals  | <ul style="list-style-type: none"> <li>- Improve maternal and neonatal health among the poor and excluded</li> <li>- Empower women and build local capacity</li> <li>- Work with health providers and administrators to link duty bearers and rights holders</li> </ul>  |              |  |   |  |
|--|--|--------------|--|---|--|
| Processes  | Participation  | Availability | Accessibility  | Acceptability   | Quality  |
|  | <ul style="list-style-type: none"> <li>- Participatory design</li> <li>- Strengthening of village development committees</li> <li>- Women-led, issue-based reflection, action and representation</li> </ul>  |              | <ul style="list-style-type: none"> <li>- Development of community transport and emergency fund</li> <li>- Mass communication methods employed</li> </ul>   | <ul style="list-style-type: none"> <li>- Gender-sensitive</li> <li>- Mass communication programme locally adapted to increase efficacy and acceptability</li> </ul> | <ul style="list-style-type: none"> <li>- Orientation and training of female community health volunteers</li> </ul> |
|  | Equality and non-discrimination  |              |  |   |  |
|  | <ul style="list-style-type: none"> <li>- Targeting of poor and excluded</li> </ul>   |              |  |   |  |
|  | Accountability   |              |  |   |  |
| <ul style="list-style-type: none"> <li>- Use of women's testimonies</li> <li>- Disaggregated data collection</li> <li>- Extensive monitoring and evaluation</li> <li>- Transparency</li> </ul> |  |              |  |   |  |
| Outcomes   | Duty bearers   |              | Rights holders   |   |  |
|  | <ul style="list-style-type: none"> <li>- Skilled birth attendance increased from 19% to 41%—synergy with Safe Delivery Incentives Programme and skilled birth attendance training</li> <li>- Department of Health Services now expanding this scheme to 10 more districts</li> <li>- Linkages between civil society partners and Government of Nepal Equity and Access Advisory Group to effect change</li> <li>- Proportion of pregnant women having 4 or more antenatal care visits increased from 45% to 60% with decreased equity gap</li> <li>- 40% of pregnant women delivered in facility (21% increase from baseline and more than twice national rate in 2008-09)</li> <li>- Proportion of pregnant women taking iron tablets for more than 90 days increased from 12.3% to 65.5%, including five-fold increase in marginalized groups</li> <li>- Radio mass communication programme evaluated as “highly popular” among population</li> <li>- 40% of village development committees and 50% of district development committees included maternal and neonatal health in their plans</li> <li>- 29% increase in demand for delivery services per year for the first 2 years of the programme</li> </ul> |              | <ul style="list-style-type: none"> <li>- 95% of community groups had emergency funds with 70% utilization by poor and excluded</li> <li>- 48% of groups had emergency transport schemes with 76% utilization by poor and excluded</li> <li>- Knowledge of warning signs in pregnancy improved most in relatively marginalized groups</li> <li>- 85% of respondents and 80% of mothers-in-law believed delivery should happen in a facility</li> <li>- For the period January to June 2008, 60% of village development committees contributed to emergency funds managed by community groups</li> </ul> |   |  |

\* The Support to Safe Motherhood; Equity and Access Programme does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.

Table A2.3.

Elements of a human rights-based approach in Aama Surakshya Karyakram (Free Delivery Programme)\*

|                  |  |                           |   |   |  |
|------------------|--|---------------------------|---|---|--|
| <b>Goals</b>     | <ul style="list-style-type: none"> <li>- Improve maternal health and reduce maternal mortality</li> <li>- Increase women's access to safe delivery services</li> <li>- Ensure availability of skilled delivery services</li> </ul>   |                           |   |   |  |
|                  | <b>Participation</b>   | <b>Availability</b>       | <b>Accessibility</b>  | <b>Acceptability</b>  | <b>Quality</b>   |
| <b>Processes</b> | Participation by the community through "people's fora"   | Universal national scheme | <ul style="list-style-type: none"> <li>- Amelioration of two significant causes of out-of-pocket expenses:               <ol style="list-style-type: none"> <li>1. transport</li> <li>2. delivery costs</li> </ol> </li> <li>- Increased mass communication methods compared with Safe Delivery Incentive Programme</li> </ul>  | <ul style="list-style-type: none"> <li>- Gender-sensitive.</li> <li>- Incorporates Gender Equality and Social Inclusion Strategy</li> </ul> | Clearly specified and required criteria for birthing rooms |
|                  | <b>Equality and non-discrimination</b>   |                           |   |   |  |
|                  | <ul style="list-style-type: none"> <li>- Higher conditional cash transfer to women from poorer districts</li> </ul>  |                           |   |   |  |
|                  | <b>Accountability</b>  |                           |   |   |  |
| <b>Outcomes</b>  | <b>Duty bearers</b>  |                           | <b>Rights holders</b>   |   |  |
|                  | <ul style="list-style-type: none"> <li>- 80% of transport payments made to mothers immediately following delivery</li> <li>- Generally positive feedback on quality of care from exit questionnaires</li> <li>- 19% overall increase in institutional deliveries in first 18 months</li> <li>- Broad-ranging agreement on appropriateness and value of programme</li> <li>- Identification of 34% false claim rate for free delivery through monitoring systems</li> </ul> |                           | <ul style="list-style-type: none"> <li>- 94% awareness of free delivery service and 100% awareness of availability of cash transfers</li> <li>- 49% of mothers made aware of entitlements through health providers</li> <li>- Excluded groups most likely to change from home to institutional delivery</li> <li>- "Majority of respondents said that there is good participation of stakeholders at central level, while at district and below participation was not encouraging"</li> <li>- 40% of women incur some expense in hospitals</li> </ul> |   |  |

\* The Aama Surakshya Karyakram (Free Delivery Programme) does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.



Table A2.4.

Elements of a human rights-based approach in Nepal's National Safe Abortion Programme\*

|           |  |  |  |   |  |
|-----------|--|--|--|---|--|
| Goals     | <ul style="list-style-type: none"> <li>- Realize women's health rights</li> <li>- Reduce maternal mortality and morbidity</li> <li>- Ensure universal access to comprehensive abortion care</li> </ul>   |  |  |   |  |
|           | <b>Participation</b>   | <b>Availability</b>                                      | <b>Accessibility</b>   | <b>Acceptability</b>  | <b>Quality</b>   |
| Processes | Partnership between Government of Nepal and multiple stakeholders, including NGOs and private sector   | Progressive increase in availability of medical abortion | <ul style="list-style-type: none"> <li>- Information and mass communication campaigns</li> <li>- Training of providers in all districts</li> </ul> | <ul style="list-style-type: none"> <li>- Gender-sensitive.</li> <li>- Behaviour change communication to modify husbands' attitudes to abortion</li> </ul> | <ul style="list-style-type: none"> <li>- Clear curriculum and training</li> <li>- Validated treatment protocols</li> <li>- Accreditation of service providers</li> </ul> |
|           | <b>Equality and non-discrimination</b>   |  |  |   |  |
|           | <ul style="list-style-type: none"> <li>- Universal scheme</li> </ul>   |  |  |   |  |
|           | <b>Accountability</b>  |  |  |   |  |
| Outcomes  | <b>Duty bearers</b> <ul style="list-style-type: none"> <li>- Over 240 providers of comprehensive abortion care in all districts by 2011-95 305 surgical abortions performed by recognized providers in 2011</li> <li>- Increasing availability of medical abortion through female community health volunteers</li> <li>- Medical abortions found to be "widely acceptable by peripheral health facility staff, Female Community Health Volunteers and medical abortion clients"</li> <li>- 2% post-abortion complication rate, in line with comparable country complication rates</li> </ul> |  |  | <b>Rights holders</b> <ul style="list-style-type: none"> <li>- Increasing awareness of abortion law</li> </ul>  |  |

\* The National Safe Abortion Programme does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.

Table A2.5.

Elements of a human rights-based approach in the 'Bal Bachau' Child Survival Project\*

| Goal         | Reduce child and maternal mortality through empowerment and targeted interventions to achieve behavioural change, improve quality, build capacity and increase access  |   |   |                  |  |  |
|--------------|--|---|---|------------------|--|--|
| Processes    | Participation  | Availability  | Accessibility   | Acceptability    | Quality  |  |
|              | <ul style="list-style-type: none"> <li>- Strengthening of village development committees</li> <li>- Enhanced participation for malaria control through schools and community-based methods</li> <li>- Creation of mothers' groups for community mobilization</li> <li>- Creation of child clubs to promote sanitation and health awareness</li> </ul>  | <ul style="list-style-type: none"> <li>- Work with Health Facility Management Committees and drug dispensaries to ensure availability of medications</li> <li>- Increased household-based toilet installation</li> <li>- Attention to immunization supply-side problems.</li> <li>- Creation of malaria laboratory-testing facilities</li> </ul>  | Collaborative interventions to make medicines and information regarding costs more accessible | Gender-sensitive | <ul style="list-style-type: none"> <li>- Capacity-building and knowledge and skills development with female community health volunteers</li> <li>- Training of female community health volunteers</li> </ul> |  |
|              | Equality and non-discrimination  |   |   |                  |  | <ul style="list-style-type: none"> <li>- Medicines freely available to most marginalized community members</li> <li>- Focus of community mobilization on marginalized communities</li> <li>- Creation of "Dabi" pressure groups to implement rights-based focus on marginalized communities</li> </ul> |
|              | Accountability   |   |   |                  |  | Support given to Health Facility Management Committees and interventions to create linkages between local government and health providers  |
| Duty bearers | Rights holders   |   |   |                  |  |  |
| Outcomes     | <ul style="list-style-type: none"> <li>- Improvement in availability of micronutrients, oral rehydration salts solution and antibiotics from female community health volunteers</li> <li>- More than 90% awareness of pneumonia diagnosis methods among female community health volunteers at end of intervention</li> <li>- All "treatment" female community health volunteers had first-line antibiotics and respiratory rate counters for pneumonia management</li> <li>- Correct diagnosis of pneumonia at health facilities increased to 88% (from 34% in one district and 70% in remaining districts)</li> <li>- Uptake of iron and folic acid supplementation by women increased from 26% and 6% to 85% and 60% respectively in project areas</li> <li>- Over 18 000 people used malaria microscopic services</li> <li>- National scale-up of Community-Based Integrated Management of Childhood Illness</li> </ul> | <ul style="list-style-type: none"> <li>- Proportion of mothers seeking trained care for children with pneumonia symptoms increased from 38% to 85%</li> <li>- Collaboration with Health Management Committees resulted in reduced cost of medicines for all and free medication for most marginalized groups</li> <li>- Clear price list for drugs available at all health facilities</li> <li>- Improved nutrition and feeding practices for unwell children; use of oral rehydration salts solution during diarrhoeal illness increased from 34% and 36% in project areas to over 80%</li> <li>- Percentage of households with an individual toilet increased from 36% to 47% in project district, with over 90% utilisation of toilet by household members</li> <li>- Rate of exclusive breastfeeding for 6 months increased from 50% to 88% in one district; no impact on prolonged breastfeeding practices (6–23 months) which remained over 90%</li> <li>- Increased awareness and uptake of existing pregnancy services</li> <li>- Over 50% of project participants were from marginalized groups</li> </ul> |   |                  |  |  |

\* The 'Bal Bachau' Child Survival Project does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.

## Brazil

## Annex 3

Table A3.1.

Human rights-based elements of Brazil's Programme for Comprehensive Assistance to Women's Health (PAISM)\*

| Goal: Implement family planning methods and improve maternal health coverage and quality   |  |   |  |  |
|--|--|---|--|--|
| Participation  | Availability   | Accessibility   | Acceptability  | Quality  |
| <ul style="list-style-type: none"> <li>- PAISM was created with the active participation of the women's movement</li> <li>- MMCs use participatory methods to collect and analyse data and information</li> <li>- Municipal and state health councils, composed of medical staff, beneficiaries, government and civil society representatives, meet regularly to evaluate health strategies</li> </ul> | <ul style="list-style-type: none"> <li>- Guarantees the availability of modern contraceptive medication and techniques through the public health system</li> <li>- Emergency contraceptives made available</li> <li>- Increased coverage of maternal health services through the establishment of reference centres</li> </ul> | <ul style="list-style-type: none"> <li>- Family planning and maternal health information and services provided through the universal public health system</li> <li>- Outreach and educational interventions on family planning conducted to inform the community</li> </ul> | <ul style="list-style-type: none"> <li>- Establishment of "Natural Birth Centres" to provide a more conducive environment for women</li> </ul> | <ul style="list-style-type: none"> <li>- Improved quality of maternal health care through standardized hospital procedures</li> <li>- General training for health professionals in maternal care</li> <li>- Specialized training for health professionals dealing with women victims of sexual violence</li> <li>- Specialized facilities for high-risk pregnancies</li> </ul> |
| Equality and non-discrimination  |  |   |  |  |
| Aims to create the opportunity for all segments of the population to access family planning and maternal health services   |  |   |  |  |
| Accountability   |  |   |  |  |
| <ul style="list-style-type: none"> <li>- MMCs monitor maternal deaths</li> <li>- Federal Government monitors the allocation of resources by states and municipalities to improve maternal health care</li> <li>- Development of targets to reduce the number of caesarean sections</li> <li>- Municipal and state health councils monitor the implementation of health programmes</li> </ul>           |  |   |  |  |

\* The Programme for Comprehensive Assistance to Women's Health (PAISM) does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.

Table A3.2.

Human rights-based elements of Brazil's Programme on Humanized Assistance to Pregnancy and Childbirth (PHPN)\*

| Goal: Improve the quality of maternal health care   |  |   |   |  |
|---|--|---|---|--|
| Participation   | Availability   | Accessibility   | Acceptability   | Quality  |
| - Municipal and state health councils, composed of medical staff, beneficiaries, government and civil society representatives, meet regularly to evaluate all health strategies | - Ensures that all public hospitals have the capacity to provide adequate maternal care  | - Maternal health services provided through the universal public health system, accessible to all | - Implementation of "humanized" care to integrate psychosocial and emotional support for individualized attention to pregnant women | - Quality of maternal health improved by linking antenatal care to delivery and postnatal care |
| Equality and non-discrimination   | - Ensures that all women are guaranteed admittance to a predetermined hospital in which they will be assisted through delivery | - Financial incentives offered to women who register for PHPN assistance                          | - Establishment of the "right to a companion" during delivery   | - Improved technical training in the area of high-risk pregnancies                             |
| - Aims to create the opportunity for all segments of the population to access all levels of maternal health services  |  |   |   |  |
| - Priority given to poorest regions of the country  |  |   |   |  |
| Accountability  |  |   |   |  |
| - Establishment of improved monitoring system (SISPRENATAL)   |  |   |   |  |
| - Municipal and state health councils monitor implementation of health programmes   |  |   |   |  |

\* The Programme on Humanized Assistance to Pregnancy and Childbirth does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.

Table A3.3.

Human rights-based elements of Brazil's National Policy for Comprehensive Assistance to Women's Health (PNAISM)\*

| Goal: Consolidate advances in family planning and reduce maternal mortality.  |   |  |   |   |
|---|---|--|---|---|
| Participation   | Availability  | Accessibility  | Acceptability   | Quality   |
| <ul style="list-style-type: none"> <li>- Created with active participation of the women's movement and other segments of civil society</li> <li>- Aims to ensure the full participation of women in decisions concerning their health</li> <li>- Aims to encourage the participation of health councils in monitoring maternal mortality reduction goals</li> <li>- Municipal and state health councils composed of medical staff, patients, government and civil society representatives meet regularly to evaluate all health strategies</li> </ul> | <ul style="list-style-type: none"> <li>- Ensures the availability of modern contraceptives through the public health system</li> <li>- Increased coverage of maternal health services in hospitals and through the PSF</li> </ul> | <ul style="list-style-type: none"> <li>- Family planning and maternal health services provided through the universal public health system</li> <li>- Ensures women have access to information on family planning</li> <li>- Disseminates publications and informative materials</li> <li>- Outreach sessions on PNAISM and its pact</li> </ul> | <ul style="list-style-type: none"> <li>- Considers the need to adapt strategies for indigenous and black women</li> <li>- Reaffirms the concept of "humanized" care for pregnancy and childbirth</li> </ul> | <ul style="list-style-type: none"> <li>- Improved gynaecological services in the public health system</li> <li>- Improved detection and treatment of HIV/AIDS and other STDs</li> <li>- Training for health professionals in maternal care</li> </ul> |
| Equality and non-discrimination   |   |  |   |   |
| <ul style="list-style-type: none"> <li>- Considers the needs of women living in rural areas, women with disabilities, black women, indigenous women, women in prisons and women of different sexual orientation.</li> <li>- Focus on the poorest and most underserved municipalities</li> <li>- Aims to include gender, race and ethnicity considerations in all strategies and measures and to consider social inequalities in decision-making processes</li> </ul>  |   |  |   |   |
| Accountability  |   |  |   |   |
| <ul style="list-style-type: none"> <li>- Development of a national pact with targets for the reduction of maternal mortality</li> <li>- Creates a commission to monitor reduction targets</li> <li>- Endeavours to strengthen the MMCs</li> <li>- Municipal and state health councils monitor implementation of health programmes</li> </ul>  |   |  |   |   |

\* Brazil's National Policy for Comprehensive Assistance to Women's Health (PNAISM) does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.

Table A3.4.

Human rights-based elements of Brazil's National Sexual and Reproductive Rights Policy (PNDSR)\*

| Goal: Improve services and offers in the area of sexual and reproductive rights   |   |  |  |  |
|---|---|--|--|--|
| Participation   | Availability  | Accessibility  | Acceptability  | Quality  |
| - Municipal and state health councils, composed of medical staff, beneficiaries, government and civil society representatives, meet regularly to evaluate all health strategies | - Increases the offer of modern contraceptives through the public health system   | - Family planning and services provided through the universal public health system | - Takes into consideration the sexual and reproductive rights of persons with disabilities | - Improved detection and treatment of STDs                                       |
| Equality and non-discrimination   |   |  |  |  |
| - Focus on children and adolescents   | - Includes vasectomy in the public health system                                  | - Ensures women and young people have access to information on family planning     |  | - Training for health professionals in disseminating family planning information |
| - Special attention to men and women in prisons   |   |  |  |  |
| Accountability  |   |  |  |  |
| - Municipal and state health councils monitor implementation of health programmes   | - Provides services for "assisted human reproduction" in the public health system | - Disseminates publications and informative materials                              |  |  |
|   |   | - Takes sexual and reproductive rights education to schools                        |  |  |

\* Brazil's National Sexual and Reproductive Rights Policy does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.

## Malawi

## Annex 4

Table A4.1.

Human rights-based elements of Malawi's IMCI approach to child survival and development interventions\*

| Goal: Reduce childhood morbidity and mortality, and enhance child development |  |  |  |   |   |
|---|--|--|--|---|---|
|   | Participation  | Availability   | Accessibility  | Acceptability   | Quality   |
| Processes   | <ul style="list-style-type: none"> <li>- Promotes partnership between health providers and families, with support from communities</li> <li>- Engages families and communities in discussion about child health and helps them to assess, analyse and take action on the problems affecting them and their children</li> <li>- Promotes use of participatory methods in the collection, analysis and interpretation of data and information</li> </ul> | <ul style="list-style-type: none"> <li>- The objectives include adequate availability of essential drugs, commodities and supplies at all levels of health care delivery system at all times</li> <li>- Strengthening community-based drug supply and management system</li> </ul> | <ul style="list-style-type: none"> <li>- Aims to reach universal access for high-impact interventions for women and children in communities</li> <li>- Aims to ensure effective links between community services and district health facilities</li> <li>- Provides free, 24-hour, integrated health services for children</li> <li>- HSAs organize outreach campaigns</li> <li>- 4000 HSAs working in hard-to-reach areas</li> <li>- Media campaigns</li> </ul> | <ul style="list-style-type: none"> <li>- Interventions family-oriented</li> <li>- Community dialogue tool and care group model are designed to be sensitive to cultural issues</li> </ul> | <ul style="list-style-type: none"> <li>- Interventions chosen in accordance with the evidence-based <i>Lancet</i> series on interventions for reducing under-five mortality, adapted to the health context of Malawi</li> <li>- Stresses the importance of training community health workers to deliver quality care</li> <li>- Clear protocols and standards for HSAs</li> </ul> |
|   | <b>Equality and non-discrimination</b>   |  |  |   |   |
|   | <ul style="list-style-type: none"> <li>- Focus on areas and populations that are underserved</li> <li>- Care provided by HSAs to anyone, at any time</li> <li>- Child-sensitive</li> </ul>   |  |  |   |   |
|   | <b>Accountability</b>  |  |  |   |   |
|   | <ul style="list-style-type: none"> <li>- Child survival and development indicators and targets set</li> <li>- Work of HSAs monitored by village health committees</li> <li>- Monthly meetings at community level to monitor progress</li> </ul>  |  |  |   |   |

\* Malawi's IMCI Approach to child survival and development interventions does not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.

## Annex 5

## Italy

Table A5.1.

Human rights-based elements of Italy's screening programmes\*

| Goal: reduce the mortality rate from cancer, diagnose the disease at an earlier stage and provide effective treatment to eligible subjects                      |   |  |   |   |
|---|---|--|---|---|
| Participation   | Availability  | Accessibility  | Acceptability   | Quality   |
| - Reforms of 1992-93 increase regionalization in order to move control closer to communities  | Screening programmes are included in the essential levels of care that should be provided by the NHS and uniformly delivered throughout the country | Guarantees access to preventive tests, e.g. mammography and Pap test | Screening programmes must provide adequate information to the target population on the possible benefits and individual risks | - Different professionals work together to reduce and overcome any discrepancies within the screening programmes<br><br>- Data collection plays an essential role, providing information for needed actions and improvement |
| <b>Equality and non-discrimination</b>  |   |  |   |   |
| - Aims to achieve full national coverage<br>- Programmes are free of charge for target population   |   |  |   |   |
| <b>Accountability</b>   |   |  |   |   |
| - The National Centre for Screening Monitoring collects data in a standardized format, enabling computation of national statistics and comparison of programmes |   |  |   |   |

\* Italy's screening programmes do not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention.



Table A5.2.

Human rights-based elements of Italy's vaccination programmes\*

| Goal: to eliminate or reduce the incidence of infectious diseases nationwide   |   |   |  |  |
|--|---|---|--|--|
| Participation  | Availability  | Accessibility   | Acceptability  | Quality  |
| <ul style="list-style-type: none"> <li>- Collaboration of the Ministry of Health, the National Institute of Health (Istituto Superiore di Sanità, ISS), regions, local health authorities, paediatricians, scientific societies, experts</li> <li>- With some limitations, parents choose which community-based paediatrician will care for their child</li> </ul> | <ul style="list-style-type: none"> <li>- Vaccinations available throughout the country</li> </ul> | <ul style="list-style-type: none"> <li>- Vaccinations are provided free of charge to all</li> </ul> | <ul style="list-style-type: none"> <li>- Community-based paediatricians subject to high standards of medical ethics</li> </ul> | <ul style="list-style-type: none"> <li>- Community-based paediatricians are the first point of contact for children</li> </ul> |
| Equality and non-discrimination  |   |   |  |  |
| <ul style="list-style-type: none"> <li>- Universal immunization</li> <li>- Programmes are free of charge for target population</li> <li>- National Vaccination Plan (2012) sets targets for vulnerable groups</li> </ul>   |   |   |  |  |
| Accountability   |   |   |  |  |
| <ul style="list-style-type: none"> <li>- A national surveillance system of infectious diseases (SIMI) has been developed to improve the quality and timeliness of notification</li> </ul>  |   |   |  |  |

\* Italy's vaccinations programmes do not have all the elements of a human rights-based approach, and this table does not necessarily capture all the elements of a human rights-based approach that might be evident from a more detailed analysis. Rather, the table illustrates some of the elements of a human rights-based approach in this intervention

## Annex 6

# Supplementary information on the literature review (Chapter 3)

### A6.1. Review methodology

The first phase of the review involved mapping the extent and nature of published research. The findings from this mapping exercise were used to refine the questions for the second phase, which was a detailed review of relevant literature to systematically address the review questions (see Chapter 3).

#### Phase 1

Seven online databases were searched for research published between 2000 and 2012 in English, French, Portuguese, or Spanish (see Box A6.1). Grey literature was excluded because of time constraints.

After duplicate and obviously irrelevant records had been removed, a total of 5842 records were screened for inclusion. Records were screened on the basis of title and abstract using the inclusion criteria listed in Box A6.2.

On this basis, 247 records were included in an initial mapping exercise. This involved extracting bibliographic details (title, author, year of publication, source) and information from the abstract on geographical location, language, population target group, forms of participation, setting for participation, outcomes measured, overall impact and whether the publication reported on process or experiences of participation. Records were kept of which publications made explicit or implicit mention of human rights or HRBA principles.

#### Phase 2. Orienting the review to focus on human rights

The findings from the mapping exercise were used to refine the focus and examine the feasibility of addressing specific questions. Records were sampled to include those that made reference to human rights or recognized elements of a human rights-based approach (see Box A6.3).

On this basis, 23 records were identified for inclusion in phase 2, which involved detailed analysis of the publications. See Figure A6.1 for an overview of the entire review process and Table A6.2 for a summary of the 23 publications analysed.

#### Box A6.1.

Searches were conducted, combining the concepts:

- participation or empowerment,
- sexual or reproductive or maternal,
- community or primary combined with services/care,
- outcome or evaluation or assessment.

#### Box A6.2.

##### Inclusion criteria

- Participation of women aged 15 years or over in the design, implementation, management or evaluation of sexual, reproductive or maternal health services in a community or primary service context, or empowerment.
- Any outcomes reported (including children's outcomes).
- Evaluative research or reviews of such research.

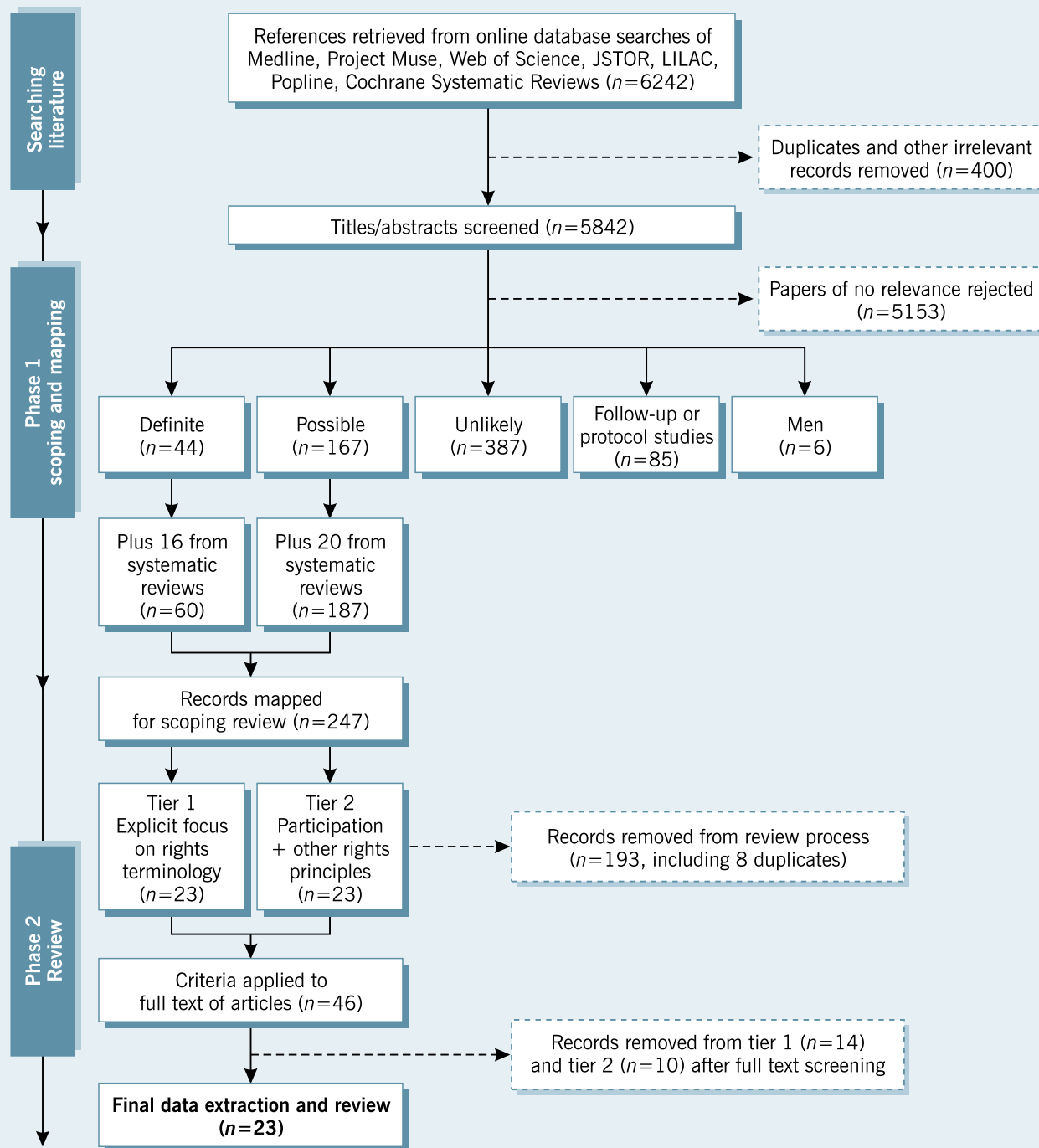
#### Box A6.3.

##### Criteria used to orient the review to focus on human rights

- An explicit mention of human rights terminology, e.g. human rights, reproductive or women's rights (tier 1).
- Reference to HRBA principles (i.e. availability, accessibility, acceptability and quality of services; equality/non-discrimination; empowerment; accountability; attention to legal/policy environments) in the title or abstract, even if these were not framed from a human rights perspective (tier 2).

Figure A6.1.

Overview of review process

**Data appraisal to systematically address review questions**

Concepts and trends emerging from the data were synthesized using broad categories, such as geographical location of study, nature of participation, barriers and facilitators for successful outcomes reported, and attention to human rights and HRBA principles.

Studies were not excluded using a hierarchical approach to the level of evidence, as the need for many different types of evidence to answer the diverse review questions was acknowledged. This resulted in the inclusion of a broad range of study designs, such as systematic reviews of RCTs and quasi-experimental trials, pre/post study design, case studies, qualitative studies, mixed method programme evaluations and national policy reviews.

Conversely, the appropriateness of study design, methods and analysis to their stated objectives was assessed and attention was given to ensuring that each study's evidence base adequately supported its stated conclusions. This was done by applying a checklist previously used by Dixon-Woods (1). No studies were excluded on this basis.

### A6.2. Comparison of findings in the mapping and the full review

#### Geographical distribution of studies

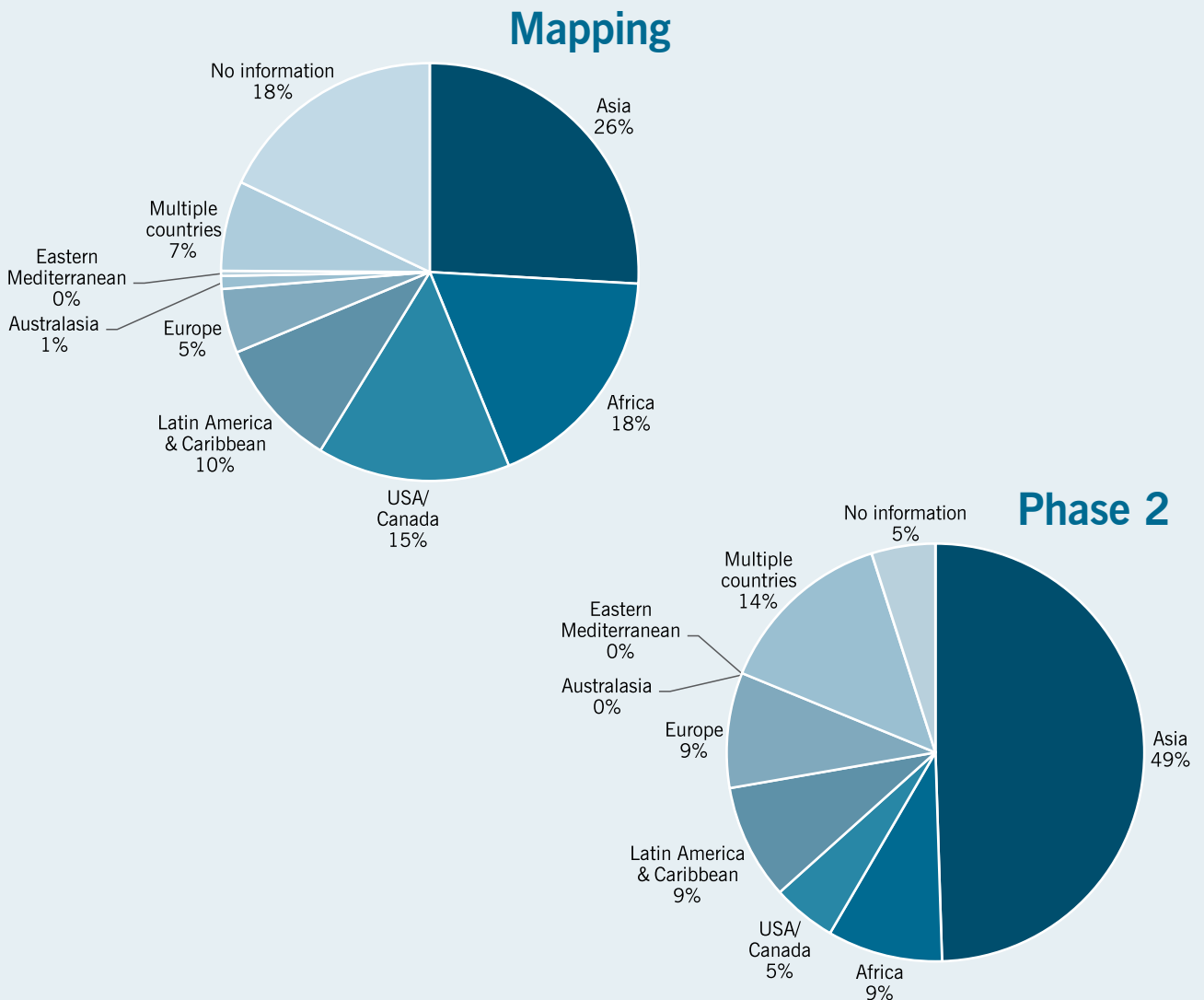
The geographical distribution of the studies included in each stage of the review is shown in Figure A6.2.

Studies in Asia comprised only 26% of the studies included in the mapping exercise but 50% of those in phase 2. A far smaller percentage of studies in Africa and USA/Canada were included in phase 2 than in the mapping exercise.

These findings suggest that a high proportion of the studies identified that were carried out in Asia made reference to human rights or HRBA principles, while a low proportion of those carried out in Africa, USA or Canada mentioned these issues.

Figure A6.2.

Geographical distribution of studies – mapping and phase 2



### ***Type of participation***

In the mapping exercise, lay or peer education/interaction and community health workers/volunteers were the primary forms of participation identified; these forms of participation were far less predominant in phase 2. Instead, women's groups, general community mobilization, and social movements featured more prominently, suggesting that these are the forms of participation most likely to be employed where human rights or HRBA principles are considered.

In phase 2, there were no studies that looked at partnerships between communities and service providers, participatory research, individual empowerment, cash transfers or participatory learning approaches.

Table A6.1 shows the primary forms of participation described in the studies included in each phase of the review. Where there were several forms of participation, and it was impossible to distinguish one primary form, type of participation is given as "multiple". However, where a primary form of participation was discernible, even if other forms were also present, the primary form is listed.

**Table A6.1.**

Primary form of participation described in the studies included in the mapping and review phases

| Type of participation   | Mapping        |    | Phase 2        |    |
|---|----------------|----|----------------|----|
|   | Number         | %  | Number         | %  |
| Lay or peer education/interaction                             | 41             | 17 | 1              | 4  |
| Community health workers/volunteers                           | 40             | 16 | 2              | 9  |
| Partnership between community and service provider            | 23             | 9  | 0              | 0  |
| General (community actions/mobilization)                      | 21             | 9  | 5              | 22 |
| Women's groups  | 20             | 8  | 7              | 30 |
| Unclear   | 16             | 6  | 0              | 0  |
| Participatory research  | 14             | 6  | 0              | 0  |
| Traditional birth attendant                                   | 13             | 5  | 1              | 4  |
| No information  | 12             | 5  | 0              | 0  |
| Social movements  | 10             | 4  | 3              | 13 |
| Not explicitly about participation but has human rights focus | 9              | 4  | 0              | 0  |
| Community leaders   | 8              | 3  | 1              | 4  |
| Support for individual empowerment                            | 5              | 2  | 0              | 0  |
| Cash transfer   | 4              | 2  | 0              | 0  |
| Participatory learning approaches                             | 4              | 2  | 0              | 0  |
| Village health committees                                     | 2              | 1  | 2              | 9  |
| Multiple  | 5 <sup>a</sup> | 2  | 1 <sup>b</sup> | 4  |
| <b>Total</b>  | <b>247</b>     |    | <b>23</b>      |    |

a These studies referred explicitly to different forms of participation: traditional birth attendants and community health workers (one study); community health workers/volunteers, traditional birth attendants and community health committees (one study); village health committees and community health workers (one study); and traditional birth attendants, drug-shop vendors, community reproductive health workers and adolescent peer mobilizers (two studies).

b This study referred explicitly to both traditional birth attendants and community health workers.

### Types of outcome

In the mapping exercise, the most frequently reported outcomes were: quality/coverage/access to care ( $n=32$ ; 13%); uptake of services ( $n=28$ ; 11%); neonatal mortality rate ( $n=17$ ; 7%); community participation/mobilization ( $n=16$ ; 6%); and women's/household's knowledge/awareness/skills ( $n=16$ ; 6%).

In phase 2, the most commonly reported outcomes were: uptake of services ( $n=8$ ; 35%); empowerment ( $n=8$ ; 35%); social capital/community engagement ( $n=8$ ; 35%); neonatal mortality rate ( $n=6$ ; 26%); and legal and policy outcomes ( $n=4$ ; 17%). Phase 2 studies included much less attention to child health outcomes (e.g. infant feeding, immunization) than those in the initial mapping.

The shift in predominant outcomes reported can be partially explained by the different primary forms of participation in each phase. For example, a high proportion of interventions involving lay or peer roles reported on quality/coverage of care, while many of the studies that used interventions with women's groups reported on uptake of services and neonatal mortality rates as outcomes.

**Table A6.2.**

Details of publications analysed in phase 2

| Author, location   | Study   | Population focus   | Nature of participation   |
|--|---|--|---|
| Bleijenbergh (2)<br>Europe                                 | Qualitative comparative analysis, comparing conditions for policy change in six country case studies  | Population level with particular focus on gender equality  | Influence of feminist pressure and European Union policies on national policy changes         |
| Cooper (3)<br>South Africa                                 | Review of policy to document changes in health policy, legislation and delivery of services in South Africa between 1994 and 2004   | Population level with particular focus on women's health status  | Role of civil society and activist groups in influencing legislative and policy change        |
| Corrêa (4)<br>Brazil                                       | Paper excerpted from a report to MacArthur Foundation. Qualitative interviews with key stakeholders and documentary analysis to examine progress in population and reproductive health in Brazil between 1990 and 2002                  | Population level with particular focus on women's health status  | Role of civil society and health activist groups in influencing legislative and policy change |
| Darmstadt (5)<br>International<br>(mainly Asia and Africa) | Systematic review (review evidence, RCTs, quasi-experimental, observational and other intervention studies) with meta analysis to evaluate interventions to reduce intrapartum-related deaths   | Rural and resource-poor communities with poor access to health-facility-based care                             | Lay roles including TBAs and CHWs   |
| Foundation for Research in Health Systems (6)<br>India     | Pre/post study design with cross-sectional survey at baseline and at follow-up in study area (1057 women) and comparison area (1048 women) to assess impact of community involvement on reproductive health                             | Women of reproductive age  | Formation of 64 health committees in all rural sub-health centres in study area               |
| George (7)<br>Not stated                                   | Narrative review drawing on case examples of participation in context of accountability mechanisms for reproductive health care   | Not stated   | Participatory and accountability mechanisms in health care settings with communities          |
| Gogia (8)<br>All studies in settings in south Asia         | Systematic review comparing intervention packages with meta-analysis to examine role of home visits by CHWs in preventing neonatal deaths. Five studies, all trials comparing groups that received different experimental interventions | Pregnant women and new mothers in settings with high neonatal mortality and low access to health-facility care | CHWs  |

| Author, location  | Study   | Population focus  | Nature of participation  |
|---|---|---|--|
| Halabi (9)<br>Indonesia   | Presents synopsis of the experience of decentralization of health services and the right to health in Indonesia   | Population focus  | Explores tensions between interpretations of participation as a right and role of participation in pre- and post-decentralization eras   |
| Ilika (10)<br>South east<br>Nigeria                                   | Qualitative study (interviews with 30 officers of organization, 25 widows and 10 women elders) to evaluate the role of Christian women's organizations in eliminating dehumanizing widowhood practice                       | Women at risk of dehumanizing widowhood practice  | Role of women's organizations in community mobilization initiative   |
| Jahan (11)<br>Bangladesh  | Review of published/unpublished documentation and personal interviews to trace the changing fortunes of health sector reforms and reform advocates from 1995 to 2002 and analysis of the major challenges and strategies    | Population level  | Participation mainly by civil society and international development agencies in national policy processes in relation to gender equality   |
| Lee (12)<br>International<br>(primarily<br>settings in south<br>Asia) | Systematic review of evidence (review evidence, RCTs, quasi-experimental, observational or other intervention studies) with meta-analysis of efforts to link mothers with skilled care during pregnancy, labour, and birth  | Rural and resource-poor communities with low access to health-facility-based care                     | Community mobilization strategies defined in terms of individual behaviour change (e.g. peer education), increased collective knowledge (e.g. women's groups) and broader community action |
| Malhotra (13)<br>Nepal  | Quasi-experimental case-control mixed methods design. Cross-sectional household and adolescent surveys at baseline and endpoint and qualitative element to assess access to youth reproductive health services and outcomes | Adolescents (aged 14–21) experiencing socioeconomic disadvantages                                     | Advisory and coordination teams and consultative committees. Community-level implementation committees   |
| Manandhar (14)<br>Rural Nepal   | Cluster RCT of women's groups to improve maternal and newborn outcomes. Intervention area=14 884 households; control =14 047 households. Birth outcomes monitored in a cohort of 28 931 women                               | Married women of reproductive age living in resource-poor rural district                              | Formation of 111 women's groups in 12 intervention clusters facilitated by local women   |
| Marsiglia (15)<br>USA   | Randomized control-group study design in one health clinic to evaluate effect of empowerment intervention in increasing rates of postpartum visits. Intervention=221; normal care=219                                       | Pregnant Latina/Hispanic women over 18 years  | One-to-one support through "cultural broker" to empower women to take active part in own care and advocate for themselves  |
| Morrison (16)<br>Rural Nepal  | Process study with qualitative design to examine participatory processes of the intervention component of a cluster randomized trial of women's groups (Manandhar, 2005)  | Married women of reproductive age living in resource-poor rural district                              | Formation of 111 women's groups in 12 intervention clusters facilitated by local women   |
| Murthy (17)<br>Asia   | Desk-based review of 18 World Bank-funded projects (e.g. analysis of staff/project appraisal documents) to examine how far participation strengthened accountability in context of World Bank health sector reforms         | Communities (concept and definition varied across projects, and included clients, residents and NGOs) | Main strategies were decentralization, community financing, hospital boards, community health structures and health sector regulation  |
| Rath (18)<br>Rural India  | Process evaluation accompanying cluster RCT of women's groups to improve maternal and newborn outcomes covering an estimated population of 114 141  | Rural and resource-poor communities   | 244 women's groups in 18 intervention clusters   |

| Author, location                                  | Study  | Population focus   | Nature of participation   |
|---|--|--|---|
| Rosato (19)<br>International                      | Literature review of community participation strategies to examine lessons for maternal, newborn and child health  | Women and families in poorest countries with high mortality rates                  | Participation in planning, operation, organization and control of services  |
| Rousseau (20)<br>Peru                             | Field research (including 20 interviews with stakeholders, observation of public meetings, secondary data analysis) to examine reproductive health policy-making in the context of the social policy reforms in Peru and Latin America             | Population level   | Role of NGOs and civil society movements in influencing policy making   |
| Sirivong (21)<br>Lao People's Democratic Republic | Cluster RCT involving survey of 148 women in intervention village clusters; and 150 women in control village clusters to see if training of TBAs had an impact on reproductive health  | Women aged 16–49 years with children under 2 years                                 | Training course for TBAs in intervention district   |
| Swendeman (22)<br>West Bengal, India              | Trial in two rural towns comparing standard care with empowerment strategy for impact on reducing vulnerability to HIV and STDs. Female sex workers selected through random sampling in the two towns' "red-light" districts (110 females in each) | Female sex workers in two rural towns  | Empowerment intervention strategies (community organizing, advocacy, rights-based framing, micro-finance) implemented in intervention community |
| Turan (23)<br>Istanbul, Turkey                    | Project evaluation of community participation in efforts to improve perinatal health based on participatory action learning cycle  | Young women who were pregnant with their first child and did not work outside home | Community participation including planning, implementation and M&E of the programme   |
| UNFPA (24)<br>Thailand                            | Review of national policy in Thailand using secondary data sources to examine progress and challenges in reproductive health   | Population level with focus on women's reproductive health                         | Participation in formulating, implementing and reviewing reproductive health policy   |

## Abbreviations:

|       |                                 |
|-------|---------------------------------|
| RCT   | randomized controlled trial;    |
| TBA   | traditional birth attendant;    |
| CHW   | community health worker;        |
| NGO   | nongovernmental organization;   |
| HIV   | human immunodeficiency virus;   |
| M&E   | monitoring and evaluation;      |
| UNFPA | United Nations Population Fund. |



## Annex 6 References

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## Annex 7

### Implementing a human rights-based approach: a selection of useful resources

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